TIM FUCHS: I mean, as you can see, as we go through the day, we wanted to set you all up this morning, just for the fact that this is going to be very interactive.

But we do have some things to share, to work through, but this, our next hour together is really part of the discussions we want to have to help flesh out some of these questions that are coming up.

So I hope this is giving you a sense of what the next day and a half are going to be like.

I think we have some good information to share.

We can help you all.

There is some training aspect to this.

But we want to hear from you too.

I'm wondering, to start that off, how many of you all have gotten down the road with this in your center.

How many of you all feel like you have had these conversations and defined at risk at your CIL?

Some?

 I saw four hands.

I saw one hand go up and back down and back up.

But a number of us, I know we've all been thinking about it, but a few of us feel like we've had these conversations, I would love for some of you all to share what definitions you've had.

I saw your hand go up.

Can I put you on the spot?

AUDIENCE MEMBER: Sure.

TIM FUCHS: Share about what you're thinking at your CIL.

AUDIENCE MEMBER: I work with Wendy in Birmingham, and Wendy has been with our CIL for 15 years, and so we have a, she's so knowledgeable.

In terms of transition, she's been doing that job for 15 years, so yes, we have been discussing transition for that long.

The hand went up and back down, because we have just started talking about at risk and diversion.

We talked a lot about diversion, but not a lot about at risk.

Mostly because at risk, as soon as I pick up the phone something is going on that, they're about to be homeless or about to lose their waiver or this, that, or the other thing.

I haven't had to look at the at risk.

The at risk always seems to find me before I go looking for it.

AUDIENCE MEMBER: Based on the data, we practically assume everybody we serve, all people with disabilities are at risk.

We know people with disabilities more than likely live in poverty, that puts them at risk.

We know people with disabilities are likely to be housing and food vulnerable.

We have already addressed the employment component.

So we just know right out of the shoot, at least for high school kids, we know they face barrier after barrier in order to achieve independence.

So it's a little bit different animal when it comes to someone who might be under threat of going into an institution.

We also know that it's hard to walk into a nursing home and say, we're here to round up people who think they might want to transition out of here.

That's a meal ticket for the people who own that place, so it's kind of a sticky wicket.

But again, we know that not all people with disabilities are technically at risk, quote unquote, but it's just safe to assume that they're going to be facing something on the horizon that could likely put the kabash on them living independently.

So what that is, and what that looks like and what that definition of at risk is going to vary from person to person cause we know there's no one size fits all.

But the data tells us, just rote data tells us that there are so many barriers that it's practically impossible to not be at risk in some capacity if you're a person with a disability.

TIM FUCHS: Right and we talked about this a lot in the planning.

So then if everyone is at risk, how do we keep it from every service we provide now is diversion.

So where is the line?

AUDIENCE MEMBER: I don't think we know yet where the line is at our center, but somebody mentioned earlier, if somebody has been screened for long-term care, we're assuming they are at risk, and for some time we've already been using their units in an at risk category.

But we have also just looked at what ILA has provided and ask people, and if they say they are, then they are, we don't challenge them or ask them to prove anything.

But that means we have a lot of individuals who work with that are at risk, because they don't believe that they are, and we're not going to say they are if they don't feel they are.

We just ask.

TIM FUCHS: Yeah, that's right from the language of the law, that people have to self-identify.

So related question, then, how many of you all, like Michelle, have developed something to help staff help consumers figure out if they're at risk?

Anyone?

So nobody, that's fine, I kind of expected that.

So what are some of those challenges then, and how can you all guide people towards figuring out if they're at risk?

AUDIENCE MEMBER: Which one?

That was funny.

The risk I have at our center over in Greenville, North Carolina, I don't know if you know about last year with Hurricane Matthew really flooded our area badly.

One thing you guys haven't mentioned much today is homelessness.

We deal, a lot of our diversion is from homelessness.

I'm on a committee that meets every week with different people from the community, different businesses on how we can try to get people out of the homeless shelter.

Our time is coming up, our homeless shelters stay full.

The waiting lists stay full.

So then when their time comes up if there's nowhere we can place them, they bet booted back out in the streets, there's nothing we can do about that.

And 75% of what comes through that list, they all have disabilities.

So that's one of our biggest diversions and biggest ways of saying that, you know, as long as we can try to give them some kind of subsidized housing, cause all the ones we pretty much take either have SSI or SSDI.

Now we can get subsidized housing and be there in Greenville, the problem is when the flood came, that pretty much in a way flooded that subsidized housing waiting list.

That's the problem we run into, not enough housing in our area.

TIM FUCHS: Right, of course.

AUDIENCE MEMBER: About a year and a half ago, our center began a process of stream lining our intake and how we screen people.

So one of the things that we looked at is what is at play when someone walks through the door or is calling us because they need services?

So our staff had done internal staff development, and understanding, for example, is mental health present and what is the role of a mental health condition with someone that may also have a physical disability.

And then, on top of that, we look at what is the effect of the trauma that this person is suffering because of either the disability or the circumstances surrounding this person's life?

These are components that we use when we start screening the individual in order to do an assessment of acuity in his or her life.

That requires a little bit of a different kind of approach because you have to look beyond the physical and try to understand factors that are not present and you have to do that through the dialogue, asking questions, and most importantly, creating a rapport with the person right on the spot.

You have about 30 minutes at most to develop your bridge with this person and getting them to either commit or accept some kind of service.

Yes, it is self-disclosed, but oftentimes they're not really sure what it is that they're supposed to disclose you.

On the other side of the table, you have someone who may not fully understand that there could be a mental health issue, a disorder, whether biological or because of an injury, and you also have the effects of traumatic advance such what has happened in a person's life and how they are coping with it.

So what we have developed is a screening process that actually looks at all the components before putting together an action plan, because what you see in front of you may be just the tip of the iceberg and you have to lead this individual to different services, you have got to have at least a basic understanding of what is happening with this person, both on the physical side, the trauma side and the mental health side in order to paint a clear picture of where you need to go.

TIM FUCHS: Thanks, I was just going to call on you.

Go ahead Michelle.

MICHELLE CRAIN: That's the reason one thing I say, how many of us as CILs actually get a consumer to come in and say, oh, I'm here to get diverted from a nursing home?

Or I'm here and I have some of that advocacy, that peer support and oh yeah, throw in a little bit of the independent living skills training.

That's not the case, when they come in, they're coming in to put out little fires and it's up to us to see that bigger picture, based upon the experience that we see.

And that person has something to share to, because every person that comes in we learn something new.

And something that we can pass on or to utilize as we are helping other people.

That's what that whole peer to peer process is, and I think we as centers should take pride in that.

TIM FUCHS: That's great.

I'd like to hear from Michelle, but also from any of you.

How do we maintain that relationship, those peer relationships, and how do we make sure that we're still true to IL when we are using assessments, and forms, and screenings?

What does that look like?

I'm picking on you, because you guys have that assessment form we were so impressed by.

But as a group, as a movement that has eschewed the clip boards, scrubs and suits, how do we maintain that and still use a form to help us define some of these things that we have to define.

MICHELLE CRAIN: Trust, have you to be able to establish that trust.

I know that we had our annual training and we're in the process of revising our at risk survey, and when we first implemented the survey, I said, okay, I want it.

I would like for you all to fill this out for each and every consumer.

Because I assumed that they are establishing that rapport with the consumer to where they could fill that out based upon what they know about that consumer.

That wasn't always the case.

However, what I found out is that our relocation specialists, it all depends when you're doing that at risk assessment.

The relocation specialist, they do it of course, after that, because they've already established a transition goal, but any time you establish a transition goal, there's a diversion goal there as well.

And so it's the time when you're filling out that information and then they were telling us, they would say well you asked us to fill it out during the intake and they were filling it out to where it became a yes/no thing as opposed to the open ended questions you should be asking in order to get at what makes that person at risk.

Why is that person in a nursing home or might end up going to a nursing home?

So it's establishing that rapport and not just checking off a list.

TIM FUCHS: Great.

AUDIENCE MEMBER: Just one of the things I've gotten to do when I talk to people and I give presentations, I will actually take a box with me and put it on the table and we'll talk about the box.

And then I pull it up and I pull it apart and lay it flat down on the table and I say see you can't use the box because there's no box.

And that's been a visual tool that has made a difference for people.

You've got to I don't know, I mean, I guess I have been doing it for so long.

But I'm in that place where I know the check list is really important, but I have also seen agencies that go through this process that there's a check box for everything and everybody they talk to they go through this long list, things I wouldn't be willing to tell people that they just expect you to be able to find out at intake, and then everything depends on you answer every single question on this survey, and then you can move on.

I don't think that that's fair either.

I think that's too restrictive and too, I don't even know the word for it.

Like I said, there's stuff on it that I wouldn't even be willing to tell people that I did not know.

Check lists are not the answer to everything.

You need some kind of, you need some kind of structure, but I just get really nervous when we start filling in the little boxes and the little dots.

I know that everybody here does too, so I don't know what to do with that my own self.

I figure the biggest at risk is if you're living in Alabama and getting $733 SSI every month and there's no available Section 8 housing.

Because how do you do it?

I mean, that's about as basic as it gets.

I hate to have people keep saying to me, but they ought to be able to do it, and I am like, but how do you do it on 733 a month?

TIM FUCHS: True.

AUDIENCE MEMBER: So we use the ILRU independent living plan kind of primer, I think Darrel, you participated in that with Roger Howard, and we're big on follow-up.

First and foremost, when we identify ourselves, we proudly identify ourselves as being a civil rights organization.

We describe what the independent living philosophy is to people, and they're oftentimes shocked by it, they've never heard this turn of phrase before.

So right out of the chute they have this understanding that we're different than other disability organizations in the city.

Our mandate is different, our mission is different, and we are fervent believers in the independent living movement.

So right out of the chute, people can identify the CIL as being kind of a unique entity they're not necessarily familiar with it.

But again, it all boils down to a few things, especially where you, I mean we can ask them questions, where do you see yourself in six months?

Where are you going to live?

How are you going to fund it?

I mean there's all these questions that we can ask someone during the intake interview that seem to resonate more with them when we call them back in a week and when we see them, when we set up our together time, our meeting times and things like this.

Again, we immediately differentiate ourselves from other organizations and not everyone is used to the civil rights dialogue that we use with them.

But it says in the ILRU independent living plan guide book, again, that rapport building, the follow up, sometimes people are so astonished, and we never expect anybody to call us back.

Because we're talking about a vulnerable population of people here where we're asking them to do something that may not be within their capability in a week, because they're oftentimes again, vulnerable on a number of different levels.

So the follow up that we initiate this oftentimes a 30 second phone call can pay such a major dividend that they're just impressed that we would consider calling them back in the first place, even though the independent living plan dictates that we do call them back every week, or we say, hey when do you want me to call you back?

I don't want to be a pest, is a week good, two weeks better?

When can we communicate again?

And again we're not sugar coaters, we're rah rah people indeed.

I'm a rah, rah guy to the letter.

However, we're decidedly forthright with folks.

Just to allay any preconceived notions that they have about how simple it is going to be or how easy it might be.

We presume competence.

That they are going to be able to understand the barriers that we are going to be looking at in the next six months to three years.

So we ask them some very pointed questions, some very again forthright questions with the understanding that again, we're not going to do anything that we know you can do for yourself.

However, it's a lot easier to go into the fray when you know you have someone in your hip pocket.

And they like that, especially when they get a phone call later, James keeps calling or Krysta keeps calling.

It's kind of one of those things where, in the end, if we end up allotting 10 hours of time for each consumer, a lot of that 10 hours is in five minute increments on the phone.

But again it all boils down to where will you live?

We're purveyors of the housing first model where we have this belief where it's extremely difficult to get a job, it's really hard to get in home services, it really hard to plot a course unless you have a safe and stable place to live.

So it all boils down to that.

And then a lot of times, if you can believe it, we encourage politicism.

Political action.

Because we're so up against it, that we encourage people to become more politically active, and it's hard to do when you lack efficacy, I get that.

It's hard to care about politics too much when you're trying to feed yourselves and your family.

But I like to think that LINK, which is Kelly Bucklands CIL of course, he started this LINK, this CIL in the late '80s.

You know, the civil rights moniker is really big for us, because people respond more thoroughly to it than if we were just another kind of milk toast organization that is spinning our wheels trying to get things in the community that simply don't exist.

So the intake to identify someone who is at risk, I mean there's a few questions we can ask them and ascertain pretty quickly what the living situation is like now and what's is likely to be in six months, what it is likely to be in a year.

The continuum is so interlaced and intertwined that you can, again it doesn't take a genius to think when people call and they are looking for certain things, we can kind of guide the conversations to get the information we need in order to be able to steer the bus in which ever direction.

DARREL CHRISTENSON: I wanted to add a little bit there.

I think one thing that is key in the discussion is what Michelle just said and that is gaining the trust right up front.

It's not a matter of coming right in full force, asking a barrage of 14 pages of questions like you do for a Social Security application.

But rather, when you come into a center, you see folks with disabilities and right there, visually, if you're new to a disability or new with a life situation, you come into the center and all of a sudden, oh my gosh, there's all kinds of folks with disabilities, that in and of itself I think helps to add the credibility and add to the trust that Michelle talked about.

The other thing I want to say is that you come in with an independent living philosophy.

You're asking them questions.

Normally that isn't the case with a medical model.

They tell you what they think as a professional.

And oh, my gosh, you come into a center and they are asking me questions and what I think, how I feel about my life, what I want for myself?

Right there, that's new, that embraces me to the center, to the staff person, I like that.

The follow-up, I can't tell you how many times my staff are doing the follow-up calls.

Consumer calls, hi, this is John Doe, here is my number, give me a call back.

And you know what?

My staff actually calls people back.

And they are surprised and shocked.

Like, oh, my gosh, thank you so much for calling me back, you're the first agency who has done so.

I'm thinking how low is the bar?

How low is the bar that people are calling agencies around the community and they don't even get a call back?

That's just appalling.

And if you're not doing that, then how can you gain the trust in order to ask the questions to know about at risk and what services are appropriate?

How does that happen?

You've set the bar so low.

The last thing I want to say, in transition diversion, nobody talks about it, but what about having purpose in life and getting a job?

Employment is like the fifth thing that we talk about.

That should be financial independence, purpose in getting up every day, and having a job.

So when you're in a nursing home or you're in an institution, what is the purpose of today?

Is it to see Jerry Springer and what 45 has tweeted out today, or is it to say, I have a job to go to?

I have meaning and purpose in my life.

I have financial independence and I'm out doing life like anybody else.

I think all these things are so important.

We talked about it during break that you can't just take one thread and pull that out.

Another thread and pull it out.

It's all interrelated.

But that's part of the questionnaire, asking the right questions.

Because how many times have we had a caller asking about something and when you spend 10 minutes with them, you find out that really is the surface, what they are really calling about are these other two things.

But does staff take the time and are they trained to really listen to what the person is saying?

AUDIENCE MEMBER: To follow up on that, at our center, we start with the phones, we feel they are critical and our staff are trained to listen to someone's story and to really hear what they are saying.

As you just said, it's usually a series of services that an individual needs, that they are not quite aware that centers perform.

So peer counseling is essential at our center.

What the young lady earlier said, it's a fine line.

How do you maintain all of your compliance data?

How do you gather that data?

And how do you help the individual to know and understand that they've come to a very, very special place?

A place they haven't been to before, ever, where someone will call them back and say, how did that work out for you?

How did that referral work for you?

So it's a fine line.

We found at our center the most successful, or the most effective methodology for us is in the beginning staff are trained to listen to the individual's story, listen to the consumer's story, let them talk.

We've got our forms, and we're very good at forms, we're very good at data, but the way that we get the data is tell us your story.

What are your needs right now?

How would you prioritize your needs?

And then again, we always know that someone has come to us where they are at some kind of risk of being institutionalized if they are not able to o locate housing, if they're not able to access their own benefits, their own medical.

But we don't tell them you're at risk, we say, let's work on housing, let's work on transportation, you need groceries?

We have some referrals for that.

Let's work on that.

So it's a story.

And the key to really keeping the independent living philosophy alive and to having people become vested in their story is to help them learn that it's their life, it's their choice and they have the right to live as they can afford and as they, well, as they choose and as they can afford, and we're there to guide them, but not just to that point.

But also bringing in the political aspect of it.

It's holistic approach that we use, you bring in a little bit of everything.

But it's their story, their life, help them to buy in it, know that we're there, we have a movement that's strong to help support them in where they want to get.

As far as identifying at risk, that is through the conversation, it's listening to someone's story.

AUDIENCE MEMBER: I really don't need to talk anymore, because.

Basically, I was going to say, Michelle, you hit it on the head when you said it's trust.

It's all about trust that you have to build that trust, no one is going to come in and tell you those dire situations that they are in for one reason, they're afraid.

They are going to think, are these people, if I tell them I'm living in my car, are they going to report me to adult protective services?

What's going to happen you know?

So you really have to develop that trust before they are even going to tell you their real situation.

And we've been very intentional in developing our initial intake around where you can go in and just have a conversation.

People are so intimidated when you pull out that stack of papers and say, okay, I have to check this off and answer this question.

But if you can just sit down and have that conversation with a person, you can fill it out when they leave or whatever.

We all have the requirements that we have to do and stuff, but it doesn't all have to be done on that initial conversation.

You've got to gain the trust of that person.

MICHELLE CRAIN: Back to what Darrel said as well, they're so used to people telling them what to do or telling them this is how it should be and we tell our staff, it's not your job to tell them what to do.

Your job is to pretty much work with them, make sure that they know what those options are so that they can make informed decisions.

AUDIENCE MEMBER: This is Jim again.

I think that sometimes our staff get this idea that numbers are so important that they have to see so many people.

And sometimes they are important, and sometimes our different funders want to know how many people we're serving.

But to me, it's more important to have quality services than it is to have numbers, and sometimes that means when I was in Los Angeles, I remember coming up with an intake form and the staff just grumbled and complained about, it already takes us two hours to get through an intake, and this is going to take four hours, it was more of a narrative and it was really trying to build that rapport with the person, sometimes it meant having a couple of meetings with them.

But I think spending the time with the person, when you consider that that initial meeting is the most important one you're going to have, you're building that rapport, that trust, and you're finding out their story, and sometimes they can't tell you that story in 15 or 30 minutes.

They have to be able to express themselves.

The other thing I think Bruce brought it up this morning, when they come in, it is not just about seeing people with disabilities, it's seeing people of color, it is seeing people who are gay, seeing people that are like you.

It might not be that person that is sitting with you, but you saw them in the office or down the hall or whatever.

I think that's really important for people to be able to have that initial trust.

Sometimes it's just a poster on the wall that will show them, hey, I think this is a safe place for me to come in and talk.

So I think there's so much more in building the trust than just hey, I'm a good person, tell me your story and I will write this stuff down.

They will put up with the writing stuff down if they think you're going to help them.

AUDIENCE MEMBER: Sorry for being such a blabber mouth, you guys, but we tell people straight-away, this is your CIL.

We exist for you.

You get out of the CIL what you want to get out of it.

We use terms like intersectionality and cross disability, but especially intersectionality.

But again, we're proud of the fact that we tell people that we work for them.

And we're very earnest in saying that, you can smell BS a mile away.

But the staff that works at LINK is so passionate about this.

We hear people say all the time, they never had anyone identify their organization as being mine.

And they again kind of identify with this understanding that this is their CIL.

And for those of you that have never been to Lincoln, I'm sure that is everybody, it's a universal access building.

It's a flag ship of accessibility and intersectional to the letter.

We're involved with other progressive organizations that promote LGBTQ issues, union issues, we talk about organized labor, and all these different organizations that we work with, when people start to see that, they start to gain a sense of normalcy or community from this.

It is not, it is distinctly targeted towards people with disabilities, but it's an integration question.

We use that term all the time, we want integration.

The language that you use in describing the CIL will resonate with a lot of folks.

Where you very earnestly differentiate yourself from other organizations within the system, because again, we know that folks are told no so regularly that if they can come to a place and be told yes sometimes, we want that to be the CIL.

Their CIL.

TIM FUCHS: Good, thanks, James.

This sounds like it's going to be easy then, right?

PAULA MCELWEE: I want to say something because I work with centers that are in trouble most of the time.

I get to come to training and stuff like this, but usually it's somebody who has gotten in trouble, so they're not doing something they should do.

So I don't always get to see the shining examples of things we're doing out there, although I know them in my heart and I know them from my own experience.

Now my experience is on the other side.

Let me tell what you I've decided the difference between the two is.

Organizations that decide that there's service delivery and they have to do service delivery have missed the point.

They get lost and they have this mission drift that happens, because they forget that we're a community.

And organizations who build community around their center are doing the right things.

I love hearing all of you talk like this, because I often don't hear that side of the story, I often hear this other one and I want to pull my hair out.

Yes, we want to do service delivery, but we want to do it within that community context.

And when we forget it, it drifts away.

If some of you are new and this is new to you, hold on to how it feels right now.

Isn't this what the movement is all about?

It isn't all about service delivery.

It's all about a community.

TIM FUCHS: That's great, thank you, Paula.

Let's pull the thread a little bit because I think there's a middle ground.

And I love hearing, I think I'm sure we're all on the same page, it's really great to hear that when you start from a position of trust and a conversation amongst peers that determining at risk becomes easy.

However, I know that there is still a challenge here.

So I would love if a few folks are willing to put themselves out there, who is still struggling with this idea or needs some help thinking about imagining yourself back in your office next week explaining this to staff.

Are there things that we still want to explore this afternoon about who is at risk, what it means to be at risk, and how you're going to put that into practice at your center?

AUDIENCE MEMBER: I have been thinking lately about the whole problem of the institutionalized personality.

If I approach my people and ask them if they're at risk, they don't consider themselves at risk.

Their default setting is I belong in a nursing home because I'm a person with a disability.

And if I fail, that's where I'm going to have to go, and I'm going to fail because eventually in Alabama the services are going to fall apart because there's many, many, many we don't have.

And so I have been spending some time trying to figure out, I have a friend who works in virtual reality for people who have traumatic brain injury.

I have been trying to figure out, I have been doing this for 15 years trying to figure out what to do or how to help with that institutional mentality that says, I have a disability, I'm going to fail eventually, the supports are going to let me down, and the only choice I will have is to go back into the nursing home.

I hear it more often with people who have multiple disabilities.

But when you think about all of the sink holes and the mines and stuff that are out there for people.

If it's overwhelming for me as a person who has been a social work professional for 33 or 34 years, how overwhelming is it for somebody who has been in a nursing home for 10 years, five years or whatever and they have absorbed that this is who you are and this is where you belong?

Yet it's hard with transition.

You can't cram a whole lifetime worth of learning into somebody in the time it's going to take to transition them.

So when you move somebody, they're going to have, there are going to be issues and there are going to be problems and there are going to be things, God help us, that we didn't think about even though we try to think about everything.

I guess I would like to know what other people think.

Bottom line, that's what I come back to again and again and again, and why I'm trying so hard with diversion.

Cause if I can keep them out and they don't get into that kind of thinking, it may be easier.

I don't think nursing homes are really all that different from state to state.

But, I've moved people ranging in age from 16 to 101.

And the common ground is they just learn to be defeated, whether it's the nursing home that's done it or their experience with their disability has done it or whether it's their prior experience of trauma or homelessness, abuse, or whatever.

I did domestic violence for three or four years, I will never forget the woman who called me and said, my husband is not abusive.

He just tried to crush me between two cars.

I was on the phone and I said, he's not abusive?

He just tried to crush you between two cars?

And she said yes.

That was how she saw the world.

It's not the same, it's not exactly the same context, but it's the same problem.

Here she is, her view of herself is, you know, she's with this guy who is not abusive.

He just tried to crush her between two cars.

So there's some overlap there, I'm not quite sure how it all works, but it's how that person views themselves, we can bring new things into it, but what can we do to empower people to see a new future for themselves when they have had this thinking for so long.

It's not easy, but it's the one problem that I keep banging my head on.

DARREL CHRISTENSON: I have a couple things to respond to that.

First of all, you need to play to people's strength base.

I mentioned this earlier rather than all the things that you can't do or need help with, go, on a strength based basis and what you are capable of doing, if they're in an institution, build on that.

It's always better and easier if you hit people with the IL message in rehab early on, because now folks are only staying for about three weeks at a crack before they are thrown out of rehab.

Insurance, that's all they'll pay, not like in the old days where they would stay for three or four months.

Okay.

So our mission should be to hit people with the IL philosophy in rehab early on with the new injury so that they don't get in that downward spiral.

Secondly, if they happen to be out of rehab and in a nursing home, hit them early in their nursing home stay for the same reason.

They haven't had a chance to become institutionalized in their way of thinking, so if you hit them up early with the IL philosophy and with the pompoms and with a strength based mission, then it's easier.

The peer mentor model, of course.

You show people that you may be a quad, I'm a quad, you know, we're all a quad, quad, so here we go.

We're all doing life.

You know, here a quad, there a quad, you know.

Cheap laugh, okay.

And self-image, I mean, it's been shown in studies that if someone has a positive self-image prior to a disability, they recover and rebound faster.

And so when we can get the pompoms out to our young people with or without a disability, they have a better self-image and body image than if a disability happens along the line, then they can rebound better with that.

So those are the ways I think that you address that whole, you know, institutional downward spiraling, this is all I can anticipate mentality.

So there's a lot of things that we can and are doing.

BRUCE DARLING: So I liked how, I don't remember the term you used.

I wrote down mine field, but the idea that there are all these places where you could basically hit something and that's what throws you into an institution.

And I think for me, you know, no one really wants to talk about those things.

You know.

I just think of myself and I probably do a bit of self-disclosure with folks to sort of build trust, to say you know honestly, I didn't want to talk about my diabetes with my doctor.

That was the last thing I wanted to discuss.

He basically had to send a letter that said, Mr.

Darling, if you die, it's your own dam fault.

Before we could actually open up a conversation in a real way.

I said I know who this letter was addressed to.

It says my name, but it's really your insurance company, I've sent those letters.

Getting to the point, like, people have to be willing to have that conversation.

One of the things that has been helpful for me, I'm not at the point where I feel I have the answers on this one.

So is potentially giving people, it is not necessarily at intake that you know that someone is at risk of institutionalization, or that this is actually a diversion.

It may actually be much later in the process, but there are some things we know are right up front, red flags.

So in my experience, previously being institutionalized is completely a flag that says, okay, this individual is at risk.

Pay particular attention.

Maybe they're just calling up for advocacy and saying, I'm having trouble with my home care agency or whatever.

That is a red flag.

Again, I'm in New York, we have providers that want to shove you away.

But it really is difficult.

I think for me trying to figure out how to translate that body of knowledge of these are the risk factors into something where we can actually make reasonable assumptions, can actually turn those into the things we need to use to report and highlight the work we're doing, that's where I'm struggling is how do we actually translate that into something that becomes useful.

I think the tool that Michelle has developed is a really good start for that for me.

I think that's one of the things I'm going to take back to my centers.

That's a real useful tool.

But I also don't want to take credit for something that we didn't really do.

So just because someone was in a nursing facility and they call up and they say, hey, I need some information on the home energy assistance program, can you connect me and we give them that information, that doesn't mean it's a diversion.

Sometimes a question is just a question and an answer is just an answer.

And I don't really feel like taking credit for that as, ha, we saved this person's independence really fits the situation.

I want to sort of be earnest in capturing the things that are real in what we're doing.

But I'm wanting to listen for where is that, I don't know that any of us has that answer, but I think that's one of the things I want to balance.

AUDIENCE MEMBER: I tell people on a regular basis that our mission is to empower people with disabilities to fully participate in the community.

I know about the services and I know about the staff, but I have an ongoing conversation with my executive director about when you're doing transition, you have to empower, you have to get to, nobody can empower you, you have to take the empowerment yourself.

And it takes people who have that institutional mind set or whose power has been taken away from them by outside events a while to begin to realize that empowerment is something that applies to them.

And so I tend to be really, really patient with people.

I don't know how it affects my numbers.

I guess I will find that out.

But after 15 years, I'm reasonably certain I know what I'm doing.

I may have just answered my own question.

Thank you, Bruce, for your ideas and Darrel for your ideas, because we're always thinking and trying.

But I think the bottom line is sometimes it take a while to empower somebody to even believe that they can be empowered.

It takes time to teach somebody or help somebody understand that they can be empowered, that they have some control here.

And maybe that's the hardest piece.

Once they pick it up and run with it, then it's easier.

But getting them to the point where they feel like they can participate and make decisions and feel empowered and not give their power away to somebody else, that's a big chunk of what's going on.

MICHELLE CRAIN: That's what that peer support is all about as well, and them seeing other individuals like themselves achieving, you know, their goals.

AUDIENCE MEMBER: So I have had so many different thoughts cause this has been such a, I think we have to be careful of some things too.

First of all, you have to acknowledge somebody's vulnerability.

If you have significant disabilities, how you're going to access health care and all of those things are not hypotheticals.

We can't say, oh, let me tell you, I'm a success, I know you can be a success too, without saying, I hear your fear, I see your anguish, hell, it is my fear, it is my anguish.

I have significant health issues, I don't know what I would do without health care.

I think sometimes, even though I'm a big cheerleader, pompom person, hey, we can do it, I believe c everybody can live to their fullest potential and you get to define what that is.

I cannot dismiss your experience, because when I do, then I'm dismissing your experience, so I have to be able to hear you.

Of course you know the adage of what's the difference between an advocate and complainer, an advocate has a solution.

But sometimes the solution is, it seems very simple or again because most of us, like in our center, most of us are people living with disabilities and sometimes that's great from the peer mentoring perspective, but it's also, well, I did it, well, if I can do it, you can do it too.

In that moment I've devalued, I have diminished your experience.

The other thing is there are serious outcomes to long-term institutionalization, there's been a lot of studies done on what that does.

Look at people who have been incarcerated for 25, 30 years, they're released.

Are they happy?

For the first day, and then they're overwhelmed by the life choices that they are having to make every day, that they have never had to make, the same thing happens when people who have been institutionalized.

We've learned some of this the hard way.

We have worked really hard to get folk out, they're out for a while, and guess what?

They want back in.

That's their choice, we can't forget that.

It's like freedom of speech.

You can't just support people when they are saying what you agree with.

Our philosophy is the same way, my job is to create choices for you, to help you access those choices, to give you the resources, give you the information, but at the end of the day you may make the very choice I don't think you should make, but it's your choice.

Now, at our center, we've created monthly social events.

Which I think have been very helpful.

Because even though I'm a peer, they still see me as not quite their peer.

But when they come together every month and there's a whole group of them that come every month and they are talking to each other, they are sharing resources, they are empowering each other, they are connecting each other.

I would say when you do your intake, put your paper down, don't look at your computer.

Have a conversation.

Let's build trust, you know.

But I think that it's, we're all doing this and we've all done it and there are a lot of people in this room that have done it longer and much better than I do it.

But I do think that we cannot forget that there was a time when I was a 29 year old young person who had this life threatening diagnosis and looked at my small children and said, oh, my God.

What am I going to do?

And I'm pretty empowered, but I was terrified, that was what I wanted to say, but you wanted to say something too.

AUDIENCE MEMBER: That's difficult to follow up.

Mine is basically a question.

One of the things on our intake, we highlight confidentiality.

That's obviously the key to all of our relationships, but there's that tricky phrase that's in there, except for we have a duty to report.

How do you guys soften that language?

Because I've watched conversations take an abrupt right turn when they hear that.

Especially when you're in a diversion context where a lot of times some of the factors that could make them a diversion candidate are things like abuse or some form of neglect.

How do you guys soften that language such that you don't shut down the conversation?

MICHELLE CRAIN: I know with us, I told you we were looking at putting that particular factor on our at risk survey, and phrasing it.

I'm glad I'm here, because I mean, I see you all as possibly helping us out with that.

How to phrase that.

Because one of the questions that was on the frequently asked questions is, what is our obligation to report once you find that out.

Be we all know we have an obligation to report once we find out that there's abuse.

Have they disclosed that to you?

Are they currently in that situation?

Of course you're not reporting past abuse, because that's been taken care of.

Well, we assume that that's been taken care of.

But we're looking at current incidents of abuse and how they disclose that and how staff is to report that to their supervisor, and then what we need to do with that next step as far as the supervisor reporting that information.

So we know that we're getting ready to go down a slippery slope by putting that on there, but at the same time, if they're being abused, don't you want to report that information?

AUDIENCE MEMBER: The other thing to remember with APS is it's up to the consumer to okay further investigation or not.

I always let them know that they have the choice to say, no, you can't interview my husband, my sister, my neighbor.

I don't give you permission for that.

So that's one way where they do have some choice.

But, Michelle, I have a question for you.

I am trying to vision going back to our staff and saying, okay, we're going to do these diversion check lists, and we know centers for independent living, mostly what we do is information and referral, whether that's right or wrong or whatnot.

One thing that we do a lot of is those benefit access applications for the free bus passes for the fixed routes.

So if someone calls us and says, can you help me with that application, I go through that screening risk, if they need that pass to go to work, if they don't go to work, they'll lose their job, lose their apartment, they're at risk.

Do I even have the right to ask them those questions?

And what if they are like, I just need to visit my aunt every week.

If you don't visit your aunt, you're still not at risk of going into an institution, so how do you negotiate those types of calls?

MICHELLE CRAIN: Well, pretty much what I said is that when an individual comes in and you're talking to that individual, they will disclose to you when you explain and when you want to communicate with them.

You being able to explain why you need that information, but that doesn't take away the fact that it's still up to them to say, I want that service and, no, I don't want you all off in my business, so either you'll help me with the bus passes or not.

That doesn't preclude them from saying, I don't want that service.

We have to keep that in mind, we don't want to force on them what they're not willing to take in.

That's up to them.

That's just part of choice.

AUDIENCE MEMBER: I'm like Bruce in this gray area where I can see our staff going, is this diversion?

Is this diversion?

What about this?

 What about that?

I don't have clear lines in my head of what that is.

MICHELLE CRAIN: Sometimes a service, like you say is just a service, and sometimes that's all they want from you, and we have to be willing to accept that.

Even then, we're still there for them.

AUDIENCE MEMBER: One more question for you, Michelle.

When you're using that check list, you're doing that over the phone or in person?

MICHELLE CRAIN: Actually, we like to do that in person.

And to be quite honest with you, when we say that we're using other tools, it's, I mean, like I said with the relocation specialists, they have gotten to know that individual that's in a nursing home to the point to where they can go and just, you know, fill out that questionnaire.

So that just becomes another tool, you know, to be able to say, okay, they are at risk.

And another reason why the at risk survey is important, because you're looking at a way to sometimes measure.

I think someone over here had mentioned something along the lines of if the individual just says, you know, they're at risk, then they are at risk and we should go with that.

And the fact that they have a significant disability makes them at risk.

Why not start looking at levels of at risk?

Because, you know, like with transition, we know that when they get out, we have a follow-up tool to where when they first get out, you call them once a week, the second month you're calling them twice a week.

And finally they just say, leave me the heck alone, I'll call you when I need you next time.

Maybe we should look at maybe diversion like that.

I think tomorrow, we're going to be talking about the different services that go into transition and diversion, and what you will find is that those services are almost identical.

They are almost identical.

So again, someone over here mentioned something about the qualitative, and of course quality is more important, but you can't forget the fact that we're talking numbers when we're talking to our legislators.

Unfortunately that's what they understand, and being able to get a measurement just for that purpose if nothing else.

We know that quality is better than numbers.

Consumers don't want to be considered numbers.

But we still can't avoid that aspect of things if we want to continue getting funding and to be able to convey how important our services are.

Sometimes that's wrapped up in the numbers, and we can say that it's not, but it is.

AUDIENCE MEMBER: I want to touch on what this nice lady right here said and the one in the white sweater and the one on the end down there said about vulnerability and comfortable.

I have had a couple, maybe a few more individuals who have called me and said, I have had agencies close the door in my face, or I had an agency that was working with me and they decided they didn't want me anymore the minute I went into the hospital.

Because they waited for them to go into the hospital so they can drop them, and then they call and they're like, I got my guard up, but I want help, but I'm afraid.

What can you do for me?

And they initially don't want you to come to their home, because they're afraid.

And they are not vulnerable, well they are vulnerable, but they're like, how can I trust you.

So my job is to say, okay, what do you want me to do for you?

I don't know what I want, but I know I want help and I want to stay in the community, but I don't want to have the door closed on my face again.

So I'm nervous, but what can you do for me.

So then that's where I come in and I tell them, okay, so let's figure out together what do you want.

And then we can go from there, and then long story short, I have got them to a place where they are comfortable and then we can meet at their home or the hospital, or where they're at and we get to that point, and then my job is to go from there to make sure that whatever the agency has done to them I'm not going to do.

And they are going to stay successful in the community.

Or once they get out of the hospital, because they're so afraid of going in the nursing home, but they have every door closed on them and they're like, what can I do.

Center for Disability Rights, I'm going to give them a call, because they can be my last hope.

MICHELLE CRAIN: That's exactly it as far as the telephone call.

That's what I tell staff.

You know you might be the reason why that individual decides to check out of life or to check in with life.

So I just.

AUDIENCE MEMBER: I don't even do the intake like what they were saying, that intake stays in my briefcase.

I don't bring that intake out until they are ready to say, all right, where do I sign on the dotted line?

And that's when I bring out the intake, but other than that I need them comfortable with me first before anything.

So then that way they can say, okay, she's not like all the others.

But there's still a process, and by the time I'm done with them, I created this great relationship with them, professional, where I can still call them up or they call me and say, how are you doing or do something down the line, like I got about a month ago they donated expensive equipment to the company because they were gracious and they were happy that they were still in the community and the company helped them because we were their last resort.

TIM FUCHS: That's great, thank you.

AUDIENCE MEMBER: Thank you, Stephanie.

I just wanted to also comment.

I mean, I'm the manager of transition diversion services, so we have our own special department that focuses on transition.

And diversion.

So we get calls in.

I mean, I don't sit there and think is that diversion?

I think just having the expertise of knowing how to discern the calls coming in and using the other supports in the agency that we have can really break it down as to what's for our department and what's for the other departments.

But I think the example that Stephanie just said is a perfect example of what a diversion is.

We have people that have home care and the home care agency says, well, you've gone through all the staff that we possibly have because of your refusals of service or they, you know, and the person says, I never refused service.

So I think it's an example of you're on that person's side.

Hearing the whole thing, not being judgmental.

We never say, well, you refused the service, that's your fault.

That's not us, we want to get the whole picture of what's going on and always, you know, always know that we're on their side.

TIM FUCHS: Great, thank you.

So what really is coming through to me is this theme, it reminds me of I'm going back to slide six from this morning, when Bruce talked about the overarching principles, the IL philosophy answers many of the questions and guides you through the process.

So whether it's establishing trust or whether it's acknowledging people's personal experience or whether it's not judging people or using the IL philosophy against them that there are some big questions that have been raised with the new core services and with determining some of these thing about who is at risk.

But to me, if you'll excuse me, at the end of the day, I think the thing that we might risk is a diversion gets counted as an IL skills training.

While you figure this out for year one.

These are some of the things we worked through with the youth training we did back in April.

What's high stakes is assisting people that are coming through your center that are at risk.

That's the high stakes part.

The forms, whether you call it the 704, or the PPR or whatever, what services are getting recorded, that's important, but it's not high stakes.

So as we work through this together as a community and as a staff, it might take us a year to nail it down.

Maybe your diversion numbers will come up as you have these conversations, figure out your forms, and protocol and how to take what's beautiful about IL, which is turning peer conversations into numbers conversations with legislators, fights for funding, that will work itself out.

I don't mean that to be a cop out, but that's kind of what I loved about this afternoon's conversations, we know what to do.

We know how to do this, and we're going to figure out some of the forms and processes over the next year.

And starting tomorrow too, like I said, this is going to be interactive, but tomorrow we're going to talk more nuts and bolts too.

We're going to look at the form we've been alluding to that Michelle's center uses, we'll look at that in depth.

We'll talk about some of the similarity and differences between transition and diversion.

We are going to talk about reporting more specifically.

So we're going to drill down into this tomorrow, but today has been foundational.

Has this been helpful?

Too much open time or about right?

Okay, good.

Well thanks, I only took over because I am watching the clock.

And before we break, are there any other general questions from today?

Things that you feel like have not been answered.

Anything else that you all want to share.

Things you want to get off your chest or comments that you have.

I am always very much aware that I am the only thing between you and the bar.

The restaurant, the baseball game or whatever your thing is.

I wanted to ask, I did, let me thank you all too, because I have been reading and typing up some of the post it notes that we got and they have been coming in throughout the day so I did not have time to pose them to our presenters yet, but thank you for writing those.

Some really poignant questions, some tips we have already taken into account.

We are trying our best to police ourselves on acronyms, I hope you will help us do that, that was one that came up.

I know there were some acronyms, I think have all gotten explained as we have gone through the day.

But help us with that.

And then tomorrow morning we will open at nine, responding to those post-its.

If there is nothing else, have a great evening.