

1 >>: *This text is being provided in a rough draft format. Communication Access Realtime Translation (CART) is intended to facilitate realtime access to oral and aural communication. It is not meant to produce a verbatim record of the proceedings.* check check check Karly.

2 >>: Check check.

3 >>: I am currently a number going to be a little bit loud because we have CART interpreters that we have included resume. If anyone needs the cart translation we have a QR code so you can access that. I will be a little loud because we cannot get the microphones to work so it's

4 using my computer audio.

5 They will be taking transcripts of all of this but you will not be identifiable unless you request to be identifiable.

6 >>: Guardianship your.

7 >>: And then we have employment over there --

8 >>: Good evening, everyone the roundtable is open feel free to make it to your topic. We have transportation, employment, guardianship and alternatives,.

9 We have CART services with and there is a QR code we have great facilitators for your comments. We will end at 7:00 o'clock.

10 >>: I will ask some questions that quite frankly will sound a little ridiculous but it's because I want to get a baseline as we go along. This to me is a big discussion. You are welcome to stay as long as you want because I like having people here but if you'd also like to check in

11 with some of the other tables and give your input on employment or emergency preparedness or accessible healthcare or transportation, that is totally fine as well. I will not hold it against you.

12 Let me start with a question that's going to seem obvious but I don't think it is because I think different perspectives -- different people of different perspectives on this. What does guardianship mean to you?

13 Other than taking off a box it says US of this meeting. What's the point of it in previous events, sure --

14 >>: What is the purpose of this? Absolutely. So the purpose of the town hall especially the breakout stations right now is to help INSILC figure out what they want to do as part of their plans and efforts going forward.

15 >>: There was a states plan years ago saying they would do something and they never did.

16 >>: What I will also say -- we got interrupted. This is even worse on the last one. I will be quiet now.

17 >>: There's a lot going on in the guardianship realm in Indiana.

18 >>: It's impossible to sit and say nothing.

19 >>: It is.

20 >>: I'm talking to my colleagues. The situation is this. In the world of independent living and the independent living movement, guardianship is something that should not have been. Because if you're living independently then what is -- you have control of yourself. Guardianship

21 is probably one of the most abused.

22 >>: Taken advantage of.

23 >>: Yes, taken advantage of, control and a lot of times people that don't have your best interest, like providers or whatever --

24 >>: Professionals.

25 >>: Yes. They are actually running the show and have no vested interest in you. They have no skin in the game, so to speak here and they are in control. It is actually the antithesis of what independent living is.

1 >>: So we said this before and it didn't go over well I am just asking, given the time, what is the purpose of her making that comment if it's going to go to the same people that did not act on it the last time.

2 >>: I don't know that it's going to the same person.

3 >>: I think that's a question for Mike.

4 >>: I guess, okay. It is me. So I guess, again, I'm going to ask the same question I asked the first time. Have they given you anything to do with this information? What is happening with it on your end?

5 >>: Okay. I am not the right person. I am just a facilitator tonight.

6 >>: Holland -- hold on. You are writing things down and then they're going to Michael. There's a specific place where this is going.

7 While some I didn't -- was not.

8 >>: I told Mike we needed to write down every public comment, who gave it and put in a spreadsheet that way you can look and see.

9 [CROSSTALK]

10 >>: We want information on the alternatives because -
-

11 >>: I don't understand --

12 >>: I believe that guardianship is a very bad word. There are some people I know in nursing homes that have no family that care for them. They have nobody except for the CNA.

13 How did they get out and have nobody.

14 >>: How did they get out when they have nobody what.

15 >>: No family or anyone to take care of them outside and they have no desire to go outside if they have dementia or Alzheimer's.

16 >>: Take away the dementia and Alzheimer's, do you recognize how many people are nursing homes -- they are there because there's no place to live. No apartment building. We don't want anyone to take care of them.

17 >>: My focus is doing this at work.

18 >>: I say X and you say Z I was quoting back to you your words. People don't have family or anyone to take care of them. I said there are a whole lot of people who don't necessarily need anyone to take care of them.

19 >>: I'm not talking about everyone in the nursing home.

20 >>: My question was very specific for reason is that what is the purpose and I told Mike we need to write down the comment in the last two times yet these events, people worked on the comments and they went nowhere so how does that statement makes that any different.

21 >>: I thought he was going to start posting them on a new website.

22 >>: There is a data analysis group.

23 >>: I will also jump in real quick and say that the only thing that got recorded last time was the independent living network table that doesn't exist anymore.

24 >>: Ported that talk about.

25 >>: The guardianship table did not get recorded. The transportation table did not get recorded. The medical thing did not get

recorded. None of those got recorded. The only transcript that was available on the website was for the independent living network table and suddenly

1 that's disappeared.

2 >>: Further the transcript was done automatically and
assist things like get your gun.

3 >>: If they used AI so the transcripts are talking about
the big round pizza table.

4 >>: Right now, the transfers are being done by CA RT.
There's an actual human who is transcribing this right now.

5 >>: Right now, there is CART right here.

6 >>: That doesn't answer the question or the concerns.

7 >>: And I think that's a compensation -- conversation to
have with Mike.

8 >>: I don't want to bother him. Poor guy.

9 >>: You think guardianship should never exist.

10 >>: I didn't say anything about that. That was Leslie.

11 >>: Against [INDISCERNIBLE]

12 >>: I'm just kidding.

13 >>: It was Leslie's we want lady in a wheelchair.

14 >>: When she was bringing up people in nursing homes you were saying let's not focus on individuals with dementia because they are an outlier.

15 >>: My word did not -- my mouth did not say the word guardianship. I don't care for dogma guardianship or the man on the moon someone who works for independent living represents residents of one in nursing homes and said who will take care of them and that's what I was focusing on.

16 I didn't say anything about guardianship.

17 >>: I want to hear from you.

18 There were times where guardianship is appropriate?

19 >>: Some of the times when I have heard of the programs that were in our building doing guardianship, they got notifications from APS Adult Protective Services.

20 They go and they check their been quite a few people
that they have met with.

21 Can you talk a little bit louder.

22 [CROSSTALK]

23 The person one individual that I know it could not see
because of cataracts in the nursing home would not sign for them to have
the cataracts removed and they were told the only way that anyone could
sign for them is if someone came their guardian.

24 >>: That in itself is the issue.

25 >>: That's the issue.

1 >>: Is not the guardianship at all.

2 It's a nursing home.

3 >>: I agree the nursing homes are a big problem.

4 >>: The nursing home is the problem.

5 >>: The resolution is not to do guardianship bids to challenge the nursing him.

6 >>: This woman got her cataracts removed and she was like 80 years old.

7 [CROSSTALK]

8 >>: I'm 77 does that mean I can't make decisions for myself.

9 >>: She did want to leave the nursing home.

10 >>: I guess my question is.

11 I lost my little device.

12 It fell right through the whole.

13 >>: So,'s recent May because I have never.

14 >>: I'm losing my train of thought so come back to me.

15 >>: I think that what are you trying to get us to talk about is temporary guardianship for someone who was in an accident because that's where you let the conversation last time and I think that it's really important to show that there is a big distinction between someone who is in a

16 comatose state and someone who has the capability to advocate for themselves when given a chance.

17 So I don't know if that is something that is necessarily even relevant to this topic because -- that is.

18 >>: Teresa.

19 >>: You just gave it as an example.

20 >>: I just was talk about one individual.

21 >>: It's hard to tell when you said she's 80. That's the issue.

22 >>: I agree that alternatives the public needs to be made of our the alternatives to guardianship there are alternatives.

23 [CROSSTALK]

24 >>: Of a 21 -year-old with autism and I've been told I should probably get guardianship of him which I do not want to do doctors have said you should get guardianship I don't want guardianship of him because I want him to make his own choices. You can manage his money if he has

25 questions you can ask me.

1 I don't want to take rights away from him. I want to be a voice for him because with his autism he does not self advocate.

2 When I am trying to change doctors they don't want to talk to him.

3 >>: They want it both ways, both looked -- basically.

4 >>: Want to be able to go in the doctor's office if he ever said hey I want to do this on my own.

5 >>: There are things to it has to deal with being informed. When it comes to doctors and things like that, being able to inform him of his options and let him know you know you can sign a medical release form that lets you be involved. You can sign different forms that will let you

6 be able to have that knowledge that don't necessarily require you to be a guardian.

7 It's just the information it's crazy I would have to get a lawyer. I want him to be independent.

8 >>: How do we make people aware of the alternatives and then were the groups we need to focus on to either educate them on the alternatives or to get those alternatives as the primary focus.

9 >>: Day groups. There are a lot of programs out there where they provide data services and day groups and a lot of times people in guardianships are placed in their to be babysat.

10 >>: You get to sit with a coloring book while you do nothing of substance while mommy gets a break.

11 >>: I think the school system needs to be made aware a lot of times children's have a disability they are getting ready to turn 18 people at the school says you need to get guardianship over him or you won't be able to do anything for him instead of saying there's decision-making and

12 medical authorization and other things I can be done that don't require the court.

13 >>: And others and going to the doctor with any person he has a right to say I want my mom in there with me because I have a use gonna be 50 in December.

14 It's hard to wrap my head around that but she has a developmental disability and have been going to the doctor with her because she acts like it. She presents herself like she can understand what you're talking about but in reality you've lost her halfway into it so I always go to

15 the appointments with her. Of never once had someone say you can't come in.

16 Absolutely if she says I can come in there I could go on with her she wanted to. The patient has a right to have their advocate, whatever that looks like.

17 >>: A lot of times there are those forms you sign at the beginning of an intake appointment for doctors that says who can we share information with and so like I can put anyone I want -- on the phone up with my seven twice removed I can do it. If I want to put some dude I met on the

18 street I can do that.

19 >>: The way you are handling it as a way people should handle it. The thing about it is we jump to the whole idea that you know, I mean.

20 That's why there isn't a center for Independent living in this country that should be anywhere near guardianship CD they need to make sure that the people providing guardianship are doing it correctly but you should not be providing it.

21 >>: And have no relationship to the Center for Independent living.

22 [CROSSTALK]

23 Susie so it's the other SII.

24 >>: How can you not know.

25 >>: Because I don't talk to Amy all the time.

1 >>: It's on the website.

2 [CROSSTALK]

3 >>: The whole premise of what they're doing with this in our SIL is they are working with the legal community, really supports guardianship because it makes it a lot easier its big money and it makes it a lot easier.

4 I can't tell you the number of lawyers and do -- the mud lawyers that do guardianship because there's money in it Susie and how hard it is to get someone out of guardianship.

5 >>: We work with this group of attorneys and judges.

6 How do you think this is going to fall out. The senders for Independent living and our voices and people with disabilities our voices will not get hurt it will be the people that take care of the people disabilities they get heard. That's our biggest problem in Indiana, probably

7 biggest person all over the country as the fact is we do not have voices.

8 We are being controlled one way or the other.

9 They romances into the idea that you have this SIL CD that will do everything for you and that's a joke and there's this idea that if you go to this place and they will do everything for you that's a joke. We just want to make it easier for you. Just call it the government saying we

10 want to help you.

11 [LAUGHTER]

12 >>: Where the government, were here to help.

13 >>: We should go the other direction because I know that's not true.'S restate my husband died seven years ago now and he had been a nurse he has had and stuff like that. Five months after he died I had to really kind of pretty chronic medical situation go on in the minute they put

14 me in the hospital, I was in there for about five weeks kidney failure all kinds of stuff they start talking about a nursing home. Well Jerry isn't here to help take care of you anymore my husband was a nurse. I'm going about all these kids living in my house.

15 There in my house they will be taking care of me and my son was aghast he was like you're not gonna put my mom in a nursing home.

16 Were you going to go when you get out I said I'm going home.

17 >>: A nursing home that is like being in a guardianship you know what the big beautiful bill that nursing home staffing and nursing homes requirement for minimal staffing in nursing homes was removed in the big beautiful bill.

18 So what you think the cares and be like.

19 >>: I can imagine it getting worse.

20 >>: Well guess what.

21 >>: You all nursing homes closing was people that have jobs.

22 Early hiring the worst of the worst.

23 >>: No place for people to live.

24 >>: While witnessing is that more than half the people at the stable live in one place in that place gets cursed out for talking so much.

25

If we were talking how the conversation going to go there is one person you're impacted by this. We are not we just work with people.

1 What I find frustrating is when people formulate their words put it together explain what their thoughts are and then nothing happens. They make these comments at the Nana meetings INSILC meetings in the minutes they ran a, Leslie said something and Jordan said something so how do

2 their voices matter.

3 >>: They don't speed you will assign" is a QR code to go on the e-mail list.

4 >>: People Susie I have no control over that.

5 >>: I did not know that was the only way to register.

6 >>: I don't hear you echoing my concerns.

7 >>: Holland know because he said it on the microphone while Anna announced on the microphone that it was just a QR code and that was only for the newsletter and that it wasn't a sign-up sheet and it was a survey and so is the point of these events is to create a community of people

8 who care about what's happening to them and have their voices heard and to have INSILC do something about it in an ideal world.

9 How will that happen if you don't even know who's been here and I'm not saying this because you have control over it but you have input and you are somebody who can say something and maybe somebody might listen to you over us since we get yelled at for speaking her mind Susie or don't

10 listen at all.

11 >>: You can make that comment at next meeting so it makes it into the minutes.

12 >>: It's frustrating that we can talk about guardianship and alternatives to guardianship, and then we can make comments at meetings and there is no community whatsoever at the end of the day how will someone say well, Breanna had a really good point or Kristin something really cool.

13 I have no idea what her last name is or how to get a hold of her. I can't remember exactly what she said I just little cynical.

14 How can we actually make change in the state let alone the country.

15 How we do any of that when none of our comments make it to anyone who can help us make change and I'm sorry for feeling what I am very frustrated with this because it's been two years of me sitting

at these meetings and wasting I know I know where she's at after 30 years in two years

16 because it's so maddening to not be listening to and waste my time every single month every single meeting and have hours of my life wasted trying to get someone to listen to me.

17 >>: I did say guardianship when I said we have an estate plan that would do away with this 10 years ago.

18 Yes me what I'm asking for.

19 >>: You said something about community's usually she doesn't know my last name all my e-mail address I know you but someone else would.

20 [CROSSTALK]

21 >>: We can't tackle the world all at one time Susie you asked me a question I answered you and now you're saying we can't tackle the world.

22 >>: At these meetings what type of information and data.

23 >>: What did I say that had to do with tackling the world.

24 >>: You did not hear what I said.

25 >>: I think maybe we need to --

1 >>: Well screw what anyone thinks why because I'm passionate.

2 >>: I want to make sure -- this is supposed to focus on guardianship and alternatives and you guys have every right to also be bringing up.

3 >>: It's connected there people in the community that care about guardianship and they are not at the table because SILC is not trying to build community.

4 >>: Essential oils want to say something similar to that that the essence of guardianship, the existence of guardianship, at the root of everything good in theory be solved by having a community to educate people on these alternatives. It could be solved by having community to

5 advocate with and for each other when guardianship comes up but again, orders and we are really discussing it here at INSILC is because we have not had the experience where that means anything and at the end of the day the only person I've connected with is you and that's only because I talk to you

6 before we set at this table because I wanted to talk to you.

7 If we want in-person which by the way, 99 percent of your meetings are not in-person I could do that because you don't leave the comments open you don't show people on zoom.

8 There is no community there.

9 At the start of anything is letting the people speak and you put a time limit on people and you cut people's Mike's and so how can they even speak when they can't unmute themselves to speak. You unmute them for them and.

10 >>: You decide it takes three minutes to make a comment what if you have difficulty speaking or talking through an interpreter doesn't matter you have three minutes.

11 >>: If you can even provide an interpreter.

12 >>: It really comes down to we need to inform people but we cannot do that if we don't know how to inform them or who to even talk to. And we also can inform them if we can't talk and if our voices aren't heard.

13 >>: Or put into the record.

14 >>: I would like to have a INSILC meeting with the conversation.

15 >>: Like this!

16 >>: Maybe might disagree but okay you allow people to express himself, like that.

17 >>: I guess.

18 >>: You can't inform people of the alternatives if your voice is not heard and there is no community.

19 >>: So much of what we are going through right now is there is a concerted effort to erase people with disabilities people with any differences because they can erase us and when they don't have to pay any attention to us.

20 That's I can be a popular thing to say here but it's organizations like SILC that make those INSILC that made that possible in Indiana because they are the what are you the pad or the cushion between our voices and the state.

21 >>: In a perfect world INSILC would be the liaison between the community and between the government entities.

22 >>: Like the way the law was written that it should do.

23 >>: In a perfect world it should function as such now as it stands it's like Leslie said their functioning as a place for people to voice their opinions for it to go nowhere so the government doesn't have to listen to us.

24

>>: The gatekeeper.

25
they leave.

>>: And then people get tired of not being heard and

1 >>: I went to be 100 percent honest.

2 >>: We've been asking that question for three years
and never got an answer.

3 [CROSSTALK]

4 >>: You bump into it by accident.

5 >>: I've had a disability pre- ADA I've been sitting in a
wheelchair paragraphs I did not know anything independent living existed
until 15 years ago when I accidentally got stuck.

6 I was the chairperson of SILC, this group and I thought
okay I'm really going to help people and be able to do all his
condescending and it was a joke really was a joke because it did nothing.
And it getting there be controlled by the center directors or the state or the
SILC when

7 they go and fight with each other but never has a big control by
people with disabilities there just isn't visible in in this group as we are
everywhere else and her son is invisible in the script just like everyone else
that's a problem. I don't want to be invisible do you.

8 I have a mouse and I'm not afraid to use it. I have a mouse and I'm not afraid to use it.

9 >>: How we make people consider alternatives and get people out of guardianship.

10 >>: You let people know they have choices. Boils down to getting them in form and having a community because up until right this second until he stumbled on a Facebook post you did know this existed and you didn't know there were alternatives to guardianship and so people just don't

11 know.

12 >>: I don't want to take lessons right away before he even tries. They've been telling me since he's 18 that he needs I need to get guardianship over him just before he was 18 I was starting to be told that you need to do this, you need to do this. I don't want to take rights away

13 from him.

14 >>: Did anyone talk to you since.

15 [CROSSTALK]

16 >>: In an ideal world there would be a community that you could reach out to again it's if you want to just save yourself some time

writing just right community is all the answer because that is what it comes down to. If there is no community everything else falls apart. You can

17 only get so far doing things alone. [INDISCERNIBLE] anything pushes guardianship the most.

18 >>: The legal profession.

19 >>: The same group.

20 >>: According to your comes from everywhere.
Someone who should be aware of alternatives.

21 [CROSSTALK]

22 >>: You have two of us and when does wheelchairs
three of us.

23 >>: All of us have disabilities at this point.

24 [CROSSTALK]

25 I think it's important that one of the things is it serves
with the community.

1 If we don't have a community there really is a community not just the gatekeeper so that the other people don't have to listen to us.

2 >>: Another obvious question do you think the medical community inappropriately persists.

3 >>: Of course. It's easier to go through mom.

4 >>: And they don't have to deal the person with the person they don't feel is capable.

5 >>: Let's look at the fact that a lot of these people that are pushing guardianship sure they have caseloads they are overworked and underpaid they are not educated or trained. Why do they care.

6 >>: Yes. Get it off my desk. Move on.

7 That's what's really important that's why again community is really important.

8 >>: It does not make America great again. You do not say those words. That's assuming America's and were great the first place.

9 >>: The thing about it is you have to go.

10 A lot of the grassroots organizations.

11 This is just another system. You've got to get out of the system and start making noise.

12 >>: Is like what we talked about. This meeting is sponsored by an organization that seven years ago said three years ago they said they would stop it you already made the commitment that no one never followed through with. They make statements so it looks good in the report. I

13 don't see writing this down. It's okay because I said it to anytime. I gotta go.

14 >>: It is a fair point because if you look at the state plan -- I'm saying this -- yes, I was going to swing what was. You cut me off.

15 The state plan which is a document that gets written by the state plan committee and it's supposed to be what does the disability community need.

16 What are we gonna do about that what can we do about that and four years ago there was in this state plan a plan for guardianship because they were told many times probably by us that there

were centers providing guardianship and that was not okay so they rode in a provision that said

17 we are implementing a three-year phaseout man of guardianship at centers and then all of a sudden we get the state plan rewritten and that is gone and Alice's guardianship is okay that creates a loophole that enables centers to provide guardianship services to continue to provide guardianship

18 services saying that it is the last resort. We just want to know what happened to that phaseout plan and every time I've asked about that I haven't gotten an answer.

19 And what's in the bill was copied from the department -- it wasn't actually written by anybody.

20 I get frustrated because the state plan number one goal is to get more resources.

21

22

23

24