Building an Effective, Comprehensive CIL Youth Program, April 10-12, 2012, Houston, Texas

Creating and Operating Services to Support Youth in Transitioning to an Independent Living/Community-Based Living Goal

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>> JUDITH: Good morning everyone. Okay. Time for us to get started again. Hope you had a good evening. Didn't get too lost in Houston.

First of all, before we get started with our program today, and it's going to be really exciting, I need to ask some people to come in. Sharon. There you are. And Dawn. Well, we've seen Dawn. And Marge. Is Marge -- there she is. I'd like to give a big round of applause. These are the people that put this together.

(Applause)

>> JUDITH: And I understood last night before the reception that we were going to have light hors d'oeuvres. Well, it proved to be a pretty good dinner for most of us.

I think we also have one thing I'd like to announce. We have a CIL director here from Birmingham who has a new building. And I would like her to tell you about it for just a moment. Because getting a new building, as you know, is a big deal.

>> AUDIENCE MEMBER: A real hairy, big deal. I'm not the CIL director, though. Please don't tell Dan Kessler that anybody said -- because the NCIL president happens to be my executive director, and we're very proud of him and proud to be moving into a new building. Projected occupancy date is May the 1st. The exciting part is where we're going to be located.

The Birmingham area has a very long and not proud civil rights history. We have a district where the 16th Street Baptist Church is located on Easter morning. In 1963, four little girls were killed in a bombing.

We have the Civil Rights Museum that is located on the one corner. Sixteenth Baptist Church is located on the next corner. And our new building is going to be on the next corner.

(Applause)

>> AUDIENCE MEMBER: When we move into our new building, we will move in as Disability Rights and Resources.

>> JUDITH: Thank you. Congratulations.

(Applause)

>> JUDITH: Right now with the economy kind of struggling and all of the campaigning going on, and all of the things, and gas going up, sometimes we have to remember there are still victories and celebrate them. So thank you for sharing.

This morning I think we're going to have a great time because all those questions that were running around the back of your heads yesterday, they're going to get answered today, we hope.

We have a set of panels, and each of the panels will have a specific focus. Our first panel is creating and operating services to support youth in transitioning to an Independent Living community-based living goal.

We're going to hear first from Kim Arnett from Toledo and Annie Kim. Wave your hand, Annie, so they remember you. David, I don't know if anyone has forgotten David yet. Christy, who is the interpreter's nightmare at the speed she speaks. And, of course, our quite, shy, retiring hard-to-get-a-word-out-of-her Cindy.

Kim will be presenting. There will be plenty of time for questions after Kim. Others have shorter presentations. Remember the focus of this one is transitioning to Independent Living.

Okay. Thanks, Kim.

>> KIM: It occurred to me yesterday, speaking with several of you after the presentations, that I never spoke about our budget, and seems how it kind of is integrated with what we're talking about today. Our budget is about 4.5 million. Two million of that comes from an endowment that we have. And 2 and a half million is grants and fundraising.

We were fortunate enough in 1940 to have a gentleman that really believed in the kindergarten that we had for children with polio, and he left us about $2 million with the provision that his last living relative had to pass before we received the money. So when I walked in the door, almost exactly 12 years ago, that money came to us. And at the time it was $38 million.

So I probably just lost a lot of you thinking, oh, that's how they do what they do. But let me clarify that and say we have a supporting organization that only allows us to take 5 and a half percent of that a year. And the reason for that is the money was not left to us to have hot tubs and great buildings. The money was left to ensure that people with disabilities were included fully in the their community. And as stated yesterday by several people, that is probably not going to happen in our lifetime. So that money is there for the long run so we can ensure that Toledo has continuing support and advocacy for people with disabilities.

So given that, the first four years that I was working at the Ability Center, we had this money. So we didn't know what to do with it. So we decided, okay, we'll build up our program. So we worked. We hired about ten new staff, started some youth programs, started to do things.

About four years into it, we decided we're not really getting anywhere. We keep doing the same advocacy over and over and over. For example, you've all been there. You advocate for IEP with a child who has spina bifida. The next day it seems you're advocating for another child, exact same situation, exact same disability. It's continual.

So what we decided to do is bring in an expert, what we call an expert. Derrick Dufresne is his name, and he is pretty revolutionary in talking about community integration for people with disabilities. So he came in and did our strategic plan for us. Well, we did our strategic plan. He was there. And we talked about kind of what our community needed, because we do have this money, and we needed to figure out what can we do to best use it since we had it.

What he did was a lot of focus groups with pretty much anybody that we could identify -- families, hospitals, community members, businesses, anybody you could think of we did -- you know, we sat down and did focus groups.

And what he came back to us was exactly, probably, what we should have figured, is they looked to us and said they're the ones that take care of the people with disabilities. They have the money. They were not buying in, which explained why we continually were doing the same thing over and over, because it was our job according to our community.

So what we did was we took that to heart and made a pretty good -- what I call a pretty good strategic plan to -- oh, you changed it for me; you can't change it for me -- to do what we call community connections, which is our main focus of our center. It's a little bit different than what most centers do, but I could be wrong.

But we focus mostly on getting our community to be the supports for our consumers. And all of our programming goes through the process of making sure that it aligns with that philosophy. So I'm going to explain that a little bit.

It's the key for the Ability Center's supports and services. One of the important facets of community is that it promotes a sense of social capital for the members who belong. Social capital refers to the connections and relationships that develop around community and the value those relationships hold for members.

Social capital, it's kind of interesting. One of the things that Derrick did was a national study with people to find out -- well, there's a picture, and it's kind of a target. And it has a person in the middle and around it, it has family, friends acquaintances, service, contacts, and agencies.

So basically what he did was a study to see how many people within their social capital circles the average person has. And he came up with a number of 150 people. If we had time, I would have you all do this, but we don't. 150 people is the average. When he did this with people with significant disabilities, the number was 15. So only 10 percent of the support that everyone else had. That's pretty alarming. And a lot of those were paid attendants, were their closest friends.

So the message from this and what they studied in this whole social circles thing is that loneliness kills. And, as a matter of fact, loneliness has been shown to kill as many people as smoking. To us we found that pretty alarming and decided we wanted to take on the mission of increasing people's social circles within our community. And like I said, everything we do is based around that. Our goal is to get our youth involved in the community and not to get them in programs that are designed just specifically for them.

So, as this says, as long as a person's experience is contained within the disability bubble, meaning being part of an organization operated by an agency for people with disabilities, according to us, it can never be better than a three star quality.

So I'm going to explain kind of what that means. We try to strive to have everything above the line, which is a three star quality. And I guess the easiest way to explain that is to go through it in simple terms and describe the different stars.

The first star is basically an absence for community. I use a dance kind of to describe this in layman's terms, I guess. First star is basically a dance for people with disabilities sponsored by human services or a disability organization, and it's held in a place such as a sheltered workshop. To this a person is absent from the community.

A two star would be an example of a dance, say, located at a YMCA held by a disability agency such as the Ability Center, but it is in the community. So they are participating in the community.

Three star is what we strive for on our everyday planning, and that is that it's held at a place such as the YMCA, sponsored by a disability organization as a partner. So the YMCA has some buy in into the programming. The person at this point is then a participant within their community. And I'm describing this really quickly. If you guys have questions, it took hours to teach our staff this. So I'll try and slow down a little bit.

Four star, an example would be is that it is in the community, such as the YMCA, sponsored by the YMCA, and then individuals are supported by invisible supports. That's usually what we really strive for is that. There then the member is a member of their community.

Five star, difficult to achieve. But basically what five star is, is that the dance is held at the YMCA by the YMCA, and we're not involved at all. And they just naturally make those supports.

So given this concept -- and introducing it to our staff was interesting. We had a lot of staff that questioned it and said, what are we going to do? We're going to work ourselves out of a job. We said exactly. That's what we want to do, work ourselves out of a job.

It was a lot of trials and tribulations with staff going back and forth, a lot of discussions, but we really adapted to deal with this. It was called from good to great. Is anybody familiar with good to great? Okay. A couple of people.

Basically what good to great states is that you have a philosophy. You follow that philosophy, and you work with your staff and identify who -- they use a bus scenario -- who is on the bus with you and if they're going to participate in what you're wanting to do and going in the same direction as you.

And then the next step that we do is you look at whose on that bus, and are they sitting in the right seats? Maybe they're a really good advocate, but they're not an advocate at this time. So you shift people around. So for a couple of years we worked on this. Some people decided to leave and get off the bus. A lot of people shifted seats.

I included a quick kind of time line so you could see how we went with this with our community. I'll go over it briefly. In March of '09, we had a staff meeting on the five star introduction. Then we had a board retreat, and they talked to Derrick and found out all about five star.

And to our dismay -- actually, it was a good thing -- they said you're doing it. So, at that point, we didn't really have a choice. We were changing all of our programming that we had available to meet this five star.

Then we had a staff meeting and said, okay, now we have to come up with goals on how to do this. In October, we had a staff presentation again saying this is what as a team we've come up with as our strategic planning.

In January of 2010, Derrick came back along with Al Condeluci, who is another specialist in the field of the social circles, and what we did is we invited our community friends to come. We had over 200 different agencies come and listen to them speak about how to make your community inclusive, which is an amazing turnout for our community.

It's a pretty small community, about 280,000. So it's a pretty good representation. I know it's kind of small, but it was the Y. It was the banks. It was the zoo, pretty much everything that we wanted to tap into to get people involved in their community. So it was a great turnout.

We did tape that. We have a two-hour video if anybody is interested on our Web site. It might be boring. I don't know.

And then we had a podcast done by Derrick and Al, specifically speaking about how loneliness kills and why people need to increase their social circles. That is available on our Web site also.

The next step was our biggest partner, per se, in our county and region is Lucas County Board of Developmental Disabilities. They have 850 employees. So we decided this is somebody we need to get on our side if we were going to change our community.

So what we did was we had Derrick come and talk to the Lucas County board staff, all 850 employees, about why people should be involved in their community. At the same time, we had Al come back and talk to our staff a little bit deeper about the social capital. And then we had five star advisory committee meeting group.

From the 200 people that attended, we picked out the top 25 that were really interested and brought them together and started having meetings on how are we going to do this within our community. At this point is when it turned into a community effort, not an Ability Center effort.

We had some really key members of our community sitting together talking about how to get people with disabilities included. The important thing that I need to say here is they were not disability agencies. They were the Metro Parks, the banks, the zoos, pretty much anybody you can think of was on this committee; very few disability agencies.

Pretty much since then we've done some follow-up meetings, community meetings. We started our disability awareness training that I talked about yesterday. Some of our community partners definitely partner with us on that to try and get as many people as we can educated in our community about the disability awareness. And we hold that monthly. We've had about 4,000 people go through our training since 2010, if you add that up it's pretty quick. We've had lot of people go through.

We've also hosted a national training -- it's called the KIT training. Is anybody aware with that? It's called Kids included together. It's a national program out of California, and what they do is they train trainers to include kids with disabilities into interesting programming.

So we had somewhere around 85 different agency members come down and learn how to train trainers to be included in the community. So now at this point, we have four or five trainings going on each three months at different agencies. So we're catching quite a lot of community learning how to include kids in their system programming. So it builds like wildfire.

Then we also started zoo day. We call it zoo day. On the anniversary of the ADA every year, we basically take over our local zoo. And everybody who's anybody that has anything to do with disability shows up and has a booth. It's a lot of our community partners.

The Metro Parks talks about they have a special trail partners program. The bank has a special loan program for people with disabilities that's zero interest for a certain amount of time for durable equipment and things like that. All these different programs that everybody has established, they come and they talk at the zoo around the animals.

I came up with a few quick ideas for people that are interested in learning more about this and how you can take steps towards community inclusion. Basically, I'll just run through them real quick.

Establishing an inclusion task force, which is basically how we educated the community and brought the key players together to talk about and discuss and brainstorm how to do this within our community. That's probably one of the best things, the one that moved us forward the quickest.

And develop professional relationships with other agencies, same -- establish linkages. Utilize resources, obviously the ADA, things like that. Attend an inclusive conference. They happen all over the country, a network of others, and ask them about their programs. Just because we have one doesn't mean we're the best out there. We still love to talk to other people about what they do for inclusion.

Maintain a 'yes first' attitude. What that means basically is always come to each situation with a you can do this. I don't know how, but we can do this. We'll come up with a reason, a way to do it.

Evaluate present facilities for accessible and promote ADA compliance for all new construction. I talked about our visitability ordinance yesterday. It's a really cool ordinance, and I'd be happy to talk to anybody about that also.

Develop marketing strategies to communicate and inform potential participants with and without disabilities about what five star is. It takes a while. It's a pretty confusing concept, I think, for some.

Establish registration procedures. This is one thing that we did to make it easy for people with disabilities to register and request for an accommodation. Sometimes that's the hardest step is for them to go to a new agency and say I need an accommodation.

For many individuals with disabilities, this is one of the most important things that I tell our community partners, is that they need to have a feeling of acceptance. Everybody is not always perfect with their ADA compliance. Unfortunately, it's something we battle every day.

But I try to make the statement really that it's about acceptance. If you're willing to work with us, we'll work with you. We're not the ADA police. We're not going to come out and find you. We're not going to take you to court. We want you to work with us to include people with disabilities. That is our biggest goal. I come across this a lot with the camp in the summertime where they say, oh, we have dirt paths. How can you get them there. I don't care. I just want them here with the kids, with their typical peers. And then we'll work on the accessibility.

The reason why I described all that is to then talk about what about we do as an agency. We have a golden child of ours called Camp Cricket. It is a day program that is inclusive for kids with disabilities and without disabilities for ages 5 to 14.

The reason why I bring this up is as we were talking to the community about how to do this out in the community, include everybody, we looked at our camp and said the golden child is what we brag about. It's how we get in the news. It's how we talk about this is what you should do with kids with disabilities. This is how their typical peers learn acceptance. We looked at it and said it is not following our five star guidelines. We need to make some changes.

So there was an obvious need for community supported inclusive opportunities for kids with disabilities. So what we have done is practice what we preach. We have started to, not dismantle, but, yes, dismantle our camp. We have an average of 120 kids who attend each summer.

Last year, we made a four-year agreement with our board that we were going to try and much as we can dismantle our camp and support the kids in typical community settings that already exist. It was crazy. Sarah over there is my camp directer that freaked out on me -- no, I'm just kidding -- when I said, hey, guess what we're going to do? So before I get into that, let me talk a little bit about how we build our community capacity to do this.

Currently, we have a great relationship with the University of Toledo that has a fantastic recreation department, as well as therapeutic recreation. Fortunately for us, both Sarah and I are certified therapeutic recreation specialists, which means we can get free staff anytime we need it.

So we use a lot of UT interns. We have a lot of clinical students every summer. We have a lot of -- last year, I think we had three or four interns at a time, which can get a little hairy.

But what we have been doing is providing internships, ensuring they're community-based versus clinical-based, the opportunities for the students to learn they about Independent Living and what we believe in. So they start out in the community in the recreation settings with the right philosophy we want them to have.

Over the next four years, we plan to continue this collaboration. As a matter of fact, Sarah is on the Advisory Board for the Recreation Committee at University of Toledo and leads the Student Recreational Therapy Club. So we're trying to get in the door as much as we can to influence these students on how people with disabilities belong out in their communities.

Some examples of supports that we plan on -- I talked about our staff going, well, what are we going to do if everybody is out there and we have nothing left to do. Biggest fear. It may sound silly, but I guess if you're faced with that, I can see where they'd think this is what I do. So what we came up with is some goals of what we thought we would do to continue to support the community.

We would continue our disability awareness training, definitely educate parents. We actually have a series of educational meetings. We try to do it once a quarter. We bring in professionals from around the country to educate parents on allowing their child to make their own decisions, what they should be getting out of their IEPs or 504s, what it looks like for them to be supported in the community. It's all different topics all the time.

Educating typical peers is something that we have taken on. Going into the school with the dogs, or whatever, brings the kids to you, and educating them on this is not scary. Get to know the kids. They're fun. They're kids. They have great opportunities out there for you. A lot of disability awareness training with them.

Providing trained staff to assist with support. I'll talk more about this a little bit more when we come back to camp. Offering assistance with program fees. I don't know about you, but has anybody ever tried to get a membership with the YMCA? I can't afford the membership at the YMCA, let alone -- it's like 4 or 5 hundred dollars year. Are you crazy?

So we provide -- this is where the Elks -- I talked about the Elks money yesterday where they give us $8,000 a year. We use that type of money and from our auxiliary to basically do sliding fee scales so that people can belong to community groups that they can't necessarily afford.

And we work with the agencies. Like the YMCA gives big discounts if you come with us and say I'm with the Ability Center. And then they'll say, oh, okay, we have a scholarship for that so if you can't afford it. And, most importantly, showing the benefit of hiring staff with an inclusion background.

The YMCA is one of our biggest partners that we have started this with. What we did was we asked them if they would be willing to hire an inclusion specialist if we'd help support that. So for the first two years of the agreement, we actually gave them money each year to provide this inclusion specialist with the agreement that they come up with a plan on how to support this indefinitely.

>> JUDITH: Please slow down a little bit.

>> KIM: I can. Sorry.

>> JUDITH: I think Kim is trying to replace Christy talking as fast as she can.

>> KIM: I'm sorry. I have so much to talk about.

>> JUDITH: You do. You're doing great. Just slow down.

>> KIM: I will.

>> JUDITH: Thank you.

>> KIM: No problem. I'm passionate.

>> JUDITH: You are.

>> KIM: So the YMCA. So we provided them two years worth of pay for this inclusion specialists. And in turn what they did was they have 13 different agencies within Lucas County. They have now hired an inclusion specialist at each agency, which works fabulous for us.

So, basically, anytime anybody with a disability comes into a YMCA and says I may need an accommodation, they have a specific person to talk to that works them through the entire process and makes them feel welcome. It's fabulous. It's the five star of all that we strive for.

Let's see. See, I'm talking so fast I lost where I was. Back to summer camp, what we have done with summer camp is we decided to split our camp in half. So 60 -- so 50 percent. So 60 of our kids last year -- it actually turned out to be 80.

But we decided we were doing to talk to the parents, educate them, and talk to the community, and find a way to invite five community agencies that we felt had great summer programs.

Then we talked to our current Camp Cricket families and said we're doing to do this. We're going to put you out there. And not only are we going to do this, but we are going to take our staff and send them to those camps to support those kids to make sure they're included, not as the camp staff but as extra supports.

So this is kind of the philosophy we have taken. We've cut our camp in half which allows us -- I think last year we had ten counselors that we basically farmed out, two at each camp to provide inclusion for kids with disabilities.

It turned out we were able to include 80 kids our first summer which to us was an amazing feat. It was a lot of work, but it turned out fantastic. And guess what? They're signing up this year, and they're signing for the community camps through the community, not through us at all. So we have to say, hey, hey, how many kids do you have there, because they're not letting us know they're coming to your camps anymore. Do you still need this support? So it's definitely working with the camp area.

This year, we worked with the county board. The county board actually came to us. They have been providing what they call summer options funding for the summer camps in the community to provide that extra support for kids with disabilities. Usually the case of what has happened is they just absorb that into their funding.

So what they have done this year is asked us if we would be willing to hire extra staff, and they would give us the funding to provide the education for those staff to go out into the communities, to ensure that they were actually extra supports and not just using the money for something else. So that definitely is helping us to thrive more support.

Next, Annie.

>> ANNIE: I'm going talk a little bit about our mentor program. It's also kind of helped assist us towards the five star philosophy that we're trying to achieve. About a year and a half ago, we started mentor program for our transitioning age individuals in working towards specific goals. So I know some of the other CILs here have a mentor program, and they're probably all used a little bit differently.

The way we use our mentor program is to work one-on-one with transition age youth to help them achieve certain goals. So just some examples of some goals. For example, if they want to get involved in a sporting -- sports or recreation or that type of thing, we will have them meet. We ask that they meet at least once a week to work on this goal, maybe explore different options that are in the community.

We have a lot of different adaptive recreational programs in Toledo, such as rowing. We've done adaptive skiing, biking, basketball, lots of different sports. So the individual and their mentor can go out and explore these options on their own and help them get involved in the community.

The way we pair people up is we try to base that pairing on interest. So more than likely, the mentor is also involved in these certain types of sports. So they're kind of getting involved in the community together. And then we hope that they also kind of form a lasting friendship or connection with this person. Our mentors are typically just out of high school or have just started college. So they're similar in age, similar interests, and that type of thing.

They can also help us in providing daily living skills. We only have so many staff, and so it's helped us reach more consumers than we would have just by utilizing our staff. So they're able to work one-on-one with individuals with daily living skills, helping them do things like study for driver's license tests. They've been able to help us with that.

And then even, and I'll talk a little bit more later today, helping us with the vocational aspect, actually learning soft skills, job seeking skills, and then helping them actually find a job. So it's been a great partnership with our mentors, and it's allowed us to do more with our resources by partnering with them and helping us -- helping the individuals that we work with achieve their goals.

Any questions about that, the mentor program?

>> AUDIENCE MEMBER: Do you like Pappasito's?

Okay. We all know since PL94142 and mainstreaming and all of that, that inclusion is --

>> JUDITH: Can you get that up closer?

>> AUDIENCE MEMBER: Yeah, sure. I feel like singing a song. What I really asked you, Annie, is do you like Pappasito's?

>> ANNIE: We loved it. Thank you.

>> AUDIENCE MEMBER: So I was referring back to inclusion and mainstreaming and all of that. I had a daughter who's blind who was in the first batch of kids that went through mainstreaming in '75, and then two granddaughters who are blind who have been mainstreamed.

What I know is that even though you can be put in an environment with a bunch of kids who don't have disabilities, you can still be pretty darn lonely. And you can still -- you don't make the peer connections necessarily.

So what I'm interested in is as you start to integrate your kids from the camp over into other community camps, I know that accessibility is provided. I know that you're provided backup staff. But what I'm interested in, is there really a peer connection for those kids?

>> KIM: What we do is the kids included together training is a fantastic resource for that. Why I say that is because it goes step-by-step trying to give you solutions to creating those meaningful relationships. It's what we use in the summer. It's what we use all year round. But specifically in the summer, we train our staff to use the kids included together philosophy and the different hints and tips they provide for that to try and create the relationships. And it is KIT training. I think it's K-I-T, and you can look it up. If you can't find it, you can e-mail me and I can send you -- or we have a curriculum if you can't afford it. I can definitely share it with you.

>> AUDIENCE MEMBER: Should I just well? I'm a Texas girl. I'm good at that.

But what do you observe, though? I mean, as far as the kids without disabilities, are they fearful? Are they inclusive? How do they treat the kids? Because I think -- you know, in our youth program, one of the biggest bonuses is that our kids are so hungry for peer relationships and peer connections that they're not getting out of the community. Those buds that they can talk about, they can Facebook with, maybe even go to the prom with, or whatever they want to do.

So I'm just -- I am really, really interested in is there true connection occurring? Are the kids really getting that kind of interaction that they're craving or are they still a little bit on the sidelines? Really, honestly, what do you see?

>> ANNIE: Well, to go back a little bit, we weren't really taking a shot in the dark. Because our camp that we had at the center that we've had for years has always been a camp for individuals with and without disabilities.

So really what we were doing that was new was taking our camp out into the community, expanding it. It was expanding at the Ability Center. And we thought why not have this be the norm for the community? Camps with kids with disabilities and without. So it was already working for years and years at the center.

But we do see those relationships form. It's a way to start that conversation with kids while they're young to kind of get rid of the fear, the thoughts that, maybe, they have starting at that young age.

I know for some of the programming that I'm involved in, we were noticing a huge problem with kids graduating from high school and never being involved in the community with their typical peers. So their parents were coming to us. They were trying to get jobs. They were trying to get involved. Suddenly, they don't have that social interaction that they had in high school. They're done with high school. They're ready to move, on but they've never been involved in their community.

So we do understand that individuals with disabilities definitely can and should have friends that have disabilities. We're not saying that if you have a disability, you must be with typical peers only. We all like to be with people that have the same interests and same background and that type of thing. But it also comes to a point where you need to be involved in the real world and be around individuals with all different types of backgrounds.

And we thought if we could start this at a younger age, maybe when they get to that point, they've been involved in their community, they've been around people that do have misconceptions or fears, and they've learned how to handle that and maybe how to educate their peers and that type of thing. So it was already working at the center. We're just kind of taking it outside of the center a little bit.

Do you have something to add on that?

>> RICHARD: What did you say the name of the curriculum is?

>> KIM: We do measure it. With our older kids we do -- I'm going to talk about that in just a second. Okay?

Although, I am glad you brought up that point, I have talked to hundreds of parents with that same concern. This isn't easy. It is a roadblock that a lot of people put up and say oh, no, not my kid. I'm not having them teased. I'm not having them lonely out in the community. It's something we work really, really hard on and every day make adjustments to on how to create those relationships.

And I'll be honest, sometimes they don't. We had one camp this year that we're not going back to because the leadership of that camp didn't believe in inclusion. And when the leadership didn't believe, they were like, oh, well, the Ability Center will take care of those kids. Well, they're not those kids. They're your kids. They're paying you to be at your camp.

So we had a lot of struggles with just one, one out of five, which is not too bad. But that also taught us a lot of new techniques to use by having that struggle with that camp director. So, yeah, it's an ongoing issue and an ongoing struggle, but the kids included together curriculum really does help you to learn how to educate others in building those relationships.

>> AUDIENCE MEMBER: So who are you training with the kids included together curriculum?

>> KIM: We are training anybody in our community that wants to be trained. Like I said, originally, we had the professionals from the program come out and train 70 different participants -- well, up to 85, I think -- different community members.

And when I say that, they trained people from the bank, which you would think, oh, people from the bank; I don't know. But the Metro parks, the zoo, pretty much anything you can think of, Mud Hens Stadium, which is our minor league stadium. We had an overwhelming amount of people that wanted to come. Maybe because it was a very expensive training and they got to do it for free. I don't know. Whatever works.

We have a lot of people out there that are able to train others on the simple techniques of trying to create relationships between kids.

AUDIENCE MEMBER: So, Kim, the curriculum is designed for the leaders, the professionals, the people that will be working with the kids with disabilities and those without.

>> KIM: The curriculum -- the kids included training is for the trainers. It's to train the trainer. So it gives you all of the information on how to train somebody else, but basically you're learning at the same time.

>> AUDIENCE MEMBER: So who do the trainers train?

>> KIM: The trainers train people in their agencies. We have different groups that get together, and we open it up to the community and say we have 30 spots. Anybody who wants to come and learn how to include kids can come to this training.

>> AUDIENCE MEMBER: Could you give us a couple of examples of what the trainers are teaching? What are they teaching other people?

>> KIM: As far as facilitating relationships?

>> JUDITH: Uh-huh.

>> KIM: One of my favorites that -- I actually do one of the trainings. And I love to brainstorm with people, how do you facilitate a relationship with a kid that has Asperger's?

For example, I have a kid in the summer that's obsessed with Play-doh, to the point that people are you're weird. That's all you talk about. You know every about it. It's little awkward.

And I said have you ever thought of having ten tubes of Play-doh, or whatever they're called, and just giving it to that kid? That kid is the only one responsible for divvying it out to the other kids. They can sit there and play with it. They can make cool sculptures. Very creative and talented kid with the Play-doh, let me tell you.

But the other kids will come out and say, hey, can I play with that? And right there, boom, you've got a relationship because they are in charge of that Play-doh. So that creates them in an empowered situation. So that's just a quick example of some hints and tips. Does that help? Okay.

Really quickly, I know that we are -- okay, I won't be really quickly. Really slowly, I know that we are talking about youth leadership later. I just wanted to give you the down and dirty of what our curriculum consists of, basically just by telling you the titles and describing them. I have this curriculum available. Anybody can e-mail me, and I'd be happy to share it with you.

But the basics that we cover in our two week -- we do a two-week summer, ten day daytime youth leadership, and then we do follow-ups on a monthly basis. So we do risk taking and problem solving in groups, planning for your future while the world keeps changing. We use Who Moved My Cheese. I don't know if anybody is familiar with that, but it's a fun little program and how the world changes.

Leadership and education. Of course disability culture and the power of your stories. We have an excellent staff member. His name is Dan Wilkins. He's a fabulous story teller and sits with the kids and really brings out their stories and makes them feel really important and empowered. It's one of our best sessions.

As a matter of fact, I have some -- they create our T-shirts for camp every year, and they're really creative. And we have pictures of them, but I don't think we brought them. Do you have them? I don't know. Maybe. If somebody wants to stop by, I'll show you later. They're really creative sayings and things. And Dan is also an artist so he does T-shirts.

City government, very important. Advocacy for accessibility. And they actually are assigned an accessibility assessments where they go out with our professionals and assess different local businesses and come up with if it meets the guidelines and what things they would like to change. One year I took them to a brand new constructed hotel, and we found out that their bathrooms were not ADA compliant. So that was an interesting process. So I got to see the whole of what you do with that.

Law enforcement and good citizenship. They get to sit in the cop car and all that stuff. But most importantly, they get to talk about safety, teach a few hints and tips of being safe, Facebook safety, all of that. Don't be vulnerable putting your information out, the things that we all know. And self-advocacy and Independent Living. So that's just a quick -- does anybody have any questions on that?

AUDIENCE MEMBER: I have a question about the peer mentoring. You said that you got them from high school graduates and college students. Are they people with disabilities? If so, how do you find those people? And then how do you make sure they're a right fit for a mentor?

>> KIM: You want to cover it, or do you want me to? Okay.

>> ANNIE: Well, that's -- our mentor program is a little bit different as they're not necessarily peer mentors. They're mentors that have similar interests, similar backgrounds that can help them achieve a particular goal. So some of them do have disabilities. Some do not. But they all identify a certain goal.

So, maybe, what is the next step? Like are you wanting to get your driver's license? Are you wanting to get a job? Do you want to get involved in a recreational opportunity in the community? And they identify that specific goal, and then that mentor's purpose is to help that person achieve that goal.

So it's a little bit different than peer mentoring. Did Mississippi talk about that? The peer mentoring, is probably a little bit different as far as they work a lot more with like identifying with the specific disability and what they went through, which is awesome. And I would love to adopt some of that.

At this point, though, it's more to kind of -- so that we can serve more individuals and kind of they really are helping both us and the individuals as far as we're able to help people achieve more goals than we were able to before the mentor program.

It's almost more of a volunteer program, but those relationships do tend to develop. And they're more long lasting relationships with that individual because it's very one-on-one and individualized and they're helping them achieve that specific goal.

And typically the mentor is also interested in achieving that type of goal, like a recreational program. They also are interested in trying rowing or that type of thing. So we pair those two. And so they're support in that goal and that interest.

>> KIM: Okay. The final thing that I want to talk about is our introduction to community that we do with our youth ages 15 to 24. We used to do what we called transition camp where we'd have a summer program where they would come and they would learn about transitioning into Independent Living and what they had to learn, social skills training, all of that, the cooking.

Since then, since our new initiative, we've decided to have that throughout the year. We still offer it. Annie's group still does one-on-one skills training group skills training. But what we decided to do with this group in the summers is to ask them what they like to do, what they'd like to try.

We use a really unique tool called the dream manager by Matthew Kelly. I don't know if anybody is familiar with that, but it's a book written -- basically the goal is towards employees. There's a whole theory out there that if you get involved in your employees' personal goals and help them to set personal goals and achieve those personal goals that they become better employees and more committed to your agency. It's been proven time and time again that this is true.

So this is with the Dream Manager. Awesome book. I would recommend anybody read it. It's very inspiring. I read it. I was trained in it. I decided why can't I do these things with the kids. So what we do is we sit down with them and do some dream managing before we plan what they're going to do and set their goals.

And the dream managing asked hundred of questions -- it's a pretty long series -- of things like if you could do anything, three things from your childhood that you really enjoy and you could repeat those, what would they be? If you could have any experience that you've heard about, what would it be? It's just probing, probing, probing questions.

I don't know about you, you're probably familiar with it. But when you sit down with a teen and say, okay, what are your goals? Sometimes they're clueless. They have no idea what their goals are. So this is a really great tool to get them thinking a little bit outside of what's tomorrow.

So that's what we use. Last year we used it with 50 of our teens, 15 to 24 -- I guess they're young adults -- and they came up with lists of things they wanted to do, a pretty broad range, to sky diving. We haven't quite accomplished that one yet, but, hopefully, maybe this summer. But just recreational opportunities, things available in the community.

We took that list of 35 activities, and we did them all. We offered them to anybody that wanted to do it. We provided the supports. We called the agencies. We supported the agencies. We educated the agencies. We had them go through disability awareness training. We had the kids look into it and find out what it was all about, what they needed, how much it cost, all of that stuff.

And we did it all, and we supported them, and they had a great time. And we plan on doing it again this summer. The most important thing with this is that it was age appropriate, which I know it's a big struggle for all of us to get age appropriate activities. It was in the public. It was community-based. And they had a great time.

So I have some pictures. One is of a kid, a young adult, fishing. The next one is, I think they were making candy. Someone wanted to be candy. There happened to be a candy class going on. So we made candy. There was some pretty broad things they wanted to do.

This is just a collage, kind of the fun things that we did this summer. Talk about stretching. We stretched to do some of these things, the downhill skiing, the scuba diving, which is awesome, highly recommended.

The rowing. We had a great rowing team. The Ability Center several years ago got a scholarship for somebody to get an accessible rowing going, and we've never used it. So we decided, okay, some kids want to go rowing. So we got reconnected with them. We knew they had accessible equipment, and we went rowing down the river.

The fishing, the glass blowing, pretty much anything a kid would want to do we did. And they are like, okay. And, number one, they wanted to go to Cedar Point again this year. That was something that they really loved. It's our six flags type of thing, actually one of the best roller coaster places in the country, if you ever make it up to Ohio.

So that's kind of what we do with that group now, and they love it. Not only do we do it in the summer, we do it four or five times a month. We find things that are happening in the community that are based on their interests, and we say, hey, we'll be there if you want to show up. We send staff and the staff is there. If people show up, great.

>> AUDIENCE MEMBER: So do you provide the transportation?

>> KIM: We do not.

>> AUDIENCE MEMBER: No?

>> KIM: Part of the our goal is if they do have a transportation issue, that's where the skills training comes in. We sit with them, and we make the plans on how they're going to work through that transportation. So little things like that -- I'm glad you said that -- come into play. They need to do things. They need to save money if something is expensive. So we teach them budgeting. They need to work on hygiene, social skills, things like that to achieve of participating in what they want to participate in.

Anybody else?

>> JUDITH: Okay. Is that --

>> KIM: That's it, besides I listed all our community partners from last year. It's a little bit overwhelming. So that's our community partners from last year, those two slides.

>> JUDITH: Thanks a lot, Kim. That was great.

(Applause)

>> JUDITH: Christy?

There was a question here.

>> AUDIENCE MEMBER: Say we're at star No. 2 of your five star process. And so I'm interested in when you did your camps and they were integrated, how did you recruit or market to kids without disabilities to come to the camp? How did you do that?

>> KIM: Our camps at the Ability Center has been integrated -- it's been going since the 1940s. And we've always -- we've worked with first like we all do, siblings. It's a great camp, honestly. We go and do so much that no other camp in our community does, that kids flock to us to go. They hear about it. They come. We go to the zoo. We go someplace every day out in the community and do different things, really fun and unique things, I guess.

>> AUDIENCE MEMBER: And do those kids pay?

>> KIM: It's a sliding fee scale. It's $300 for two weeks, or it might be $375 now -- 375? 300.

>> AUDIENCE MEMBER: Is it a sleepover camp?

>> KIM: It is not. It's a day camp. So you just make it fun and inviting, and the kids will come, I think. If you build it.

Is that it? Okay.

>> DAVID: Okay. I've got a few slides as well. Obviously, the way as Judith described earlier, we'll have a lead presenter on each panel, and then we'll follow up with some lighter reflection.

Before I walk through my slides, though, I want to take just a moment to do a little sidebar to acknowledge, I think, a challenge that many of us might be thinking about. Because I know we've talked about this last night, and I've been thinking about it as well.

And as we -- especially as we look at programs for youth with disabilities, we are presented with a fairly unique challenge. And I think you'll see some of the variations in our programs. And the variations that you have in your programs, perhaps, may be acknowledging that challenge.

But the challenge is that we have a struggle, because we look at either -- you know, we started with integration. And we quickly learned that integration creates a presence for people. So then we moved to the concept of inclusion, because we recognized that inclusion creates or is intended to or implies a participation.

But as we move forward to creating more and more inclusion opportunities and participatory opportunities for kids with disabilities, we have to be very, very careful, I think, and maybe some of you think this way as well. But I think we have to be very, very careful that we don't cross that line into total assimilation. Because the last thing we would want is for individuals with disabilities to lose that cultural context that they have with their own community.

We were talking about this last night. And the example that I used was Malcolm X, in the early 1960s when he consciously broke from Martin Luther King and Ralph Abernathy and the movement as it was proceeding at that time. Because his position was, I don't want assimilation. I don't want what everybody else has. I want something better.

And I think that that's the unique challenge that we have, especially for programs for youth with disabilities, that we don't cross that line into total assimilation, because total assimilation can have an unnecessary and unwanted side effect of invisibility. And I don't think that's what we're trying to create here.

So I just put that out there as food for thought, that as we think about the balance that we're looking for in our inclusion programs for youth with disabilities that we keep in mind those lines of integration versus inclusion versus assimilation.

So I'll move now into my slides, I guess, unless there's -- if that raises comments or questions with anybody, I'm happy to hear your -- yes, over here. I don't know what the table number is.

>> AUDIENCE MEMBER: I hear what you're saying. But it's good to have that time together, Independent Living where that same common issue. But in our goal to be a part of bigger community and somehow, someway, you can't make your disability disappear.

But, I mean, you want to be a part of a (indiscernible) community. I hate when people come up to me and say what do you people like to be called? Well, my mom named me Mike. You can start there. I don't know. When you said assimilation, it's like, I mean, we don't want that, but we kind of want that.

>> DAVID: That's the balance I'm talking about, Mike. That's the struggle and the challenge that we have. Because I agree with you 100 percent. We want to be able to find our way in the larger community, but we don't want to lose our cultural identity either.

So I agree with your comment, and you summed it up very, very well. That is the essence of the challenge that we face. Where's that line? And it's an individual line for every person. It's not one solid line that is fixed for every individual. It changes by individual. It's a challenge and something we have to be consciously aware of as providers of service, and we're the role models in many cases as well. So we have to be very mindful of that. So thank you, Mike.

>> AUDIENCE MEMBER: Along those lines, I think one of the things that we try to -- I don't want to say teach, but demonstrate to our youth is the importance of disability pride. They're proud of who they are and what they can accomplish. And I don't want to lose that because that is a really difficult concept to get across to them because they're all in their time of life when they want to be like everybody else.

So if you finally get them to see that they're pretty amazing people, because they're accomplishing things in the face of a major disability that other people are accomplishing without. That's a matter of pride. That's at the heart of the Independent Living movement, too, is that we don't feel less than. We feel good about who we are, and we don't have to hide it under a blanket or something.

>> DAVID: Exactly. I hear what you're saying, and I agree with you. The disability community has a very, very deep and a very, very rich culture, and historical culture. And we don't -- as we move forward with trying to create greater inclusionary opportunities for people with disabilities, not just youth but adults as well, again, that's that balance that we're constantly searching for.

>> CHRISTY: You have two questions out here.

>> DAVID: Christy. I think your hand was up before Augusta's.

>> AUDIENCE MEMBER: I agree with what you're saying. I understand it. I know that for Centers for Independent Living, I think if we truly operate on that philosophy of Independent Living versus living independently, that we would see what we're doing is, just like you said, offering opportunities.

Each individual being so different and as we've empowered them, I really don't see an overwhelming concern for that because they're going to make that choice. Just like you were talking about Mr. King, they really are going to make that choice for us. And while some may want to be invisible, some may not want to be.

And fortunately for us, we're dealing with very dynamic and individualized people that are going to -- they're going to create that dynamic in what we do. And they're going to be fully included or they're going so say, hey, I need an accommodation. They're going to do that if we work to do what our full intentions were was to empower them to make the choice for themselves.

I just wanted to say that. I agree with what you're saying, but I think that offering those opportunities is up to us, but making that choice is up to them.

>> DAVID: Right. And I agree with you. And, again, it's that's balance that we have to constantly look for.

Augusta.

>> AUGUSTA: I think, also, we need to -- when you were bringing the scenarios of Malcolm X and Dr. King -- it's our responsibility as the older allies and the leaders in our centers to make sure that our young adults know our disability history.

I think that we are kind of missing out on teaching when we start talking about Justin Dart and people like that. Our young adults need to know who these people are, and then they will have their own sense of pride. And then they can decide whether they want to be included or secluded or whatever the word that we want to use. But if they have that history and they know their own pride, then they can make some informed decisions on how they want to live their life. But we have to make sure we're teaching our history.

>> DAVID: I think that's absolutely correct. And it begs another question of how many people in the room know the history and the life of Red Roberts? See, not very many hands going up. That concerns me. That concerns me.

We have another question back here, and then I'll move on.

Thank you, Judith.

>> AUDIENCE MEMBER: Not really a question as a comment. A lady over here said something about people see it as amazing or -- okay. I don't want to be seen as amazing or heroic. I think that I have just made the best of a bad situation. When I -- when my disability becomes more invisible, I believe that I become more visible as a person.

>> DAVID: Okay. Thank you for sharing that. And, again, I think that speaks to that constant balance that we have to search for.

Did you want to add something real quick before I move into my --

>> CHRISTY: No. I think they summed it up.

>> DAVID: Okay. Well, then, I'm going to move into my slides.

As I mentioned yesterday when I talked about the transition program at MCIL, we currently have two individuals, two employees that re-dedicated specifically to transition services. And one of the things I want to say about these two individuals, they -- and I'm going to slow down. I have a habit of talking too fast as well. So I'm going to try and slow down and be conscious of that.

The two individuals that are employed at MCIL to provide transition services to youth with disabilities are both themselves young people. And I think this was something that came to my mind when you were talking yesterday, and that is that one of the very, very important things about our transition programs, at least from our perspective, is that when young people with disabilities come to the Center For Independent Living or get connected to us in some fashion, whatever it might be, it's really, really important and critical that they see themselves in the organization.

That if they're going to be drawn into participation, whether it be to receive services, to be a mentor, to be part of the leadership circle of the Center for Independent Living, they have to see themselves in that population or they're not going to be invited to come in. They're not going to feel a part of that community. So the two individuals that we employ at MCIL in our transition program are themselves younger adults to create that inclusion.

Additionally, we have other staff that intermittently respond to those transition requests. Very much in the way that Annie talked about the peer mentor program at their center. Folks from our peer mentor program are general IL services, and the other programs, the IL/VR collaboration, etc., intermittently become involved with those transition aged students as well.

As we talked about yesterday, the core of our program in our Center for Independent Living is our relationship building and our site selection. We selected -- currently in this current school year, we have four schools located geographically around the metropolitan area where we insert one of the MCIL transition staff. So they are literally in those schools one day a week every week eight hours day. And then they spend that fifth day in our offices attending to other tasks and responsibilities.

Yeah, Mike. See, I remembered your name.

>> AUDIENCE MEMBER: Yeah, thank you.

>> DAVID: You're welcome.

AUDIENCE MEMBER: When the transition coordinators, or whatever you call them, are in the schools for that day, what kind of activities are they doing during that time?

>> DAVID: It's a great question, Mike. And actually the activities they engage in vary greatly. They may be doing one-on-one interaction with students. They might be taking part in a larger instructional setting in a classroom.

They might be assisting a student with getting connected to other services in the community through what we call our Disabilities 101 or DB 101. And we use that as a resource tool to connect young people and adults, quite frankly, with other social service opportunities in the community.

The young person might be aging, becoming of majority age. So we want to get them connected to other resources and benefits. We might be helping them connect to early job interviews and opportunities and transporting them to those interviews and things like that.

So the activities really vary greatly. Good question, though.

Yes, ma'am.

>> AUDIENCE MEMBER: For the two that are in the schools, can you please tell me a little bit of their background education-wise and what they specialize in, perhaps?

>> DAVID: Sure. The gentleman, Nick, who spends most of his time in the schools, he has a master's agree in vocational services. And he's been working at the Center for Independent Living now for about five years. So he has a very background -- he is a person with a disability himself who has been the recipient of transition-based service as well. So he's got some personal experience as well as educational background and some employment experience.

The second individual, Matt, does not embed in the schools. He serves the transition population in our center. His background is in direct service. He has worked in a variety of different camp environments for kids with disabilities, young people with disabilities. He has a very, very, very strong technology background as well. So he tends to work with the students on technology skills, utilizing our Web-based programs that we offer for our transition services. He teaches classes in our tech lab and things like that. Okay?

So as I just mentioned, we also utilize some specific Web-based tools to build the transition program as well.

Some of the other regular services that are provided to transition students that are also part of our regular IL program are cooking classes -- I mean, these are just examples. This is not an exhaustive list by any means. But cooking classes, money management, bus training. So teaching people how to use the public transportation system in and around the Twin Cities.

Managing your DSP. A lot of young people, as they're working through their teen years, might be experiencing the use of a personal care attendant or a direct service professional for the first time. And we think it's really important that they learn early on how to supervise and interact effectively with those DSPs.

Hygiene, personal needs, interpersonal skills, and, of course, that whole other of all those other independent living type skills that we teach.

We also do a peer mentoring program with our youth with disabilities. And much like Annie described in Toledo, it's really designed to match someone with another individual who has recently transitioned into community living. So it's one person with a disability teaching another person with a disability and very, very much the heart of the Independent Living philosophy.

And it also helps -- you know, these peer relationships also help build those interpersonal skills, and they are very, very goal oriented. I always tell people when I talk about the peer mentor program that it's not really designed to create friendships, but that's often an outcome of those relationships. And our peer mentors they're not paid salaried staff, but we do provide them with a monthly stipend to help defray some of the costs of participating in the peer mentorship program.

Other resources that are available to our youth as they're transitioning into community living are housing search. We keep them in an active list of available housing stock in and around the Twin Cities. Our disability benefits that I mentioned when I responded to Mike, the Disability 101, really allows us to sit down with the student and do a really strong assessment of what their needs are going to be in terms of other community supports and then begin to connect them to those to make sure that they're getting connected to all the supports that they should be connecting with.

Connecting to other county services, getting those relationships started. Assisting with the identification of other community-based resources that would be available and useful and valuable to them. And we do a lot of that through our operation of the Disability Linkage Line, because that's really our big, huge resource asset that we have at the center. I'm wearing my DLL shirt, as a matter of fact.

We also use a Living Well With a Disability curriculum that I mentioned briefly yesterday. Much like a couple of the curriculums that Toledo spoke about, it has varied chapters in it; setting goals; problem solving; healthy reactions; healthy communication; beating the blues, there's that lonely piece that you were talking about which is so critical; seeking information, how to do a good information search if you're looking for additional services and opportunities; physical activities and the importance of those; eating well; and the importance of self-advocacy are all issues that are covered in this particular curriculum.

And then my contact information. Thank you. Yeah, Mike.

>> AUDIENCE MEMBER: I'm sorry. I keep asking you questions.

>> DAVID: Mike, that's why you're here, man. Don't apologize for asking questions.

>> AUDIENCE MEMBER: We also just started our youth program in October, and we're starting to try building relationships with the schools in our area. How did you guys get your transition coordinator into the schools?

>> DAVID: That's really an excellent question, Mike. It actually started out with one or two relationships that we had built with not only the transition program in those schools, but what we have in the state of Minnesota we have a program called Transition Plus that really provides ongoing educational services for young adults 18 to 22. And we already were embedded in a couple of those programs. We sat on a couple of the CTICs, the Community transition Interagency Committees. We had a presence on those committees.

So we had some relationship building already started. And we actually became -- we were invited by two of the schools to come in and create a regular presence there. And it was so successful and somewhat popular that other schools started lining up themselves saying, well, if they can have that then why can't we? We said okay.

Now the next step, in order to expand this, is now to go back to them and say, well, we've been here embedded like this. This is our second year. It's going really, really well. If we go away now, would you miss us? And, invariably, I think they're going to say yeah. Then the next question is, then, what value do you place on it? Are you willing to start supporting this with some financial contributions so that we can expand the program? So it was really the result -- the short of it, it was the result of that relationship building.

Thank you, Christy.

(Applause)

>> CHRISTY: Good morning. I don't know how much time we have left, but I want to start by just asking a basic question. How many of you in here were born with your disability? Okay. And how many of you are over the age of 40? Oh, good. Okay. I don't feel so all alone in the world anymore.

When I was born with my disability in 1963, so let me tell you how it went down. This is before sonograms and all that kind of stuff. And my parents had absolutely no earthly idea that they were about to -- my mother was about to give birth to a child who had a significant, as they put it, disability back then.

So when I was born, the only thing my mother remembers about my birth is the doctor saying knock her back out quick, there's a problem. That's all she remembers. So they knock her back out quick, right? And then they go outside and they tell my dad, who was a very calm individual, had majored in psychology. So he was able to immediately put that to use, I guess, and explained to him what was going on.

He leaves the hospital. He goes to a good friend's house who's a psychiatrist and talks to him all night. They go back to the hospital. They go in. They explain to my mother that I was born -- this is how they put it. She was born with no arms and only one leg.

And so before they ever even brought me to my mother, they said to my parents we think -- we have no idea if she will ever be able to walk, if she will ever be able to talk, and I'm quite sure that there's been times in my life when my parents wished that might have come true.

So we believe that you need to put her -- don't even take her home. Put her in an institution. This was 1963. And, of course, thank God, my parents said no thanks. We don't want to do that. Bring us our child, and we'll take her home.

They didn't have a clue what they were doing. They knew nobody else with a disability, had absolutely no earthly how to go about this. So they take me home and do the very best they can. And they do an excellent job, if I say so myself.

But like many of you have mentioned in here before, and Cindy talked about it yesterday, I was sent to private schools because my parents felt that's what would be best for me. They thought that perhaps in a private school setting I might be picked on less, I might have more friends.

That was not necessarily true. In fact, most of my friends, particularly in high school, were at the public schools, and I begged to be transferred. But by that time it was like uh-uh. We've put too much money into this private school. You're graduating here.

So in 1966 when I started school at this private school, they integrated me. I had my own little attendant. She was with me in kindergarten. She helped me go to the bathroom. She helped me eat until I learned how to do all those things on my own.

When I graduated from kindergarten or whatever and went into the first grade, Mary went with me. And she went with me to the second grade. And by the third grade, I didn't need Mary anymore.

But I never knew anybody else with a disability until I was in high school. And it was one person, and we learned how to sail together. I did not know very many people with a disability until I was 19 years old and started working at the Center for Independent Living part time in the summer.

So my world, I was raised in a world where I really was alone. I knew I was different. I had anger issues, needless to say when I was a teenager. Most teenagers do. My parents took me to a psychiatrist, and the psychiatrist said she's fine. She doesn't need to come back. Yeah, she's angry, but she's 15.

There was something wrong, and what was wrong was I was different. I was trying to pretend like I was like everybody else, but I wasn't. I did things differently. I didn't feel all that great about myself. And then I turned 19. I started working at the center, and I'm around all these other people with disabilities, and I was like, halleluiah, I found my home.

So I learned how to live in this world, and then I came over here and learned how to live in this world. And the disability world, whether we want to admit it or not, if we have a disability, this is our comfort zone. But one of these days, and, again, it's been said, it might not be in our lifetime. It probably won't. But one of these days, our world will become everybody's world.

Because let's face it and let's remind the rest of the world, disability is the only -- we are the only minority that you can join in an instant. Anybody in this world at any time can join the disability community in an instant. Right? It takes that one instance when you dive into shallow water and break your neck, or you get behind a wheel of a car when you've been drinking, or you have a stroke, or you're diagnosed with MS, or whatever. You can join our world anytime in an instant.

So when the rest of the world realizes that we are a part of them and we're here to stay, then I think that we will have done our jobs. I had to say that. That's not what Judith wanted me to talk about this morning. You can look at our slides and see, and I will try to go through this as quickly as I can. And I'm not good at this little thing here.

>> JUDITH: You've got about ten minutes.

>> CHRISTY: Okay.

>> JUDITH: Christy, you've got ten minutes. Okay?

>> CHRISTY: I do? Thank you. I've got ten minutes.

As I mentioned yesterday, we are quite different than most of the -- well, all of the Centers for Independent Living in here. I guess they asked me yesterday when we were up here if I had seen someone's mouth drop open when they found out that we serve the whole state of Mississippi. And, yes we do. And I think that because we're unique in that matter that Judith kind of wanted us to focus on that.

Because one of the things that we do, yeah, we have a youth program called HOT. But our staff for the Healthy Opportunities Program, they are a part of all the rest of our staff. All the training they receive is what everybody else gets. The other people in the LIFE organization receive most of the same training that the HOT staff get.

We have assimilated our HOT staff into everything else that we do within the center. They are a part of the center. I don't think that they feel any different. Cindy is shaking her head no. Oh, she says we're special. We're hot.

Again, we're unique in that way that we're -- the HOT staff are just a part of the rest of the center. And, yes, we serve the whole state, and we have six offices in the state. Now we have four independent living transition specialists, and the only difference there is the word transition. The rest of our Independent Living specialists are Independent Living specialists. But the four that are called transition specialists are those four who work with our youth, and they are the HOT specialists. And they are all hot.

There are four of them. We have them in each -- we have them in four of our six offices, and they're pretty spread out. We've got an individual in Chiefallo. We've got one in Greenwood. We've got Desmeon in the Jackson office, and we have Cindy down on the coast. So they're pretty spread out across the state. They're spread too thin, I'll admit. And we need more money so we can put a full-time person in every single one of our offices. But that's the way we work our program.

All the LIFE staff receive the same training. I bring them all into the Jackson office on a quarterly basis, and they're all trained. We talk to them before -- at the end of the training and say, okay, what is it that you need to know more about? What can we do to make your job easier? What kind of information do you need? And then we make that happen.

We focus on the same four core services that we all do -- advocacy, skills training, and peer support, and information and referral. We talked a little bit yesterday about how, yes, the information that we provide and the things that we're teaching and imparting to the young people, it is different than what you're going to give to an adult.

So I'm going to let Cindy talk a little bit about the difference of those four core services with young people and those that we provide to adults. And she's going to be really quick about it.

>> CINDY: I am. So we use the typical four services, but we adapt them to try to, A, look at them now and look at the future, but also adapt them to the youth. So like advocacy. As soon as I get a youth, whatever age they are, I am teaching some advocacy, because you can be a self-advocate at any age. You may not be a fabulous one, but you can say what you mean. So I want to teach that. So what we do is we teach self-advocacy from the beginning.

So we teach advocacy, but also that will also happens a lot in IEP meetings, which we'll talk about a little bit later. Where, also, the teaching and the doing, I will step in if I have to be an advocate.

Let's jump to the next four core training -- services and skill training. I'm not really following the thing, so don't shoot me.

Of one of the skills training, though -- I saw it the Americorps and I wanted to mention this -- with the fact that we are -- if a goal of my student is to be independent and be on their own, we need to look in the future for housing and all these different skills trainings to be independent. I mean cooking, I'm not going to teach them because I don't cook. So you really don't want me to teach them to cook, but I will get them somebody that can.

And we have an Americorps program that we talked about many times about our nursing homes transition and prevention. And something that kind of fell out there is a lot of people don't think about a youth can one day be institutionalized easily. That was one of eye-openers when I was in Americorps is I saw children in nursing homes. I saw young adults in nursing homes. And I was like, oh, snap. So that was an eye-opener to me. So I work a lot with Americorps to get the resources, to get the training, all that kind of stuff. So that's a partner thing.

So then next is --

>> CHRISTY: I thought you weren't following it.

>> CINDY: I know. But I'm trying to make sure -- I'm trying be a good girl. Wait, wait, information referral.

So information referral, that is going to be -- what I do is like we have waivers -- we all have waivers in different states. I am very aware of what waivers take longer, what waivers will -- you know, all these different kinds of things.

Say I have a 12-year-old, and they need, or they have a developmental disability. I know that our developmental disability waiver is extensively long. The parent may say they don't need it right now, but I am going to strongly encourage that parents who apply now. Because you need to look in the future and see. They can always say no thank you when their name comes up.

So, again, that's one of those when we're working with our youth, we don't get to just look at the now, we have to look at the future. So that's an information and referral thing there. We have lots of relationships with Department of Rehabilitation and all those different things.

And also with vocational rehabilitation, they have transition counselors that you need to get to know by name. Try to get a cell phone number because you're going to do a lot of meetings together.

Okay, next. The whole person. Nobody is the same, disability or not. So what we have to do is, I don't want go so you have Spina Bifida. So this is what we're going to do with you, check, check, check; all righty, then I will talk to you later. No. I have to get to know all my consumers. They're different and their personalities.

And since I do 15 counties, the area can make a person. As you all know, in a rural area, the consumer is not going to be as used to having different access things, or they're not going to have transportation. They're not going to be used to getting out and about.

And so that's something I have to keep in mind. Okay, you live here. So let me not scare you and throw all these things at you. Let me take it down a little. Whereas, if I do a Gulf Coast, they are in the -- that's more of a rural -- not a rural -- more of a city and metro area.

So if I start talking rurally, they're going to look at me and turn me off. So I have to keep in mind -- you have to keep in mind where's this consumer from? What is their culture? Because a lot of cultures, no, we take care of our own. We're good. We don't need anything.

So maybe you have to not be so forceful, kind of go, okay, I'm just here and kind of be a little bug on the side reminding them. And one day they'll probably go maybe, maybe, maybe. I do need that. So that's something that we look at. That's something we do. It's a unique process for each consumer.

And since we are in different areas, we each have different experiences, different techniques, all those type of things. But you get your niche, and you kind of go with it. And once you get comfortable, you get a new consumer that totally throws you off. So it keeps it fun.

But what we do is we take the four services, and we adapt it just pretty much to, okay, we're looking at this consumer as the transitioning. What do we need to look at now? Obviously, they need a vehicle mod now. We need to do that now, but what are they going to need in the future too? Are they IEP.

Oh yeah, also, I'm not going to get into the deep part of this. But in the IEP, there is a transition page. Part of the goal of an IEP is Independent Living. Make sure that you have what the goals of being independent on that transition page because the school is supposed to help.

>> CHRISTY: Thank you.

One more thing that I wanted to mention when Toledo was talking about the age appropriate activities, and somebody wanted to learn glass blowing, I think you said. What Cindy is getting at, in Mississippi in different areas of the state, we've never had anybody ask to us learn glass blowing. We've had people ask us to learn how to go mud riding or get up in a deer stand and kill an animal, how to get their hands on a six-pack. Of beer not ab's I'll add. Not that we teach our youth how to drink, mind you, not at all.

But, really, when you're talking age appropriate in the state of Mississippi, again, the whole point is that each child, each young person, each young adult, each up with of us in this room, we're all different. We all have different goals. We all have different desires. And so the best thing that you can do for a young person with a disability is to empower them to be their own person in whatever it is that they want to do in life, whatever it is they want to be in life, is to empower them to learn how to make those own decisions for themselves.

Because my parents didn't know -- they honestly didn't know what they were doing. You know, they really didn't. They did a good job. But the main thing that they did was to teach me how to advocate for myself and teach me how to be empowered to make my own decisions. And that's best thing that we can do for our young people.

So if we treat them -- if we treat the whole person and talk to the whole person and teach the whole person, then we will teach them those skills that they need. And I think that's the most important things to remember if you want them to be integrated into our communities.

Thanks.

>> JUDITH: Thanks to the panel.

(Applause)

>> JUDITH: This was excellent. I think there was one question at the back, and then we'll break.

>> AUDIENCE MEMBER: I'm an education advocate at my local CIL in Daytona Beach. You mentioned the youth transition page of the IEP. I have two questions about that. One is how do I get my consumer to be motivated enough to want to contribute to that page, because I know that that is a major part of their process?

And then how do I add more to it in addition to what the school already has in there saying that they'll coordinate the student and the parent with VR and other agencies? Because that's basically what ours say right now.

>> CINDY: Okay. We're going to talk a little more later about post secondary. But the biggest thing is you can get a copy of a blank transition page and just kind of have a conversation with your youth. What do you want? Explain a little bit about what's out there.

Then when you go to the IEP meeting, you say we need to look at the transition page because what they'll do is flip past it usually. So you say whoa, whoa, whoa. And then say I already discussed with Sally, and Sally says she wants to do this and blah, blah, blah. You kind of make it easy for them a little bit, but in the end you go, okay, now this is what you all are going to do. So that's how you do it.

>> JUDITH: And we'll get more of this during post-secondary. And I can just see Cindy smile and say now you all are going to do this. I didn't know whether getting in a deer stand, whether one of the life skills was skinning the deer too?

>> AUDIENCE MEMBER: Yes.

>> JUDITH: Gotcha.

I want to thank the panel very much. Kim, you mentioned several really excellent resources. If you can get those links to Darrell at ILRU, she can put them on the Wiki that was created for this conference.

Okay. You have a 15-minute break, and then we'll be talking about health care. Thanks.