TIM FUCHS: And we're going to go ahead and kick off the afternoon sessions, obviously.

We're going to talk about first with Darrel, target populations, who are we serving?

So who will receive these new core services and what does that look like and then later we'll hear from Michelle about the types of institutions we're talking about.

We touched on that this morning in our discussion, but really what do we mean by institutional setting and we will flush that a little bit.

And then who is at risk?

That's a conversation we'll continue throughout the week, but this will be our first foray into who is at risk and what does that mean.

That's this afternoon, after our presentations, we'll have again, another group discussion to flush this out, hear how you all are thinking about this, what you are already doing about it and what you might do about it.

And we'll go from there.

For now, I will turn it over to Darrel.

DARREL CHRISTENSON: How is everybody doing?

Lovely, good.

Lunch, awesome.

Thumbs up.

Are we awake now?

No.

Let me tell you that's not the answer I wanted to hear.

All right.

Whatever you need to do, but stoke it up, because we have a full afternoon here, okay?

I know, right?

I said stoke it up, I didn't say toke it up.

You'd think you were in Colorado or something, right?

Anybody from Colorado?

No.

All right.

Target populations, who is intended for and what programs, funding does your CIL and state have?

Catchy title.

So the diversion or the transition diversion populations, we kind of talked about a little bit this morning.

But for transition currently residing in a nursing home, assisted living facility, skilled nursing facility, for all the acronyms, it's SNF, and other types of institutions.

That's the transition.

Diversion is anyone currently residing in the community.

So there's the difference in the terms right there.

For the transition, CILs assisting person to a less restrictive environment of their choice.

You know, we talked as a group a little bit this morning and then in our planning about what type of institution or setting are we really talking about.

Certainly it's easy to say transition from nursing home.

That's the easy one.

It's an institution, choices very limited to none.

But then you start to go along that continuum, and then you start maybe looking at assisted living facility.

More community based, a little bit more residential in feel.

Still you have services provided.

You have some choice.

Maybe what you want to wear for the day.

But your money is pretty much taken from the agency or the group that owns the residence.

They may be paying the rent, so whatever income you may have from SSI, Social Security or Social Security Disability or any other funds, that's all going to go to the organization that is running the facility.

Okay?

And backing up then with the skilled nursing facility, again a little bit more of an institutional line of things.

One thing we talked about as a group though, is what about say a residence where you have four women that are in a home, in a neighborhood, residential in setting, they are not related to each other, they are not four sisters or anything like that, mom and three daughters.

Four individual women in a residence in the community.

Is that institutional or transition?

Or is that community based residence?

How would you categorize that?

This is the audience participation part now.

Jim.

AUDIENCE MEMBER: Community based institution.

DARREL CHRISTENSON: Now you're riding the political balance.

Sir.

AUDIENCE MEMBER: It depends.

DARREL CHRISTENSON: On?

AUDIENCE MEMBER: Depends on did they come together on their own accord?

Did they coordinate that themselves, these individuals who are living in one place?

Did they choose to do that?

DARREL CHRISTENSON: Okay, so help me understand.

If they did choose to live together, they were friends from church or wherever, then they chose that, as opposed to four random women who were on Craig's list.

How would that differentiate for you?

What's the difference there?

AUDIENCE MEMBER: Choice.

I mean, in both situations, if they were four different women who met through Craig's list and they decided they wanted to live in this particular residential home in a neighborhood somewhere, or whether they were four friends who decided they were going to do that.

DARREL CHRISTENSON: So that would be community and choice?

AUDIENCE MEMBER: Yes.

DARREL CHRISTENSON: Would it matter who was paying the mortgage or the rent?

AUDIENCE MEMBER: No.

DARREL CHRISTENSON: No?

AUDIENCE MEMBER: Well, if the decision process for how they spent that money was their own, you know, you have some state agencies, for example in Florida, provide I budget money to individuals that they can spend as they see fit for services.

So if they decided to take that money and spend that money to live in a group setting together because that's what they wanted to do, then.

DARREL CHRISTENSON: So would there be a difference, say, if the rent was $1,600 and each of the four kick in $400 as their share, is that different than, say, if an organization or corporation paid their rent, they just took their money and, as opposed to a landlord, would that make a difference for you?

And again, we're trying to define community based versus institution.

That's why I'm asking the questions.

AUDIENCE MEMBER: You know, again, I think it's based on the decision that the individuals make.

If they direct an agency or a corporation to take a portion of the share of the money that's rightfully theirs or that's been awarded to them, whatever wording you want to use, and use that to pay part of their rent, then I see it as still community based.

As long as the determining factor is who is making the decisions about what happens with that money.

DARREL CHRISTENSON: Okay, so let me go one step further.

Thank you for letting me put you on the spot.

You have the mic, so have you no choice.

Let me ask this, can it be an individual's choice to live in a nursing home?

Because they just want to, just say, you know what, I'm tired, it's overwhelming, you take over, I choose to move to a nursing home?

AUDIENCE MEMBER: Yes.

DARREL CHRISTENSON: So that would be a community based setting then.

AUDIENCE MEMBER: No, an institutional setting.

DARREL CHRISTENSON: But your definition is it is their choice.

AUDIENCE MEMBER: Well, their choice doesn't.

DARREL CHRISTENSON: Their choice to live in a nursing home.

AUDIENCE MEMBER: Whether it's community based or whether it's an institutional setting, choice is still the determining factor.

DARREL CHRISTENSON: But their choice could be that they want to live in a nursing home.

AUDIENCE MEMBER: Their choice could be, yes.

DARREL CHRISTENSON: See the dilemma we're in?

And the other question would be what about services?

Services in a community based setting versus services, you know, nursing home versus community.

AUDIENCE MEMBER: I have the mic now.

DARREL CHRISTENSON: All right, Jim, you're in the hot seat.

AUDIENCE MEMBER: I am thinking, I was talking to somebody earlier at the break about, you know some states have what they call host homes, and it's where an individual lives, there was a lot of discussion about people having to live with somebody in order to qualify for Medicaid services, and some waivers are host homes in the developmental disability system, and I have worked in that system.

I have worked in group homes and in those small three bed homes, and it's a matter of whether, not just the choice, but it's a matter of if the day is laid out for them, if they have no choices in what they are going to do.

If they can't go off by themselves and do something individualized, if they have to do everything with everybody else, to me that's an institution.

You can have an institution with one person, and you can have an institution with three, or with eight, or with 20.

It's not anything about the number of people.

It's about the lifestyle and the fact that you don't get to make your own decisions.

DARREL CHRISTENSON: Okay.

People agree with that?

No?

Tim, can you help us with Miguel is it?

He was shaking his head very clearly here.

Sir, disagreeing because?

AUDIENCE MEMBER: He's saying community based, and in an institution.

Institution, nursing home, they come take care of you, take care of your bed, give you your medications.

When you're at home, you either get somebody to help you take your medicines or help you change your bed or wash your clothes or go shopping with you.

So that's why I say it's not.

That's why I disagree with what he's saying.

DARREL CHRISTENSON: Okay.

And I think, Jim, if I can clarify your point, you're saying that as long as they can choose their schedule, if they come or go, and make choices, the numbers as to how many people are in that residence really don't matter.

Is that fair to say, Jim?

Okay.

He's saying yes.

Okay.

So it's kind of an interesting deal here about what is community based and what's not.

Go ahead, sir.

AUDIENCE MEMBER: I've worked in group homes and ICF nursing homes, and four bed group homes don't survive.

They make no money.

Six bed group homes break even.

Eight beds make money.

And eight bed group home, there's much more staff there.

There is some choice for the individual that lives there, what they wear, what they eat, but unless you have enough staff, I can't leave so and so home alone, because so and so has this issue.

Now, years ago, I worked at the ARC.

At one point in time, one individual, now moved away, was allowed to be by himself in a group home, it took about five years to get that privilege, but I called there once for something else, and Paul answered, I'm here alone, and I said, really?

And he goes, yeah.

They are in the community.

The ARC built group homes all over the county last year and they closed down their ICF about two years ago.

DARREL CHRISTENSON: ICF?

AUDIENCE MEMBER: Immediate care facility.

DARREL CHRISTENSON: As long as everybody knows.

AUDIENCE MEMBER: Yeah, immediate care facility.

That was closed down now, it was the last probably in the area that large.

But choosing what you wear and what you eat and where you go, I mean, you can slice hairs until there's nothing left.

If I choose to live in long-term care, because I worked in one and Leonard was my age and had no actual visible reason to be there, he just found it comfortable to live there, and chose to live there.

That's what he chose for almost eight years.

I was there a couple years ago, he liked it there.

It was comfortable.

It was simple and safe, and he had other issues, so that was his choice, I guess.

He had no problem with it.

DARREL CHRISTENSON: Okay.

I think one thing, other comments?

Jim.

I'm sorry, no.

Behind you.

AUDIENCE MEMBER: What I was looking at is that you have choices and then you also have control.

Choices will give you an amount of control up to a point, but when you're making choices within a system, then your ability to have control of the outcome may be limited by policies, by procedures, by laws, by regulations, by contracts, you name it.

So when you posed the question, what was the difference between a community-based living and an institution, immediately I think of institution you have a system in place.

I am allowed to make decisions within a certain scope of that system, but how much control do I have of the outcome really has to do with the parameters that they place upon me as the person making the decision.

So you have decision making process and then you have how much control do I have of the outcome that I want to achieve?

In an institution, having worked in institutions for 25 years, I know that, yes, people are allowed to make decisions.

As long as those decisions don't fall outside of the boundaries of what their parameters are.

In institutions, that is the lifestyle.

In a community based setting, then perhaps your choices can guarantee you a greater control of outcomes based on whatever system that is, whether it's a group home or something else.

But I just want to point out that, yes, decisions will guarantee you control up to what point?

Especially within a system.

DARREL CHRISTENSON: Keep in mind too that, you know, let's say an individual is living in their own apartment, and they happen to receive 40 hours a week of attendant care.

With that also, you have choices.

And like anybody with or without a disability, you have rights and you have responsibilities.

And so someone living at home by themselves with an attendant, you have rights to be the employer, to hire and fire as you see fit.

But you also have responsibility to be a good employer, to manage people and, you know, what happens if somebody doesn't show up?

What happens if your attendant who was scheduled to come in at seven in the morning calls in sick?

Then, you know, your choices or your options after that are, okay, I need to call my backup.

So there's that piece of it as well.

I think one thing, and I see a hand over here, one thing that we need to as a group remember is it doesn't necessarily have to be under some Medicaid program or a state or federally funded program.

I think when you look at this discussion in only those terms, folks, you've really limited the scale.

You really have.

We have.

That we need to look at a much broader picture.

Granted, centers don't typically get calls from affluent people with disabilities that are able to afford their own attendants or their own services.

If they are rich enough to be in that position, as centers I think we would all agree, we tend not to get those calls.

They have means, they find their services.

It's skewed to the low to moderate income folks with disabilities where we get all the calls.

So I just want to remind us, don't just exclude people because of their income and keep that wide open from little to no income to conceivably you could have a millionaire with a disability calling for services.

I just want to throw that out there for opening the door, literally.

Sir.

AUDIENCE MEMBER: I was just going to echo what you were saying about responsibilities.

I feel like that's where the biggest, the easiest to define gap is between institutional and community based, obviously outside of location, outside of the physical is the dignity of risk aspect.

You don't get a choice in a nursing home about, well you know what I'm not feeling hungry tonight.

I'm not feeling up for eating today.

They are going to make you eat.

It's that idea that when you're out there, you have to problem solve on your own when things arise.

It's your responsibility to figure it out.

You do have support systems built for you, but you also have to reach out to your circle of support when things go awry.

In addition to that, you can make decisions of, you know what?

I don't feel like eating tonight or I want to eat Debbie Cakes.

Whatever you want to do.

I think that's what's so hard when we operate in these governmental systems, because they do not tolerate risk like an individual can make the decision to tolerate risk.

So I think that for me that's the big difference between institutional and community based.

DARREL CHRISTENSON: That's an excellent point.

Thank you for making that.

As was discussed before, under the medical model, there's always that, you know, safety and don't take a risk, we can't let that person out on their own because that's too risky.

And speaking from my personal experience, I was born with my disability without the arm, without sight in my right eye, and I maintain and my parents maintained that they would rather me have a chance to fail than never have the opportunity to succeed.

The chance to fail rather than never having the opportunity to succeed.

And give you an example.

Back when I was living up in Minnesota and with the winters and such, we had a gentleman, I think with MS, Multiple Sclerosis, living in an apartment, and the apartment complex was kind of down a little road from a Holiday Inn, which had a bar area.

And he went one January evening out for a couple drinks.

Okay, no big deal.

Guy goes out for a couple drinks, he's an adult.

And he was coming back and his power chair got stuck in the snow bank, and in the morning, they found him dead.

Okay, very unfortunate.

Very unfortunate, I miss him still.

But he had the opportunity to fail and had the chance to succeed, because he was living the life in the community that he wanted.

I mean, as parents, we want to keep our kids protected.

We don't want them to fail.

We don't like to see disappointment in our kid's face.

We want to protect them and isolate them in whatever way we can, but let's face it.

When we grew up, your parents may have been saying, you need to do this or you need to stop doing that, right?

But your real test of learning came from experience.

Maybe your aunt and uncle said the same message as your parents and you heard it from them.

But chances are, you learned the lesson through experience.

And so while his experience was living on his own rather than a nursing home, it happened to turn out badly for him, but that whole risk factor, we have to take a look at that and allow people the chance for independence and choice.

Question over here?

AUDIENCE MEMBER: I just had a statement.

Whoever controls the money has the decision making power.

In Illinois, we have the CILA Community Integrated Living Arrangements for folks with DD.

I happen to teach a class to a group like that around some advocacy and I work at a center for independent living.

It wasn't, even though you're not with 20 people with developmental disabilities, you're only with three, they start complaining the staff yell at me when I don't eat what they cook.

The staff they don't buy in their phones.

So it's all in the belief system of how that money should be, until that money is attached to the person and that person has the control, I don't feel like they are able to have much decision making powers.

DARREL CHRISTENSON: And I agree with you that money certainly plays a big part in people's lives.

Just follow the money, right?

But what I hear you saying also is the self-advocacy.

That maybe some state agency from Illinois controls the purse strings.

It doesn't mean that the person has given up all choices, because they have certain parameters that they can speak up for themselves.

And to teach people that their rights are important and need to be spoken for.

AUDIENCE MEMBER: Yes, education is key.

DARREL CHRISTENSON: Yep, yep.

So diversion then, as I say, is residing in the community.

Whoops, what did I do?

There I am.

Just seeing if you're awake.

So then transition is assisting people to less restrictive, and diversion is staying in the community of their choice, we said that.

Transition, existing center for independent living services to enhance skills, resources, knowledge and confidence to move to a less restrictive environment.

Diversion, existing center for independent living services to enhance skills, resources, knowledge and confidence to enable people to remain at home or in a least restrictive.

Again, I'm trying to help you understand the two terms.

Transition, usually but not always, individuals under 65 with a desire to move back to the community.

Diversion, up to any age with a desire to remain in their home.

In Phoenix, we have a program that primarily works under 65 moving out of nursing homes, but if someone is 66, 67, it doesn't matter.

It really doesn't.

And that, like income, shouldn't be a factor for you.

The point about the desire to move back, I mentioned earlier the gal who really couldn't understand or conceive of the idea of life in the community, sometimes it takes a few times to work at it.

And before that light bulb starts to flicker.

Diversion, transition and diversion, anyone with a significant disability who wants to work towards achieving goals with center for independent living assistance.

That's a commonality between the two.

Transition funding, some states have Money Follows the Person to help pay for household set up expenses.

Again, we all know that those states that do have it wave it goodbye, and those of us that didn't have it say, well, at least you had it.

As I mentioned this morning, our particular center board of directors had an annual 20,000-dollar slush fund to help folks out of nursing homes, and that too has dried up.

So it is just any tools that you can find to make it happen.

In Arizona, our Medicaid monies used for home care services, attendant care and home modification, and let's see, maximum 2,000 per person is available for our consumers as a contracted transition service.

So the second bullet point here is that we're working with the Medicaid provider and they have the $2,000 and we are working with one of the providers and now it went to renegotiation and now there's going to be three providers starting October 1st in Arizona.

Or for the Phoenix metro area.

And we are in negotiations to do this type of service for all three of the providers.

What it really does is to take a lot of the weight off their case management team.

Because we have staff that can go out and help with the transition.

My staff even goes out to different places to get bedding and kitchen ware and furniture and such.

I don't know how she does it, but she gets some really smoking deals.

I'm telling you she gets some good stuff and really can furnish and set people up, and we just take a 300-dollar piece of the 2,000.

Certainly not making money.

We're not even meeting our expenses, but that's what our board of directors has chosen to do.

So the funding, I know that funding is going to be Thursday morning, so stay tuned.

Don't take an early exit on Thursday.

Our Community Development Block Grants do the home modifications.

Again, if we can put some money into a ramp, widening doorways, a tub cut, high-rise toilet, grab bars, a roll in shower, and make that possible to stay in the home, providers know it's a lot cheaper than going to a nursing home.

Currently, with Community Development Block Grants, we have contracts in Phoenix, Mesa, Peoria, Surprise, and general funds are used in the City of Tempe.

Previously we had funding from Glendale, Scottsdale, Chandler, and the town of Gilbert, and the funding comes from HUD and has decreased over the years.

And you've seen that in your communities.

And the president proposed budget eliminates this funding all together and this started back in the Nixon era.

So a long time standing funding that has worked well for a lot of purposes.

The center for independent living staff provide key core services to consumers and little to no new funding for these that are for these existing positions.

As I say, at one point, I had been with Ability360 now for 19 years, and for quite a while, we had two full-time reintegration coordinators, and now we're back to a half time position.

So funding cuts, limitations, the needs come up, the funding goes down, we get it.

A couple case examples I want to share with you in the moments we have.

Twenty-five year old gentleman with spinal cord injury living in a nursing home for three years as part of that transition from rehab to community.

Helped him get out.

By providing information and referral, IL skills, the peer support, socialization through recreation, and there we have four activities a month.

Two at the center and two out in the community to help people become more acclimated to their disability in the community, feel comfortable, and six years ago now we were fortunate to build a sports and fitness center.

The biggest barrier, as I mentioned this morning, accessible, affordable housing.

How many have that as an issue in transition too?

Let me reverse the question.

Who has plenty of housing in their community?

Yeah, you're lying.

Yeah, the greatest asset is a motivated consumer.

I mean, sometimes, folks, look, sometimes you just have to get your pompoms out and cheer folks on.

Right?

If they don't see the possibilities in themselves, use your pompoms.

I tell my staff to do that.

You know, cheer people on.

You can do it.

You haven't lived in the community yet since your injury.

You can do it, we can help.

You can do it.

Glass half full, half empty.

Let's look at it as half full.

So often people get picked and prodded, poked, tested and retested.

You can't do this, can't do that.

Need help with this, need help with that, can't do this.

You know what?

Let's celebrate their abilities.

You know what?

You can do this.

It may be slower, but you can do it.

You can do that, with our help, you can do it even better.

Get your pompoms out.

If you're in management, bring pompoms back to your staff, tell them to use it.

A motivated consumer is the best asset you can have.

And the results, you find housing, go back to school, live life like anybody else.

A couple more, 58 year old woman, stroke survivor, living in a manufactured home alone, with no family nearby, feared her only alternative was to move to a nursing home.

We put up a ramp, she was more independent, she is doing great.

Again, the same types of services.

The biggest barrier here was she was lonely and had poor cooking skills, asset was a motivated consumer again, and results, we got her a peer mentor, socialization, helped her gain confidence in the public, the IL cooking skills, gained confidence, and greater safety and independence in the kitchen.

Real quick, when I was back in Minnesota doing direct service, I would teach independent living skills, including cooking skills.

Now folks, my wife can tell you I'm not a gourmet cook by any stretch, but I can do a mean box of mac and cheese, okay.

To teach people who say were stroke survivors using limitation on one side, how to stir that pan without the pan spinning with the spoon.

I was able to teach folks, small but significant strides of independence.

And that's my story and I'm sticking to it.