They're looking at me like, what?

All right.

I'm pretty sure that's

what we're doing now.

So come on down folks.

Yeah, so that's what

we're going to do next.

Hopefully that will

give you some ideas.

And how we're going to do it is,

we're going to give a couple examples

of how ‑‑ and you heard

some of them already.

Deb gave a couple really great examples, how information came in

and how that moved into a

systems advocacy from

an individual advocacy.

So we'll give a few examples of that ourselves and open it up for you all to also participate in that.

So, Deb, why don't you kick it off and you can introduce your special guest.

DEB LANGHAM: Hi, hope you all are

alive and well and I have been in

this wonderful ‑‑ I know I've said it before, but this is a great climate.

Unfortunately my allergies have just kicked in so I apologize for the voice

and the sniffles and the

runny eyes and all that.

So this is Autumn Misko next to me.

Autumn is our resource center specialist and does ‑‑ leads our

I&R team and also does transportation advocacy for our agency and our

community, and she's going to

talk a little bit when I'm done

about what she's done.

We have groups or advocacy teams, consumer advocacy teams in our agency.

And that we developed ‑‑ oh,

I've been at IndependenceFirst for about 15 years,

and I think we started them a couple years after that and they were just

consumers that we had worked with who are very interested in some of

the same things, eliminating barriers from our community.

And so we thought, well, you know what, we've got these folks who

are hot to work on advocacy,

so why don't we corral them all

in the same spot and get them together and let's see what we can do.

So we work on long‑term care issues, transportation, employment and long‑term care.

Did I get them all?

Oh, God.

I told you allergies

are setting in here.

So we work on ADA and other

disability rights legislation

or laws that we see.

So I think I've mentioned to some of you that we teach a high school

transition curriculum in

our area high schools,

and we've been doing that for many, many years.

And part of that curriculum

is a part on advocacy.

You know, get them while they're young and train them in the right way.

So we had a group of high school students who were pretty interested

in doing advocacy and were just kind of wondering how they could do

some things in their community.

And I remember Diana on our staff who taught that particular class and

telling them, well, you know,

if you ever have an issue or whatever,

give us a call and, you know,

we can see what we can do.

So the class ended whenever, September.

And so on the day after Halloween,

so that would have been November 1st,

we get a call ‑‑ Diana got a call from one of the high school students

who said, "Hey, I went over to the state fair and tried to go through the

haunted house and I

couldn't do that."

And Diana said,

"Well, it's always been accessible.

I'm not sure why you couldn't roll

on through there and be scared to death just like everyone else."

AUDIENCE MEMBER: You have

the right to be scared.

DEB LANGHAM: That's right.

You have the right to be scared.

That's right.

So Diana called and said,

"Well, come on in and let's talk

about this and see what we can do and figure out why after it's been

accessible for so many years,

why it isn't all of the sudden."

So she came in and brought five or six of her closest friends who were also

wheelchair users, and some had been in the class with her and some were in other classes, and friends.

So this group of young folks were really concerned because, again,

this was something that they had enjoyed doing, and all of the sudden

it was kind of ‑‑ the floor was kind of taken out from under them.

So Diana called and ‑‑ the state fair and made an appointment for them

to go visit and talk

with the management there.

So they went in and talked

and the manager says,

"Well, you know, we really

just rent to these venues.

We don't ‑‑ you know, we don't know why they didn't ‑‑ or didn't make

the place accessible."

So they brought in the person

who was running the haunted

house and they said,

"Well, you know, we've been doing this year after year and only,

you know, two or three people in wheelchairs come through,

and we've made this accessible."

And we're like, "Well, it's

only two or three people that

this was serving."

So after, you know, kind of a long drug out thing over about two or three

months, state fair agreed to put in their contracts that when they

contract out with any venue,

that they have to be accessible

to people with disabilities.

So this young group of folks ‑‑ this was about, oh, I want to say six years ago, five years ago.

Do you remember this Harvey?

AUDIENCE MEMBER: I wasn't around.

DEB LANGHAM: You weren't around then?

Sorry.

But, you know, these ‑‑ this

young group of teens ‑‑ well,

teenagers then, and now they're

young adults and they're also working with us on other issues.

So it was just a really great thing.

And, you know, how empowering is

that when you're 17 years old or

18 years old to really make a true systematic change in your community.

It was pretty cool.

And I also want to turn it over to Autumn and let her talk about some

things she's doing with transportation.

AUTUMN MISKO: Good morning everyone.

Again, I coordinate our transportation consumer

advocacy team.

What's neat about our advocacy

teams is they're consumer driven.

So our team members are who

decide what the goals are

we're going to work on.

So through information referral, which is another part of my job,

when I first started,

I was hearing lots of complaints about our paratransit system.

Which I'm sure it sounds like everybody here has similar issues.

So we kind of attacked that issue after a couple of years.

And working with the ‑‑ Transit Plus is our paratransit provider.

Working with those providers, we found we weren't getting anywhere.

They kept denying that there was problems because they weren't

receiving a large amount

of complaints actually.

Maybe 20 a month when they're

doing 20,000 rides or more.

Actually, way more than that.

So they were kind of saying, you know, well, you're only hearing a few

complaints that we're getting

and we knew that wasn't true.

We knew there were a lot of issues.

And we started to find out, you know, consumers were unwilling to complain

mainly because they were worried about their transportation

getting worse.

Worried that maybe their transportation would get

taken away from them and it

wouldn't be an option anymore.

So we tried to ‑‑ you know,

how can we address this because

it's obviously a problem and we want to see people getting transportation

that they can rely on,

not getting them to work an hour late.

So what we did is we developed

a comment form that we worked on with

our paratransit company that

allowed people to anonymously

submit a complaint.

We got some information so that they could at least determine the driver

and the situation, and then hopefully address the situation still,

but consumers felt a little

bit more comfortable.

We also put our information on these forms so they could contact us if

they wanted more advocacy,

but they also had the option

of just submitting the complaint

and calling it a day.

Also, the paratransit company,

their form was pretty much,

describe what happened.

So it involved a lot of writing.

We developed check boxes so that people could just check if it was,

you know, a ride and how late

it was and things like that.

Well, we developed the form and we realized that there was still not

enough knowledge with our consumers about really what they should

be complaining about and when.

Sometimes, you know,

we have a 0 to 25 minute window

and people didn't realize that.

So maybe they were complaining

too early most of the time.

They weren't complaining enough.

So we developed something called Transit 101 which is a two‑hour

workshop that gives people information about their rights

and responsibilities when

using public transit,

including fixed route

as well as paratransit.

And so we go through,

you know, the window,

also the next‑day service,

what's a denial override,

all of the things that people

really didn't understand.

So that really helped us

kind of increase the comments

that were coming in.

And then we would filter those through Transit Plus,

and then also keep track of it ourselves which was really helpful.

We saw lower complaint

issues up until recently,

but we have a new director

of our Transit Plus company and

so we're addressing that.

And also from our concerns, which we voiced with the county many times,

they're auditing the program and we were involved with helping them have

focus groups to kind of see

what issues were happening

behind the scenes.

Because it seems like the information that they were providing showed,

you know, that there

was little complaints.

So just one way that we address some of our transportation issues.

DEB LANGHAM: I just want to

add also that we provide training

for our advocates on how to advocate.

And, again, bring them along at the – at the rate that they're comfortable with and encourage

them to ‑‑ to do what they're comfortable with, and then later

encourage them to step outside

their comfort zone and, you know, make some more contacts.

We have a goal with all of

our folks who belong on our teams

and do advocacy for us.

Again, much like consumers,

we ask them to ‑‑ we help them to find

out who their legislators are,

who their alder persons are and their

supervisors, whatever that is,

and go say, "Hey, hi, I'm a voter and

I have a disability and I live in

your district and this is what I

would like to see from you."

So that has been an amazingly empowering deal also for

our consumers.

Yes?

AUDIENCE MEMBER: I was just wondering, do you guys offer

any training to what we call handi‑transit drivers at home?

Do you offer some disability awareness training to the drivers?

AUTUMN MISKO:: Yes, our staff works with staff both who drive the

paratransit vans, as well

as a fixed route.

We're very involved with that training, and we actually

developed a very good relationship with our transit company.

It's been a love‑hate relationship, but I encourage developing a

relationship so you can

help with training.

When budget time comes and routes

are looking at being cut and fares

are increased, we're an asset to them as well because we're out there

encouraging that funding

be thrown their way.

So, again, it goes both ways where we're advocating to improve service,

but we're also advocating to keep service and make sure they've got

the education to work with

people with disabilities.

AUDIENCE MEMBER: I think it's important that consumers learn

the difference between bitching and how to complain in an effective way.

There are a few ‑‑ a few years back, people were rolling through my office

door telling me how they had ridden for two and three hours on a

paratransit vehicle, or that they had made a reservation for a certain

day and time and that ‑‑ that reservation had been lost.

At the time, our paratransit was making reservations on little

Post‑It note size pieces of paper

and kind of tacking them onto a spreadsheet.

I organized our consumers to start attending advisory councils that our

paratransit had, and those were namely sessions where the

paratransit people would sit and nod as the consumer would tick off their

list of no shows or riding

three or four hours.

So there is a process for holding your paratransit's feet to the fire

through filing OCR complaints which we went to the meetings and continued

to ‑‑

AMINA DONNA KRUCK: OCR, what's OCR?

AUDIENCE MEMBER: OCR, Office of Civil Rights.

We went ‑‑ we continue to go to the meetings and voice our complaints.

We wrote letters to the executive director of the paratransit,

created a volume and Xeroxed

that and sent it to OCR.

And following the bulk mail that we did to them, every consumer that

brought a complaint to our attention, to my attention, that complaint

was Xeroxed, a complaint form from them went to OCR until it triggered site visit from the DMT.

The document that they compiled as a result of their site visit,

we turned around and used as evidence in a class action suit that resulted

in my core group getting a

year's free ride.

AMINA DONNA KRUCK: So once again we hear document, document, document.

Once again, when people call us,

I say, "Don't complain unless you're

willing to take some action here."

And I can see a lot of nods about that.

Do you, Roger and Darrel, while we're on the topic of transit, want to say anything about what's related to it?

DARREL CHRISTENSON: I was going to say, we contracted with the

City of Phoenix to provide

quality assurance monitors,

and these are folks with disabilities that undercover make reservations

on the Dial‑A‑Ride system and

then document their experience,

their wait time on the phone,

wait time for pick‑ups and drop‑offs,

the type of quality that they see with the drivers, is the driver on the cell

phone while they're driving,

are they making sure they stop

at all railroad crossings,

those types of things.

Compiling it to a coordinator that was hired on to this program to put

together a monthly report,

and we have quarterly meetings

with the city so that it really ‑‑ and what it's meant to do is have

that dialogue with the Dial‑A‑Ride provider so that there's a real

partnership with the city,

with our monitors and with the

Valley metro folks

providing the system.

So it is truly a partnership.

When we get into those quarterly meetings, it's not one

of an adversarial nature at all,

but it's, here's what we're noticing.

Thanks for bringing

it to our attention.

Let's continue to bring

the quality of service up.

So we've been doing that

for a few years now.

We've been involved in access to transportation for quite a long time,

and our city transit system boasts the accessible fixed route,

and the paratransit has really improved as a result of the

efforts of our consumers.

And, you know, like Amina says,

folks would call us and complain and,

you know, it's real easy to say

you're talking to the wrong people.

You should be complaining to the transit authority, you know.

But let us help ‑‑ help you figure out how to complain effectively.

And we ended up with a small core group of folks who worked and

actually ended up collaborating with our regional transit authority that

operates the fixed route and the transit, and the idea they came

up with, you've probably heard of this idea, of secret shoppers where

people go in ‑‑ are paid to go

into restaurants, you know,

department stores and act

like a customer and make reports.

Well, they labeled their effort "The Secret Stoppers," as in bus stops.

And this was with eventually the

full support of the regional transit authority.

So now what we've done –

they have rather.

I say we in a collaborative

sense of all of us.

They've used the ‑‑ it's software.

It's called Qualtrics and

it's for doing surveys.

So folks who sign up to be a secret stopper can access a survey.

And if they ‑‑ every time they file a report on this program,

whether it's good or bad, you know, yes, this time the fixed route driver

called all the stops and did it

in a way that was understandable to

everybody on the bus or, you know,

the bus went right by me in

the bus stop.

Those sorts of things.

But anyway, if they do that,

they have an ID number and they

get a free month bus pass

for doing that as a reward.

And, you know, because it's

a cooperative relationship,

the consumers that worked on this basically have the transit authority

now believing that it's their ‑‑ the transit authority's own quality

assurance program, not something that was forced on them.

So it's been real effective.

AMINA DONNA KRUCK: That's when

you're successful, when they

call it their own.

We have this great idea,

they brag about it then,

you know, you're really successful.

Well, that's really what Darrel's program is, a secret stopper.

Anybody go on the Light Rail

that goes by here?

Did you try that out?

What did you think of it?

AUDIENCE MEMBER: I'm spoiled.

I see Portland, Oregon's Light Rail, which is probably top of the line,

but actually went to downtown Phoenix, was able to navigate

it pretty well.

Yeah, I thought it was nice.

It's different that they actually stop at stoplights or, you know,

that they have to deal with that versus some other cities,

but I thought it was pretty good.

AMINA DONNA KRUCK: It was actually modeled after the Portland system, Claremont.

So that Light Rail is one of the

most recent advocacy activities.

In fact, we just had an event at our city on Saturday night because when

you see the deck,

the Light Rail goes right by us.

In fact, right next to us

is where they come offline.

They have, like, a whole, you know, little repair shop and everything.

But where we are is the longest part of the entire route without a stop.

We're right in the middle,

and it's almost a mile each way.

Because it was planned before we were there, and it's an area that's

scheduled for redevelopment in plans ‑‑ in the long range plans

for the city.

And so we're now in the process of advocating to get a stop there,

which is a very expensive proposition.

But we did get them to approve a study.

And when they put the Light Rail in, then they reduced the frequency of

the bus line that used to go down there which used to be a main bus line which was very frequent.

So it is a burden right now for people coming to our center and to the other businesses nearby us.

One thing I wanted to say was, in the old days, we actually brought ADAPT here to help us organize our folks.

And one of the first things

that people had to get educated

in this idea of Transit 101 is,

who pays for it?

And the bottom line, like,

what's the difference in the

cost between paratransit and a bus ride cost to whoever's providing it?

Because what our advocates had

to understand was,

until we got dedicated

funding for transit,

we weren't going to get transit,

and that turned them into advocates

for sales tax in the city of Phoenix and the city of Glendale and the city of Tempe to get dedicated funding.

So the public transit is really different from city to city here

in this metropolis area based

on if they have dedicated

funding for transit.

And when the ADA went through,

we didn't have any paratransit

in the city of Phoenix.

So they had to create a

whole paratransit system.

And like I said, a lot of people

call it "Dial‑A‑Wait."

So it's been a long process of

getting a regional system,

not just city by city,

and that will probably

be dropped off.

We advocated for,

first unsuccessfully

and then successfully,

dedicated transit tax

in the City of Phoenix.

Tempe is so good that they've got circulator buses bringing people

to the main lines, and the bus lines are all free to all students.

Then we finally got past the dedicated transit tax for the –

for the county which provided

them this regional thinking

that's happening now.

That's what was the seed for the Light Rail system that we have which is now

getting ready to go into an expansion mode to the communities that said,

"No, we don't want it."

But when they built it, they came.

And when those gas prices went up, they really came.

And so now the cities that didn't ask for that expansion are clamoring for it to get attached to that.

So it's been very, very popular,

but it would never have happened

if people didn't understand.

Because if you're competing for your transit dollars with the police and

the fire department,

you will never get them.

And one of the things that came out of this meeting that we just had

Saturday with a bunch of consumers and long‑time transit advocates was

that with the recession, you know,

we were really ‑‑ we really helped

energize that campaign because the first time they tried to do

a transit ‑‑ the first election vote for a transit tax in the City of Phoenix failed.

And when they looked into it,

it turned out the bus riders

didn't vote.

And so we really did big campaigns to educate people and talk ‑‑ push –

the disability community pushed them to go sooner for another election

than they had planned to go back and try again because we could see where the error was in the process.

But now with the recession,

a lot of disability services

have been cut down.

We don't have on-demand anymore paratransit.

We only have ADA Dial‑A‑Ride,

and that's been a problem

for some seniors, for instance,

that aren't as capable or

comfortable using the bus system.

So we are going to have ‑‑ so it, like, kind of comes and goes.

We had, like, a heyday

there for a while,

and then when the money went down, we're going to have to go back now and

reenergize those advocates that are complaining to us about the problems

they're having to go back to the city and the Valley Metro to say,

"Hey, you made some commitments in your long‑range plan when we helped you get this tax passed.

And as the economy goes forward,

you need to come back and replace some

of these routes that have been cut or expand some of these services."

And it will be a battle

just like it was before.

Because once it's taken away,

it's just like starting over again,

and it's a ‑‑ kind of, in a way,

a fresh crop of advocates.

So I just ‑‑ so this is how it happens.

Okay?

We had a meeting about the Light Rail, and then we started hearing about some of these problems.

Although on one level, we're partners.

It is a love/hate relationship.

Recently they had a feedback session.

They did a report on what have

we accomplished with this transit

tax for the county.

And I've got ‑‑ you know,

I have spies everywhere.

Told me, "You should come

to this meeting."

So I rushed down,

and presence is everything.

I was the only person that went and testified at that hearing.

And they followed me out to thank me and ask me for ideas about how to get the word out better in the future.

So because as part of their requirements to be doing these

public things, and if

nobody is participating,

it makes them look bad

to their funders.

So it just reminded me again,

that's how I got this job.

I just am a show-up person.

I can go in not knowing what's going on, and then I'm there and you see

what's going on and it's not too hard to make comment usually because

it's so clear where the problems are.

So, yeah?

DARREL CHRISTENSON: I think –

I'm going to keep it kind of short

so we have time for questions

in our limited time.

You know, I think no

matter where we're from,

if it's a big city or small or not, seems to be four areas of advocacy

that I think most everybody experiences and discussed

certainly in the transportation piece is one of the top four, I think,

medical issues would be another one, employment certainly.

You know, it's embarrassing to go in front of groups and say that we have

the highest unemployment rate among any group, you know, at 68 percent.

And then the other piece

certainly is the housing.

You know, we have ‑‑ you know,

like many of you have programs

assisting folks to get out of nursing homes and, you know, we can do a much,

much better job in getting folks out if there were accessible affordable housing units available.

And then also not only four topics, but I think there's different styles of efficacy.

While some might be ‑‑ people are more leaning towards more of an in your

face type aggressive or assertive type of advocate, my personal style is more of that of an educator.

I think if we can educate

the folks that we're working with,

then we can look toward

a win‑win situation.

I'll give you a couple examples.

That a few years ago because

of ABIL's positive reputation

in the community,

and with our customer service that kind of follows us over what,

31 years, folks have approached us knowing that we're sort of the experts in accessible housing.

And so a few years ago,

probably about three,

four years ago now,

a developer in Milwaukee,

actually Gorman Company,

came to us and said, you know,

we're building these ‑‑ this 28 unit complex in Glendale which is a suburb

just west of Phoenix,

and our architects have designed –

I think it was, like, 3 or 4

of the 28 units to be accessible.

I said, well, you know,

back in high school,

I wanted to be an architect

and so I took an internship.

But I wanted to be an architect

so I know how to read blueprints.

And when I sat down with the architects ‑‑ and they were

very receptive and open‑minded.

It wasn't just this token meeting with community that they needed to

do to check off a list of things

to do to meet with community leaders

about this, but they were actually open and receptive.

So we looked at it with the same footprint, same size lot,

same square footage, we were able to more effectively use the space.

So, therefore, we were able

to redesign all 28 units

to be accessible.

Yeah, and that was very cool.

I was in meetings with a very

large hotel in downtown Phoenix.

And walking out of that with

their folks, we knew we were their total community need.

We gave them many solutions,

many options, and they blew

us off completely.

And just to do that token meeting

was disgraceful, but this with

the Gorman folks, the developer standpoint, they listened to us.

And I think in looking at a win‑win situation, we were able to say, look,

with this you can market now

to 100 percent of the population,

not just 80 or 85 percent

of the population,

because now you're accessible

to everybody.

You can ‑‑ your ability to rent up those units increases tremendously.

And when you talk to folks,

you need to know what their high points are, and to them it's money.

We understand that.

They don't have a lot of money

to spend in these tax increment financing projects.

The margin of error

is very, very tight.

So we knew they basically had a finite amount of money to work with.

And we said, with that amount,

you can market to so many more folks.

You can lease out those units.

It's a win‑win situation.

We were talking their language.

We ‑‑ they also did a project that just opened up about six months ago

in downtown Phoenix about less than a quarter mile from the rail station,

and they took what they learned

with us and made those 60

units accessible.

I was fortunate last April to

go down on, yes, a baseball tour.

And when in Miami, I met with one

of the Gorman reps and talked

about a project that they're

doing in Key West.

So they're spreading the news,

the word throughout their

entire company nationally.

So what started here in Glendale

and continued in Phoenix is now hitting some impact in Miami.

And so, that company is now

dedicated and committed to it.

It's a win‑win situation.

They see the results of that.

AMINA DONNA KRUCK: Can I add to that?

ROGER HOWARD: Yep, yep.

Let me ‑‑ yep.

There's also another project that Gorman is doing here in Tempe,

just probably about half a mile east of here on the Light Rail system,

and that's called Gracie's Village.

On Light Rail, it's for working families, and that too will have total accessibility.

It will be open November.

So three projects.

And that's just so cool, and they get it, but they ‑‑ again, we have the

reputation of being a partner and not someone that just comes in with both

barrels blasting right away wanting to stop and get the facts.

AMINA DONNA KRUCK: Can I do

something related to that same thing?

ROGER HOWARD: Real quick.

AMINA DONNA KRUCK: Darrel is right.

I always tell people there's room

for every kind of advocate,

and we need every kind of advocate.

Okay.

Darrel's the educator,

I'm the come in full guns blasting.

So he hooked me up with Brian to bring in the full guns blasting ‑‑ because

there was a lot of opposition to Gracie's Village in Tempe by

a historic neighborhood of shacks that lived behind it that it was going

to bring down the neighborhood

when those people moved in.

So then my job was to get the word out, our empower advocacy list,

to get people to show up to

those city council meetings.

We sat in six‑hour city council meetings to get people to testify

in favor of the benefit of this,

which people did and succeeded.

ROGER HOWARD: There were three meetings that went till midnight.

AUDIENCE MEMBER: Wow.

AMINA DONNA KRUCK: Because it turns out, there's a lot of ASU professors that live in those shacks back there.

ROGER HOWARD: Thank you

for bringing that up.

It was important to

have different styles.

But staying on topic,

I think a great deal of it, again,

from my little perspective

of 25 years worth is relationship building.

I went to one of the conferences last year in Chicago about housing,

and they reminded me about

how success is really all

about relationship.

I think another piece that I ‑‑ well, I sit on the NCIL housing subcommittee.

And one of the pet projects

that I would love to see passed is

the inclusive home design act.

This is a bill that a person has

been introducing in the last three, four sessions.

Visitibility would be for minimum standards for single family,

duplex and triplex.

Everything under what's covered

with the fair housing.

For single housing and

duplex and triplex,

and there's been a wave across the country of visitibility where city

ordinances and even state ordinances have been passed to have this to the objection of construction.

Because they keep thinking

this is a niche population.

And to make these changes which

is one‑half of one percent just for a niche population is not worth it.

I would love to be able to –

I'd love to go to D.C.

when visitibility gets signed and

be there at that signing,

but that's another piece

of the effort in housing.

So relationship building,

education, stay with it.

Build those relationships for

your housing folks and you

can move forward with it.

ROGER HOWARD: You've all heard that politics makes strange bedfellows.

AMINA DONNA KRUCK: Oh, I just

brought that down right here.

ROGER HOWARD: Darrel just finished

up by talking about visitibility.

You kind of have to take your

support where you can find it.

And a very interesting thing is

that Newt Gingrich has been

going around the country

promoting visitibility.

AUDIENCE MEMBER: Really?

ROGER HOWARD: Yeah.

He refers to it as aging in place.

Why are we building homes that people have to move out of when due to age,

they can no longer climb stairs and, you know, the bathrooms aren't big enough and stuff like that.

And so, you know, I use that when

I'm talking to folks who are

very conservative.

Who knew?

When I think of ‑‑ you know,

our title was connecting the dots

between consumer services and systems advocacy, I think of

it as sort of like the Light Rail here where it runs in both directions sort

of from the top down where you start with high‑level policy work to try

and work down to, you know,

increased and improved services and access for people with disabilities.

And then from the ground up,

your grassroots efforts that –

that culminate in policy

change at the top.

And a good example of

the first one, in Idaho,

as I mentioned the other day,

we only have three centers

and we're very far apart.

Boise, where I'm at,

is the state capital.

The center in north Idaho

is 400 miles north of us.

The center in southeastern

Idaho is 400 miles east of us.

And so, just because of that and funding, we all work on the

systems advocacy and systems change all the time, but the other centers

tend to work on local issues within their areas where the brunt of the

legislative stuff falls on my center just because of our proximity

and because we've been there

for a while and have presence.

And the legislators, you know,

they see us coming and go,

there we go again, you know.

Well, as I mentioned the other day, somewhere around 1998,

we had been working on a series being the consortium of people from Idaho

with disabilities which is an organization kind of like an

inner‑agency work group of about

28 disability related

organizations around the state.

And we had worked on several initiatives to improve the

delivery of personal assistance services in Idaho.

And in 1998,

we decided it was time to really push for self‑directive services,

and we did that and it was successful and it really did not involve much consumer grassroots advocacy.

It was really kind of a

high‑level policy thing

that the policy worked on.

But what it resulted in is now over a decade later, Idaho has really,

really well structured self‑directed personal assistance services

programs that lets people who are eligible for Medicaid and eligible

for personal assistance to

basically exert full control over their in‑home situation.

And so, that's kind of an example of things that worked from the top down, if you will.

From the bottom up,

around the year 2000,

we started getting a lot of calls,

more calls from parents with disabilities who were in custody.

And we were providing advocacy

and referrals to, you know,

family law attorneys because, you know, for lot of us, you know,

our children, this is a life‑and‑death issue,

you know.

And almost every case

was unsuccessful.

And, so, we started to look for the root cause of this, and what we

found was that Idaho law in terms of termination of parental rights,

child custody and divorce and,

you know, when the state takes over,

you know, when a child becomes a ward of the state and those sorts

of things, that our state statutes had been ‑‑ not been updated since about 1938.

And at that time, had been written with the best interests of the child

in mind in a way that actually handcuffed the courts.

And the law basically said,

in any of these situations,

the court must look at

the following factors.

Number one was the presence of a disability in one of the parents.

And it was written in such a way that as long as that ‑‑ that evidence

was introduced, it was pretty

much a done deal.

The courts felt they ‑‑ that was

the deciding factor, and obviously discriminatory as hell.

So we started contacting the parents who contacted us and said,

"Do you want to work on this issue?"

It wasn't just yes, but hell yes.

And so we got people organized.

And I bring it up because sometimes one person ‑‑ you know,

this was a really big group

of people working on this.

Sometimes it's just one person,

and one of those ‑‑ that one person

was a mother and nine years

prior to this, she had had a child

out of wedlock when the father found out about the pregnancy, he was gone.

He hadn't been seen in nine years.

And at that time, she had a progressive visual impairment.

Well, so she has the child and,

you know, she's a loan officer

at a bank, you know, so she's

very well put together.

You know, has a, you know, beautiful golden retriever guide dog and all this stuff and was doing just fine.

Well, nine years after the birth

of the child, the father came back

to start making amends.

You know, had one of these

big changes of heart.

As soon as he realized that

she was blind, he filed for and

got full custody of his daughter.

He hadn't paid child support for

nine years, no contact at all.

Okay?

So will you come talk

to our legislators?

And she agreed which was

outside of her comfort level.

You know, she did not want to stand up in front of the Idaho legislator

and say, I had a child out of wedlock and all this stuff, but she did

and she came forth and made a huge impression on our legislators.

And as part of her testimony,

the court had required that

basically like a home study be done to determine her fitness as a parent.

And, you know,

you can't make this stuff up.

So she brought copies of that

home study and it was by somebody

with a doctorate in psychology.

And I kid you not, it started out the very first paragraph said,

"I have no experience evaluating

a parent with a disability to fulfill their responsibilities,

but in my opinion, parents with disabilities rob children of

their childhoods." Okay?

And that is the exact reaction

that our legislators had.

They need ‑‑ you know, I mean,

you know, some of these closet

things we do, it's all this stuff,

but when you hit them with something

like that, you know, and she's

right there, you know, and calmly telling this story.

It was that ‑‑ finding that one person, I'm totally convinced

won that battle.

And about five sections of

Idaho code were modified.

Not exactly how we'd like them.

There were a lot of compromises

and things like that.

And we had to do a lot of convincing that we were not trying to make

the state award custody to parents who couldn't do the job,

but you can't say just

because a person has a disability,

they can't do the job, you know.

The courts were actually looking at, you know, the ability to financially

look after the child, and abuse

and neglect were lower standards than if a parent had a disability.

So we felt really good about that.

And I'm feeling really good about

it now because the National Council on Disability just issued a study on

state laws involving parental rights for people with disabilities.

I think it just came out

a couple months ago.

And in their review of state laws, they only came up with three states

that they thought adequately protected the rights of people

with disabilities,

and Idaho was one of them

because of that work.

ROGER HOWARD: Thanks for the

pat on the back,

but I didn't do it.

They did it.

We helped them do it,

and I have this thing I'm

going to just show

really quick, if it comes up.

Oh, there it is.

Based on that, one of the things we did was put together this slide show.

And as you can see, it's labeled

"Consortium of Idahoans

with Disabilities."

I'm number four.

We work with them on projects like this, and basically this is training

for consumers to communicate effectively with legislators.

And it isn't just

limited to legislators.

It can be used for any policymakers, city councils, public hearings on transit and things like that.

And I'm pretty sure this is up on

the Wiki too, and I encourage you

to use it, but it's pretty basic.

We emphasize that your personal

story is what really counts

with the legislators.

How to meet effectively with them.

How to write, call and e‑mail

them and how to testify.

How that works, you know, because we realize that people have to get

out of their comfort zone, you know, and I'm not ‑‑

DEB LANGHAM: A cartoon.

ROGER HOWARD: Yeah, we have a snail getting out of its shell here saying,

"I'm getting out of my comfort zone."

But basically we have a template for people that they can fill out that

guides them through developing their personal story and about what

they think needs to be

done about the issue.

And then they can use that story,

that template to communicate

one‑on‑one with legislators to develop testimony, to write letters,

send e‑mails and things like that, and the PowerPoint just simply runs people through the process.

But one of the things we found in using this approach, you know,

do you need to have a PowerPoint

to teach this to people?

No, you don't.

But what we found is when people take part in something like this,

you know, a lot of us see lots of PowerPoint presentations and stuff.

But to other folks, this is

kind of a new thing and it's

kind of a self‑esteem builder.

They really feel like they're part of something, you know, bigger than them

that they can contribute to,

and they can really get fired

up just because it's put

in a formal presentation.

They feel that they're valued,

if you will, by being approached

in this way.

And so I only brought

this as an example.

I'm not going to run

through the whole thing.

Probably be good if we can drop it off the screen so it's not distracting other folks who want to talk.

Thanks.

AMINA DONNA KRUCK: Thank you Roger.

I have written down strange bedfellows and courtesy.

And I used to go down

to the legislature.

I'm the designated lobbyist.

And for the last few years,

there's been nothing for me to do.

All they do is cut, cut, cut, cut.

But I always like ‑‑ I get

so mad listening to them talk,

and I get so mad at this

courtesy stuff going on.

And over time I learned

a couple things in my life

about the value of courtesy.

Because I have attention deficit,

I interrupt people and I'm

opinionated and I was proud of it,

you know what I mean.

So I was told once by a healer that I was born with a sword in my hand and

it's taken a few years to learn how to use it appropriately and there's been some casualties along the way.

And everybody that knows

me would agree.

But over time, I got it because you don't know who's your enemy on

this issue that will be your best friend on the next issue.

And I had an advocate just

after the issue going,

"How can you be so calm, you know?"

Well, I didn't used to be able to be.

For one thing, I say the serenity prayer and pray before I walk in the

building because I realize I am

not going to be in charge of what comes out of there.

And it's a ‑‑ I tell people,

this isn't a sprint,

it's a long distance run.

So we're seeing that right now.

I mentioned it earlier in this training about some of you may

have seen our Governor Brewer

on the news,

and we have some reputations of her being pretty oppositional to the

Federal Government on the various issues and with President Obama.

And she recently came out in favor of the Medicaid expansion as part of

the Affordable Care Act,

and what that could do for our

economy and our health system.

And prior to being the governor,

she was an advocate for the

mental health system.

And during her stay with the

budget situation, she had to cut mental health funding severely,

and she does have a child who

has a mental health disability.

And, like, 120,000 people have lost Medicaid care over the last

three years with the freeze that's

on it because of the budget.

And so she came out in favor of it, and literally the chair of the

Republican party in

Maricopa County testified that,

"Jesus had Judas and we

have Governor Brewer."

So there's a huge fight within the Republican party that controls the

Senate house and the governorship, which is good for us because that

means they can't just slam‑dunk past things like they could the past two years and did cut, cut, cut, cut.

So that debate is going on.

And guess what, I'm getting e‑mails from AHCCCS, our Medicaid agency,

asking me if I signed up on their website yet in favor of the governor.

Reminding me to be at the hearing.

The legislature last week,

a front row seat was saved

for me to sit to testify.

I got a follow‑up e‑mail, what a great testimony I did, and would I pass

the word to the disability partners about getting their logos and their letters up on the website.

And I also say often,

the people who are my worst enemies as advocates are my best teachers.

I've learned how to do this from watching how they do it.

And let me tell you,

she's got a good P.R.

person running this campaign

and I'm taking notes.

So keep that in mind.

And as I had said earlier too,

I tell people, and we do legislative

training like this, and we take people down to the capital because

we're also in the city and we bring legislators in to talk to them.

And we bring friends and not friends because nothing gets an advocate

riled up like a legislator that's not a friend, or even one that thinks

they're a friend that are patronizing.

You know, for those

people ‑‑ those people.

And so one good example,

we had of a real success where we had

to change a cultural perspective was the Medicaid buy‑in which was part of

the ticket to work which is a health plan, Medicaid health plan that

allows people to earn a lot more money if they're disabled and working.

And in our case, there's no asset test so it doesn't restrain the family if there's a spouse that's working.

They can save money.

And when we went to go to our legislator to do that,

our legislator's primary perspective about disability was,

people with developmental disabilities and why they

needed segregated settings.

And we have an association

that is a strong advocate.

Their director was a previous legislator with a child in a

group home and a sheltered environment who was a wicked

good advocate because she was a legislator -- very well connected,

who had brought people down to testify year after year about,

you know, people chasing their supervisors around with knives

and things like that and why they need to be separated and protected.

The big protection word.

So when we wanted to pass the Medicaid buy‑in, we had to change that

perception about the wider range

of people with disabilities and

employment and why

this was important.

And so we had several poster children we say that were people ‑‑ one of them

was a gentleman that worked

in the mayor's office.

So he got the mayor of Phoenix on board and who presented very well.

We had to get somebody in every legislative district to go talk

to their legislators face‑to‑face to break that stereotype about who

we were really talking about,

and Fernando on our staff

was one of them.

We have several staff members that did that and different advocates.

Well, one of the best advocates

for this bill was a woman who kind

of was like ‑‑ she just died recently and she was kind of like Palumbo,

that detective.

Kind of bumbling, soft spoken, confused a lot, you know,

bad driver on a scooter,

bumped into everything,

but she was a registered

Republican and she had very good

independent living philosophy

and she participated on many

legislators’ campaigns and

political figures’ campaigns.

She stuffed envelopes.

She made phone calls for them.

And when they got elected,

she had their ear.

So when we were getting stuck,

she was right in there

talking to them.

Can I just talk to you for

a couple minutes this little soft

spoken ‑‑ she's crashing into their walls with her scooter and stuff.

And even who is now Governor Brewer because Governor Brewer was our secretary of state prior.

That's how most become governor, they're secretary of state and

the governor leaves for some reason and then they become governor.

So she was critical at being

able to get into those

conservative Republicans.

And, you know, employment is a cross party, if not a party specific issue,

but they needed to have this other experience because they heard so much

from this other legislator, previous legislator who had really prejudiced

them to see disability

in a certain kind of way.

And with that we had, you know,

like 98 out of 99 votes in favor

of that program that got passed.

And during the downturn,

some states lost their

Medicaid buy‑in.

We did not.

So I always use her as a great example of the other kind of advocate.

You don't have to be brash and

loud or even persistent.

What you do have to do to

be an advocate is show up.

Presence is everything.

And when I went down to the legislator this year ‑‑ and I really hadn't gone down last year for anything.

I'd done some testifying online and stuff ‑‑ I realized, oh, my God, we have a whole different legislator.

They're younger.

These tea party guys are younger.

And I thought, you know,

I've got to get down there more

and get my advocates to meet

with their legislators.

It's absolutely key because they have to meet people face‑to‑face.

It makes a big, big difference.

Just like the story that you're helping people develop how to talk

about themselves is they need to meet them to break those stereotypes

and understand the issue better.

So that's really all I have.

We want to hear from

you all about ideas.

April, do you have any?

I'm thinking our peer mentors too.

They're such great advocates.

APRIL REED: That was just the

one thing I was thinking as everyone

was talking, you know, sometimes

with the recession, we get focused

on the cuts and the losses.

And what we've seen is there's been a real opportunity to engage people

that have never been interested in advocacy before and never got it.

And, you know, we do advocacy training as part of our peer

mentor training.

We have training at the center and we were seeing about three or four

years ago people showing up and

I'm like, "What are you doing here?

I wasn't expecting you."

Well, they got a letter

saying you're getting cut.

Your AHCCCS is getting cut,

your food stamps are getting cut,

or at a group or activity at ABIL, they started talking to a friend

and they heard about their cuts.

And so sometimes the cuts,

the negativity,

that gets people interested and they want to find out, how do I stop this?

How do I get educated about it?

So I think now is an

opportunity for us to, you know,

not huddle and close ranks,

but really do more training,

offer more trainings,

engage more people.

Because I think if you can get

those reluctant advocates,

now's the time because they're connecting the dots about these cuts.

How do they happen?

I want to know why this happened.

And you can make that connection that this does impact their daily life.

So I think now is the time

to do this more than ever.

AMINA DONNA KRUCK: Yeah.

And people are afraid,

the legislators pair them up with people who are more comfortable.

When we go, we have other people

who are willing to help them sign up and go to their legislators.

And this year we're trying to do a little better follow‑up with it.

The other thing is those years ‑‑ the thing about being attention deficit,

the helpful thing and having had chronic illness, I've had to learn

how to be patient when a door

is closed, and when it's open,

run through it because I'm here

today and I'm gone tomorrow.

So that works pretty good for me.

I rely on my comrades for strategic planning sometimes other than the

strategic planning I've learned going to baseball games with

Darrel which has been helpful.

But you have the issues you want to work on and you have more than one.

You never know ‑‑ like how we see immigration opening up right now out

of the blue and the change about gay marriage, you never know when there's

going to be a shift or an opportunity.

So during the last couple years

when we haven't been able to do

legislation around funding

or program issues,

there have been language

changes and policy changes.

So partly you have to figure out also, where is the barrier?

Is it a policy?

Is it a law?

Is it a person?

Is it funding to know what it

is that has to get changed as

an advocacy group?

And then when you can't do one thing, is it a good time to work on some

of the other things?

So we got a lot of the language updated for mental health and

for intellectual and cognitive disabilities during these last couple years, and even voting rights

limited guardianship for people who have guardians so they can now vote, if they want to.

In the last election, they were able to do that for the first time.

Okay.

Thanks.

So the next half‑hour, we do wrap‑up and we're saving 10 minutes of that for Tim to do your evaluation.

So any stories you want to share about successful advocacy or questions

you have about it that you

would like to share?

Mark?

AUDIENCE MEMBER: One of the fortunate things about being in Texas,

in Austin specifically,

Bob lives in Austin there,

and for those of you who don't know Bob, he's been, I guess,

a lifetime advocate, an extraordinary person.

And I wanted to not only back up Amina about what she's saying about

showing up is, don't do it just once, continue to show up and get educated.

There are people that are experts many times in the issues that you

may care about, and it's not that hard to start linking up to these people,

and they can give you reinforcement and education, help you to get

comfortable in talking

with legislators.

And it's not as hard as it may sound.

It's a little intimidating at first, but you get used to it pretty quick.

The surprising thing to me about going in to speak to like the

House Appropriations Committee or the Senate Finance Committee,

because there's a lot of powerful republicans on those committees.

But what was comforting for me to

find out is folks, Republicans and

Democrats, good people, they care about what they're doing.

They come at issues from a different perspective, but don't categorize

people before you get in there

and start speaking with them.

Oftentimes they care as much

about the issues as anyone.

And there will be situations where you will have strange bedfellows,

to use that term, just because the organization that may ‑‑ you may not

agree with and may make you uncomfortable being on the same side

of the issue, you have to kind of stay focused on what's important.

Keep your eyes on the prize,

so to speak, and recognize that

today you may be on a different issue, on a different side of an issue

with someone, exactly

what Amina was saying.

Tomorrow or the next day, you don't know who's going to be on your side.

And probably the biggest thing

that's important in my mind is

to be courteous, be informed.

Show up not once, show up again and again and again.

A lot of those folks in Texas are powerful politicians that have

been elected multiple times.

They know Bobby, first name,

and they trust and respect his

knowledge and awareness

of the legislation.

They may not agree with it,

but you can count on it that

there's an issue that they recognize as being important to the

people with disabilities.

He's going to get a call and

he's going to get a hearing

and his voice is respected.

So just wanted to kind of

reinforce some of the things.

AMINA DONNA KRUCK: And always thank them for their service whether you have advocacy or not.

AUDIENCE MEMBER: It's not

easy to be a legislator.

AMINA DONNA KRUCK: Thank you.

Shannon, did you have something?

AUDIENCE MEMBER: So every time

I think I have a handle on lobbying, I use it all.

It's something that's hard for me,

so I tend to stay away from it.

It's good because I get to really empower consumers and people I work

with to speak out on their own issues, help them find that passion.

But I was wondering if you could

speak a little bit to kind of the line between advocacy and lobbying?

AMINA DONNA KRUCK: There is no line.

The line is simple.

If it's a bill,

it's lobbying.

If there's a bill number,

it's lobbying,

and everything else is advocacy.

And we are allowed to lobby also.

There's a certain percentage of

your funding as a nonprofit,

and also tutorials about that

I'm pretty sure up on ILRU

because they've done

trainings on it regularly.

That's a big myth that

you can't lobby.

You can lobby.

When you look overall at the amount of money spent at your center and

the little bit of time you spend lobbying, it's fine.

You just have to be honest about it, and there are some grants that

you have that may prevent

you from doing it.

So that was tricky when the working, planning and assistance program

went down, luckily I wear

a lot of other hats.

I'm not totally funded by them,

so I can still be in their face about what I wanted to have happen.

So that's it.

You're not allowed to support a person running for an office.

Those are the only two things that you're not allowed to do.

Lobbying you can do, but you have

to call it lobbying and you need

to register with your

secretary of state to do it.

So somebody from every center should be registered as a lobbyist ‑‑ as the designated lobbyist for that agency.

AUDIENCE MEMBER: Just a clarification,

you can't do it with Title VII money.

Your federal money,

that's not an allowable cost.

AUDIENCE MEMBER: So God bless

RSA for pushing diversification

and funding.

AMINA DONNA KRUCK: There you go.

Because we always have other funding, but on the other hand,

my job is through them to

do a community systems change.

Isn't that interesting?

So, yeah, so watch your bookkeeping and how you ‑‑ you know we have different funder codes,

and I have a different funder code

and they also require they're

on your time sheets.

Thank you for saying that.

Is we actually do ‑‑ I put in how many hours I do lobbying under that funding code for my time sheet.

It's the only thing is Part C,

time spent and lobbying are the

two things that I have to report on my time sheet specifically legally,

and that came out of

one of our site visits.

So definitely have to prove for other funders what I did for them in

a different way,

but I'm saying on my

official time sheet,

if we do lobbying,

we have to report it

as such on our time sheet,

how much time was spent.

That's how they can tell how –

what's going on.

AUDIENCE MEMBER: And just

one more note on that.

When we do the financial

training in May, there's a

whole day that we're talking about how that time issue allocation plans,

and how you have to keep track of your time, and that is a very –

sometimes feels very complicated.

And if you're not about to attend that workshop, we will have that

all posted online right

after this workshop as well.

AMINA DONNA KRUCK: And where

will you find it?

AUDIENCE MEMBER: ILRU.org.

AMINA DONNA KRUCK: Other comments?

Kind of wrapping it up

for the whole thing.

Kind of hard to do.

It's like having had a whole

banquet three days in a row.

It's a lot.

A couple questions over here.

Yeah?

AUDIENCE MEMBER: Oh, I just wanted to get some ideas on how you promote

when you do have successes on a local and statewide level, the people

that help support a bill or

an ADA success or anything?

AMINA DONNA KRUCK: Well,

we have a newsletter.

So, we have a monthly newsletter,

and so we put stuff out on that.

If we've been advocating for a certain bill, and I will –

I'll state in there,

ABIL supports this, or, ABIL,

I'm doing this for your information.

ABIL does not have an

opinion about this.

And if it goes through,

then I will send out another alert.

"Good job advocates.

Yay, we did it!" And a lot of times, I'll even ask people on those alerts

when I'm asking them to do something, I will say, if this is important

to you, this is the

action you would take.

I don't tell them do this.

And then I often will ask them,

let me know how you found out.

And I always remind them,

my teacher Tim says make

sure you include the ask.

Ask them how they're going

to vote on this issue.

Tell them to get back to you on how they're going to vote on this issue.

And don't belittle their

secretaries because they're

really your gateway to heaven.

You may never talk to

the actual legislator.

And certainly your state senators

you will never talk to probably.

At least in our state we never

will unless we're crawling across

the fence on the border.

I heard last night they met one.

DARREL CHRISTENSON: And our newsletter is on our website.

I think that's a great,

great way that senators have

not maximized on using their

websites to really get this information out there.

And like you're asking too,

to give recognition to the

community heroes that have

been supportive to you.

So use your websites.

AMINA DONNA KRUCK: Facebook, Twitter, whatever you're into

related to social media because that's really a powerful thing to do.

Yeah?

AUDIENCE MEMBER: Over 28 years

I've collected around 700 e‑mail

addresses that I either used for action alerts or E‑advocacy.

And so, it's kind of like they've come to expect when a piece of legislation

is moving to see something

drop into their e‑mail box.

AMINA DONNA KRUCK: And then

I get complaints sometimes,

stop sending so many e‑mails.

Just delete them if you're

not interested right now.

I think some centers are not

using that, and you need to be

collecting ‑‑ we just found out

by accident because of something,

we actually don't have an official place on our application for

e‑mails yet, even though people were collecting them and they weren't getting into the database.

Collect e‑mails.

Get yourself an e‑mail list because a newsletter, even if it's monthly is too slow when advocacies happen.

You have to communicate with

people using social media.

AUDIENCE MEMBER: I've grouped mine into the issue that we first encountered each other on.

So I've got these people who are interested in transportation.

They're all grouped over here.

And the LTC, the Long‑Term –

AMINA DONNA KRUCK: Care.

AUDIENCE MEMBER: ‑‑ Care Coalition, they're over here.

So everybody doesn't get

everything all the time.

AMINA DONNA KRUCK: Probably I should do that, but I haven't done that.

What else?

AUDIENCE MEMBER: I just

have a comment.

When we've been working on legislation and for, you know ‑‑

AMINA DONNA KRUCK: Who's talking?

Raise your hand so I know where you are.

DEB LANGHAM: Oh, me.

I'm here Amina.

It's the whole voice thing.

I just know it.

We have been ‑‑ when we've

been fortunate to have

legislation passed,

we bring our advocates in and suggest to our legislators that they have

the signing and the agency and we invite the press and try to make a big

deal out of it whenever we can

and to congratulate the

legislators and thank them.

A big deal for them and they're very happy to come and have their picture taken with all of us smiling.

AMINA DONNA KRUCK: Very good point.

I hesitate you said that

because sometimes some people

don't want to get credit.

And it doesn't make sense to give them credit because they've helped you

and they don't want anybody

to know they've helped you.

So you do have to be cognizant of that too because you're going to have

other secret supporters that because of the world they're in, they're not

able to be upfront about that that's what they did, but they'll give you information, they'll call you up.

They'll ask you to send e‑mails.

You know, our legislators now, they've got computers with them

right then and there, and you can e‑mail a legislator right while

they're in a committee testifying to give them support for their position

if you've got a good story, and they may just read this e‑mail out loud.

I've seen that happen.

What else?

Yeah, thank you for raising your hand so I know who was going to speak.

ROGER HOWARD: Yeah, that would be me.

Folks have ‑‑ you know,

throughout this whole thing,

we've talked about

lots of different stuff.

And I just want to remind us

all that this stuff doesn't happen overnight, you know.

A lot of this has been in

the works for a long time.

A lot of these system advocacy initiatives, sometimes it

takes a decade.

You know, just because a bill or a measure or initiative doesn't

get ‑‑ gets defeated,

doesn't mean it's done, you know.

You've got to keep coming back.

And I think it was last summer,

but June Kailes who's a long‑time

effective and creative independent living movement icon received kind

of a lifetime achievement award which she said made her feel pretty old,

but she kind of laughed and shook

her head and said, you know,

she describes herself

as a raging incrementalist.

So what she's saying is she's always on fire, but it's usually this much,

one step forward,

two steps back,

all that stuff.

But that quote really helps me sometimes when I'm feeling like,

you know, we're not getting anywhere.

You know,

I just keep raging on that incrementalism.

AMINA DONNA KRUCK: Yeah.

And after a big defeat, sometimes you just have to go lick your wounds for

a little while with each other.

Do it with each other because you're not the only one licking wounds,

and then you get revitalized to go back at it again surprisingly.

No, not yet.

Other questions, comments?

Anything that doesn't have

to be about this.

Anything that's come up for you

about the whole training session

we covered so much?

Yeah, Mike?

AUDIENCE MEMBER: Actually, this might be for Darrel,

but one of the emerging areas of concern for us in Los Angeles County

right now is the paratransit system, and I'm curious about your

quality assurance monitors.

The program, I think you said

you contracted with the city.

I don't know if it was

a grant or contract.

I'd really like to know a little more about how that came to be, and then, who are your monitors?

Are they consumers?

Are they volunteers?

Are they paid positions?

And that whole process.

And if you want to do this by e‑mail later, that's fine, but I really

would like to know more about your program and how it came to be.

DARREL CHRISTENSON: No,

I can answer real quick.

It came to us by default.

Easter Seals used to have a contract, and then they, for whatever reason,

didn't work out, or some

staffing changes or whatever.

And then they went to another community person, our agency,

to help them out with this program because it saw such benefit to it.

So, again, with the reputation that ABIL has in the community,

Easter Seals said, hey, you might be interested in contracting with

ABIL to do this work.

The folks that are the monitors are individuals with disabilities with

mobility impairments who are users of the Dial‑A‑Ride system.

It's a paid position so they get certain stipend per leg of their

trip, and it's usually ‑‑ it's always a three‑leg trip.

So you're going from home to point A, to point B and back home.

And for that three‑legged trip,

they get a stipend per trip with X amount of trips per month allocated.

AMINA DONNA KRUCK: If you complain long enough, they'll just hire you.

Our transit system,

in particular,

has been like that.

We have a long‑time advocate,

Bill Stoke, that now they have straps for tie‑downs called Stoke straps.

And he was such a pain in their butt that their hired him at the

City of Phoenix, and he worked for their transit system for years.

Because what Phoenix did from the beginning because a bill was not

to paratransit, but start getting buses accessible even before the ADA.

And so he ended up getting hired and worked for them for a long time,

and Easter Seals used to

have that project something.

They had federal money coming in,

and that's why we worked for them

for years prior to Darrel even

coming to Arizona, and so

they knew us very well.

So when they bowed out and

that money was no longer,

they weren't doing that project anymore, they referred people to us.

That's the thing, if you're out there as an advocate on an issue, again,

even though sometimes

it's been adversarial,

if you're also collaborative, educative as Darrel said and

persistent, they come to you because they already see you as the expert, like you said about Bob.

They see you as the expert.

So that's why AHCCCS is on my back right now to show up all the time

because I showed up all the time before and they can count on me as a voice for the disability community,

and the connections I have and relationship building Darrel said.

DARREL CHRISTENSON: And with the program, a piece I really love is we are a third‑party objective group.

It's not like metro is

monitoring themselves.

AMINA DONNA KRUCK: They have

to get something else.

DARREL CHRISTENSON: But we can talk.

I'll give you my card.

AMINA DONNA KRUCK: Roger, your secret shoppers, are they volunteers?

Do they get paid?

ROGER HOWARD: The only thing they get out of it is the satisfaction that

they know they're making a difference and occasionally free bus passes

for their service.

AMINA DONNA KRUCK: Yeah?

And then, Tim, you

probably want to give ‑‑

AUDIENCE MEMBER: I've got

two questions.

One fairly broad and

one fairly specific.

This just may be my own ignorance,

but does ILRU or is there any formal

or informal group that kind of works with new centers who are just coming

on‑line to help them stand up and try to get their processes and procedures

in place so they can kind of help ensure them their success?

AUDIENCE MEMBER: That's what

Paula does, technical assistance.

And it's APRIL, you said,

that they go out and visit

and do peer support.

AUDIENCE MEMBER: Does anybody

know about how many new

centers come online in a given year?

Is there a number that makes ‑‑

AMINA DONNA KRUCK: Zero.

I'm hearing zero over here.

ROGER HOWARD: You know,

the last time new centers came

on board was four years ago when the American Recovery Reinvestment Act

was passed and money was set aside specifically for centers for

independent living, and there was a slight appropria ‑‑ increase in appropriations under Part C.

And so RSA, you know, basically held grant competitions in states where there was identified unserved areas.

I know Texas was one, New Jersey, Alaska, Georgia, maybe ‑‑ I don't know how many states.

Maybe 15, but I don't believe any new centers have come online since then.

AUDIENCE MEMBER: Yes, they have.

There's two other ways new

centers are coming online.

One is, centers that have more than one grant sometimes separate.

So you have a new center with

one of those grants, and they separate into two centers.

And another way we're seeing centers come online is the money from

a closed center goes back on bid.

AMINA DONNA KRUCK: Okay.

Tim needs time now to talk with you about doing your evaluations before

you leave because we want you

to have plenty of time to do

checkouts and things.

I just want to thank you.

This has been such a pleasure being with you all and getting to know

some of you, so I look forward

to talking to some of you in the future via phone or e‑mail.

So thank you very much for what you've been doing.

Good job to everybody.