

## **“Transforming Community Living”**

**Virtual Event held via Zoom Webinar on 10/26/2023, 9 AM – 11 AM EST**

**Host: Western Pennsylvania Disability History and Action Consortium**

### **Closed Captioning Transcript**

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00:00:00.000 --> 00:00:01.000

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00:00:02.360 --> 00:00:14.519

Cindy Leonard: Good morning and welcome everyone! I’m Cindy Leonard, the Project Director for the Western Pennsylvania Disability History and Action Consortium since January 2023.

I know your time is precious and we are so grateful that you have chosen to spend a few hours with us today to learn about and discuss this important topic.

The Consortium was founded eight years ago to preserve and honor the historic struggle of people with disabilities to attain human and civil rights -- and to share the lived experiences of today -- in order to promote community access, participation and equal opportunity. We serve as a resource for the region’s rich history of disability rights advocacy. We use this history—through presentations, media, events, and exhibits—to educate the public. As our motto states, using disability history to ensure disability rights.

As I’m sure many of you here today are aware, throughout history, people with disabilities have faced barriers and discrimination in many areas of their lives. One of these major areas of life is having a place to live that meet one’s support needs in the community of one’s choice.

Historically, people with disabilities have not only had limited opportunities for successful community living but also lived in a society that favored segregated settings. We have come a long way since the days of wholesale institutionalization, but we still have a way to go.

That is why we are here today. This event -- “Transforming Community Living” -- presents a roster of action-oriented visionaries who will take a look back at the point in time where activists turned the tide

toward community living, explain the trajectory to current day concepts, and share best practices and ideas for the future.

Before we get into the program, I'd like to turn the podium over to Sierra Green from Heinz History Center who will let you know more about the History Center's initiatives for preserving and sharing disability history.

Sierra Green, has been an archivist at the Heinz History Center's Detre Library and Archive since 2012, and she's been a steering committee member with a consortium since 2,016. Sierra.

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00:00:17.760 --> 00:00:33.000

Sierra Green: Thank you so much, Cindy. I really appreciate that. Hello, everyone. I'm really honored to be here today we History Center staff have had the honor of working with numerous community groups to preserve their histories on and off. Since our founding in 1879

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00:00:33.040 --> 00:00:43.670

Sierra Green: As a founding member of the Western Pennsylvania Disability History and Action Consortium, we have had an unparalleled opportunity to learn about and preserve local disability history.

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00:00:44.210 --> 00:00:55.100

Sierra Green: And honestly, it's not an understatement to say that this partnership has resulted in the preservation and sharing of foundational stories in Western Pennsylvania disability history

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00:00:55.500 --> 00:01:05.039

Sierra Green: in the museum world we aspire to preserve and share history through people as well as through the items that they created and collected throughout their lives.

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00:01:05.200 --> 00:01:22.010

Sierra Green: These items can be as small as a handheld recorder and as large as filing cabinets full of reports, memos, and telegrams. As a result of our partnership with the consortium. We have thousands of documents and photographs that shine a light on our topic of focus for today.

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00:01:22.660 --> 00:01:33.490

Sierra Green: And our goal at the history center has been to work with the consortium to document this transformation from institutions back into community, from multiple perspectives.

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00:01:33.970 --> 00:01:51.070

Sierra Green: So we started by preserving original records that illuminated measures taken by disability rights advocates, such as Pat Clapp, Bob Nelkin, and Ginny Thornburgh, to expose human rights violations, abuse and neglect at student institutions, beginning in the 1970s.

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00:01:51.490 --> 00:02:06.360

Sierra Green: We have since also preserved records originating from service providers who now provide home and community-based services, and we're then boots on the ground, assisting with the literal transition of institutionalized people back into the community.

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00:02:06.780 --> 00:02:29.300

Sierra Green: finally embracing the adage, "Nothing about us without us," we've had the honor of also preserving photographs, documents, and artifacts that reflect formally institutionalized individuals as well as pioneering individual who embraced newly created educational and community-based services in the 1970s and beyond.

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00:02:30.150 --> 00:02:37.830

Sierra Green: perhaps most excitingly, however, we have seen these historic materials become activated. What do I mean by that?

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00:02:37.960 --> 00:02:55.490

Sierra Green: I mean that stories related to deinstitutionalization, and then the transition to home and community-based services have been included in our exhibits, our publications, our social media presence, and, of course, through events such as that where we are here today.

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00:02:55.620 --> 00:03:03.969

Sierra Green: In addition, teachers, students, filmmakers, and scholars have incorporated their stories, these stories into their work.

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00:03:04.220 --> 00:03:15.410

Sierra Green: And because many of these items are preserved at the history center, these opportunities for activation and sharing of these stories are truly endless. When we think about the future.

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00:03:15.560 --> 00:03:26.389

Sierra Green: So we are so honored to play a role in documenting local disability history, and we remain so eager to continue to work this work with the consortium. Thank you so very much.

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00:03:29.490 --> 00:03:35.930

Cindy Leonard: Thank you, Sierra. We appreciate you being here, and we appreciate Heinz's help with the with the webinar today.

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00:03:36.270 --> 00:03:44.420

Cindy Leonard: First up on our agenda is the viewing of 2 short films that would set the stage for our keynote and our panel discussion.

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00:03:44.530 --> 00:04:01.370

Cindy Leonard: The first film is titled "From Wrongs to Rights." and was originally produced by Lisa Sonneborn, ~~born~~ Institute on Disabilities at Temple University for the United Way of Southwestern Pennsylvania, who has given graciously given us permission to share their film.

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00:04:02.180 --> 00:04:09.419

Cindy Leonard: This short film details the advocacy effort to expose problems of overcrowding, understaffing, and seclusion

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00:04:09.440 --> 00:04:21.110

Cindy Leonard: in state-run and state-funded institutions, including Polk State School and Hospital in Venango County. And now here is "From Wrongs to Rights."

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00:04:33.970 --> 00:04:46.440

Now is the time to transform the dark yesterdays of man's inhumanity into man into the bright tomorrows of justice and freedom. Now is the time.

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00:04:48.450 --> 00:05:03.619

In 1969, there was a lot of social unrest in the whole country. The issue was to see the Arc as an advocacy organization not unlike the NAACP.

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00:05:04.690 --> 00:05:20.420

I don't see people recognizing what Jean Isherwood and Pat Clapp, Barb Sistik, and those people went through to get good services in the community. There was a confrontation with a

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00:05:20.750 --> 00:05:33.239

under deputy secretary, or something or other from the Department of Welfare. And yeah. he leaned across the table and said, you're not playing fair.

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00:05:33.660 --> 00:05:36.719

and Barbara's responses were not playing at all.

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00:05:43.520 --> 00:05:57.390

We didn't have a social worker. We had great family and wonderful neighbors, but no official supports. The Children's Institute, Peter was attending encouraged me to join the Arc.

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00:05:57.430 --> 00:06:09.140

The Association for Retarded Citizens in Allegheny County. We had a very strong chapter, and the minute I got involved with the Arc that changed my life.

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00:06:18.300 --> 00:06:28.980

In 1972, I went to Western State School and Hospital. I saw people naked or almost naked, or rocking back and forth.

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00:06:29.000 --> 00:06:45.829

you know, standing up or on the floor in a fetal position. wooden slat benches and very little furniture in the room. and then there's a glass window, and the staff are looking out through the window monitoring the situation, and I thought.

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00:06:47.140 --> 00:06:56.899

how could this be in the early 1970s? That we're essentially warehousing human beings and just ignoring every human need that they have?

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00:06:58.030 --> 00:07:02.820

And I thought, if only people can see inhumanity.

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00:07:04.070 --> 00:07:06.400

then they'll do something.

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00:07:07.590 --> 00:07:37.200

Bob was the one who first took me out into review and see what institutional care was like. There were 2 other moms I traveled with, Jean Isherwood and Barb Sistik. Bob Nelkin was the driver, and we would go to inspect, make unannounced visits to these centers, we would hear of abuses. We would hear of a lack of programming. And we were following up on that

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00:07:38.070 --> 00:07:50.610

this group of moms we're traveling all over the State. They were monitoring conditions at private facilities, in our public facilities, and I think it just got to a breaking point

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00:07:51.000 --> 00:08:09.610

were these very, very courageous moms that said, we've had it. We were mother bears, and there was a confrontation we had with a superintendent who said, well, are you more interested in safety? Or are you more interested in program?

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00:08:10.140 --> 00:08:20.979

And one of us said, That is an immoral question. The men and women and children who live here have a right to both safety and program.

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00:08:28.470 --> 00:08:41.400

I came to Pittsburgh in mid 1974, and having visited Polk many times I was astonished the first time that I went onto a ward.

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00:08:41.590 --> 00:08:43.090

and saw just

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00:08:44.600 --> 00:08:57.089

bed after bed after bed after bed, very little space in between. perhaps as many as 40 individuals living in a communal bedroom. Individuals would just

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00:08:57.910 --> 00:09:09.069

come up to you, almost like beggars wanting attention. wanting a hug. As a young professional it was. It was just shocking to me.

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00:09:09.590 --> 00:09:21.490

So on one visit, the 40 years ago, April 1973, we insisted upon seeing a back ward. and we saw cages.

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00:09:22.450 --> 00:09:36.980



We saw a human being in a cage, and the cage was about 6 feet tall, wooden slats on all sides, and on top. The superintendent, Dr. McClelland, was with us and

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00:09:37.230 --> 00:09:46.059

and we said, This is a cage. Why do you have a cage? He said, I don't have enough money to have enough staff.

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00:09:47.270 --> 00:09:58.650

I have lots of restraints that I have to use to protect the individuals and protect others. So we asked him if there was any way he could not use it. He said.

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00:09:58.730 --> 00:10:02.939

No, in fact, our medical staff help design it.

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00:10:04.440 --> 00:10:23.030

I think we knew that this was a pivotal moment. We immediately called Helen Wolgemuth, who was the Secretary of Public Welfare, and she, either the very next day or the day after, came, saw the cages and fired the superintendent.

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00:10:23.390 --> 00:10:35.849

And there's this great iconic Post-Gazette, April 1, 1973, above the fold. Big headline. Superintendent fired,

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00:10:35.940 --> 00:10:47.460

staff to be retrained. and it's the staff to be retrained part, which is really the exciting moment, because it wasn't just, we're going to change the captain of the ship. It was,

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00:10:47.480 --> 00:11:00.559

this is unacceptable. We need to find a better way. What happened next was pretty amazing. My colleagues and mentors at the Arc had blown the roof off the place.

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00:11:00.890 --> 00:11:14.799

They had done the work necessary to convince the Department of Public Welfare that those conditions were deplorable, unacceptable. And so the Department, without litigation in this case

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00:11:14.900 --> 00:11:25.260

decided that they were going to rapidly move hundreds and hundreds and hundreds of people back to their communities.

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00:11:32.020 --> 00:11:39.180

Some younger families take it for granted that the supports that they received were always there.

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00:11:41.140 --> 00:11:53.760

I work to help younger families appreciate that the family members who preceded them left, really, their blood on the street to create the community support system that we have.

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00:11:54.520 --> 00:12:04.610

It was very hard work. We learned from each other. We strengthened each other. We, as parent advocates, learn so much.

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00:12:04.650 --> 00:12:14.989

Instead of just concentrating on our own son or daughter, we were able to see other people, and that was a very strong healing process.

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00:12:15.150 --> 00:12:33.730

I see people advocating now in just as strenuous ways. They may not be looking at institutions with 6, 5, 4, 3,000 people in them. But you know, as a mother, as a parent, as an advocate, you never rest.

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00:12:33.970 --> 00:12:35.730

You never rest.

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00:12:39.010 --> 00:12:41.110

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00:12:44.510 --> 00:12:46.470

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00:12:50.500 --> 00:12:51.600

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00:12:55.920 --> 00:12:57.140

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00:13:04.960 --> 00:13:06.790

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00:13:10.820 --> 00:13:23.329

Cindy Leonard: our next video is a brand-new short film produced by the consortium, with funding from AW Mellon Foundation, and with the assistance of the excellent film-making company Artifact Studios.

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00:13:23.850 --> 00:13:30.509

Cindy Leonard: This film is entitled "Polk Center, 1897 to 2023: A Reflection"

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00:13:30.750 --> 00:13:38.259

Cindy Leonard: Polk Center opened in 1897 in rural Venango County closed its doors on May first, 2023.

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00:13:38.460 --> 00:13:42.029

Cindy Leonard: Once one of the largest institutions in the Nation

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00:13:42.060 --> 00:13:48.560

Cindy Leonard: Polk Center reached its peak population of more than 3,000 people. In the 1950s. And 1960s.

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00:13:48.770 --> 00:13:52.239

Cindy Leonard: The population decreased dramatically over the years.

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00:13:52.380 --> 00:14:02.459

Cindy Leonard: In May of this year the care of the Center's 27 remaining residents was handed over to Verland Community Living Arrangements based in Sewickley.

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00:14:02.660 --> 00:14:10.769

Cindy Leonard: The company plans to utilize one building on the Polk campus to care for the residents until 4 group homes are constructed in the area.

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00:14:11.240 --> 00:14:16.400

Cindy Leonard: And now here is the debut of Polk Center: A Reflection.

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00:14:30.690 --> 00:14:53.579

Society's capacity to appreciate humanity's diversity is an ever-evolving process. Though we may not recognize it, our perspectives can be narrow, and it takes time to get the full picture. How we care for people with intellectual and developmental disabilities has evolved tremendously since Polk State School opened its doors in 1897.

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00:14:55.430 --> 00:15:13.759

Polk was founded in Western Pennsylvania, as what was then called an institution for the feeble-minded. The purpose of such institutions was to create a self-contained place where people with disabilities would live, work and be cared for. Separate from mainstream society

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00:15:13.940 --> 00:15:23.720

isolated in a rural area. Polk was a community unto itself, where residents grew their own food, made their own clothes, and had their own activities.

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00:15:25.440 --> 00:15:44.260

Like many institutions of its time, Polk's population became very large. Many residents came as children, and spent their entire lives there. As more and more residents arrived over the first half of the twentieth century. Overcrowding led to people being warehoused and neglected

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00:15:44.510 --> 00:16:18.550

by 1955, Polk had more than 3,400 residents. It had become one of the most populous institutions in the nation, and one of the most troubled by the late 1960s. Families and advocates across the nation began pushing for greater transparency and alternatives to the institutional system. In 1972, a small group of activists from a local chapter of the Arc of Pennsylvania, exposed inhumane conditions at Polk, demanded immediate changes and propelled the deinstitutionalization movement.

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00:16:18.550 --> 00:16:30.409

We would go to inspect, make unannounced visits to these centers. I was astonished the first time that I went on to a ward.

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00:16:30.460 --> 00:16:32.400

and saw just

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00:16:33.610 --> 00:16:45.999

bed after bed after bed after bed, very little space in between, perhaps as many as 40 individuals living in a communal bedroom we saw cages.

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00:16:46.670 --> 00:16:57.390

We saw a human being in a cage, and the cage was well 6 feet tall. Wooden slats on all sides and on top

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00:16:57.870 --> 00:17:21.119

advocates called for services in the community, and laws that would safeguard the rights of people with disabilities. They called for special education which would create a path to self-sufficiency rather than dependency. A landmark lawsuit led to the 1972 PARC consent decree which guaranteed the right to education in Pennsylvania, and became a model for the nation.

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00:17:21.280 --> 00:17:32.400

Society's thinking continued to evolve more and more people with intellectual and developmental disabilities began to receive services at home and in their communities

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00:17:32.860 --> 00:17:44.539

the movement to end institutionalization prioritized individualized services, self-determination, choice. and the opportunity to flourish in the community.

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00:17:46.510 --> 00:18:05.750

By the 1980s, Polk's population declined dramatically as people moved into communities, even though many residents remained at Polk. It continued to be the place they called home, a place they considered to be their community and even their family. It was like a college campus.

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00:18:05.960 --> 00:18:17.809

so it always reminded me of green farmland, and it was beautiful. But institutionalization and congregate care have inherent drawbacks.

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00:18:18.370 --> 00:18:34.159

regimentation limits to freedom. The movement toward home and community-based services continued. There was a very strong evolution. The population declined. The services that were available, and the way they were

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00:18:34.300 --> 00:18:46.360

it managed declined, changed with fewer and fewer people being sent to Polk. The number of residents dwindled by the 1990s. From a few 1,000 to a few 100

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00:18:47.530 --> 00:18:58.510

it became clear that the need for places like Polk no longer really existed. Pennsylvania has 2 remaining State institutions with a steadily declining census

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00:18:59.140 --> 00:19:29.319

Advocates continued to call for their closure. We now understand the vital importance of people with intellectual and developmental disabilities to be able to live like everybody else, to have individualized support, to be empowered, to be able to advocate for oneself. We were created to live in community. We weren't created to live in isolation, and that's been proven through so many different models, not just

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00:19:29.320 --> 00:19:38.830

institutional or workshop model in the field that we've been involved in. But I think you know, throughout society we know how that fails.

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00:19:40.720 --> 00:19:43.090

Polk closed in 2023.

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00:19:44.250 --> 00:19:46.500

Its closure is a powerful symbol.



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00:19:47.570 --> 00:19:49.650

But this is not the end of the story.

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00:19:51.020 --> 00:20:03.580

The system of support for people with intellectual and developmental disabilities continues to evolve. Many are in desperate need of services. A smooth road ahead is not guaranteed.

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00:20:06.590 --> 00:20:27.549

Polk's legacy is a reminder that we must continue to evolve our understanding of humanity. Society thrives when it is diverse. have a chance to be included and participate. A society is just and fair when its citizens face their assumptions and prejudices about who belongs and who does not.

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00:20:27.720 --> 00:20:39.399

Polk reflects a time when we thought that removing people with developmental and intellectual disabilities from society was the right thing to do. Now we know that it's just the opposite.

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00:21:02.820 --> 00:21:10.050

Cindy Leonard: I'm sure these films inspire a lot of emotions and questions on your part as the audience as they do for me.

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00:21:10.110 --> 00:21:15.739

Cindy Leonard: You will have a chance to ask questions after our keynote speaker, and after the panel discussion

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00:21:16.690 --> 00:21:28.129

Cindy Leonard: next on our agenda we are so pleased to have with us today. Jill Jacobs, the Commissioner for the US. Administration on Disabilities for the Administration for Community Living

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00:21:28.250 --> 00:21:36.749

Cindy Leonard: a program of the U.S. Department of Health and Human Services. Ms. Jacobs was appointed to serve in this role in February 2022.

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00:21:37.180 --> 00:21:51.400

Cindy Leonard: She has more than 2 decades of professional experience, managing disability services, organizations, analyzing policy and working toward improved health and disability programs and services at the local state and federal levels.

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00:21:51.670 --> 00:22:02.849

Cindy Leonard: She's also been an active grassroots organizer, leading campaigns to depict President Franklin D. Roosevelt seated in his wheelchair in the National Monument in Washington, DC.

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00:22:03.080 --> 00:22:11.990

Cindy Leonard: And to ensure the inclusion of children with disabilities in schools as well as organizing disaster, response efforts for

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00:22:12.000 --> 00:22:26.219

Cindy Leonard: people with disabilities following hurricanes Harvey and Maria, just to name a few of her accomplishments. In addition, Ms. Jacobs brings to the role the lived experience of her own disability, and as the mother of 2 disabled adults.

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00:22:26.530 --> 00:22:40.070

Cindy Leonard: So after Ms. Jacob's talk, we will have a Q and A session, and we'll be pulling questions from the Q and A feature which you'll see in your tool in your Zoom toolbar. At the bottom of your screen there should be a little Q&A button.

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00:22:40.290 --> 00:22:48.310

Cindy Leonard: so as Jill speaks. If you have questions, feel free to add them in the chat as you think of them.

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00:22:48.700 --> 00:22:50.200

Cindy Leonard: Jill. Welcome.

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00:22:51.550 --> 00:23:04.309

Jill Jacobs: Hi! Everybody! Thanks for having me here. Can you hear me? Okay, we hear you fine. Thank you so much. Perfect. So I'll start with the visual description of myself for those of you who maybe can't see me right now.

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00:23:04.430 --> 00:23:08.410

Jill Jacobs: I am a white lady, middle-aged.

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00:23:08.470 --> 00:23:16.270

Jill Jacobs: I didn't do much with my hair today, pulled up in a bun. I'm wearing glasses. A grey sweater and

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00:23:16.360 --> 00:23:17.879

Jill Jacobs: fleur de lis necklace.

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00:23:18.330 --> 00:23:30.919

Jill Jacobs: I mean my office. There're pink and yellow walls behind me, a lamp and some artwork. So first, I want to thank you all for inviting me here today.

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00:23:30.980 --> 00:23:35.390

Jill Jacobs: I'm really happy and honored to be here.

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00:23:37.950 --> 00:23:42.400

Jill Jacobs: you know, in the position I'm in right now. I just have

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00:23:43.680 --> 00:23:50.610

Jill Jacobs: amazing opportunities to talk to people. You know, real people about

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00:23:50.860 --> 00:23:56.499

Jill Jacobs: our history, about the disability community, about who we are, where do we come from?

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00:23:57.390 --> 00:23:59.689

Jill Jacobs: Where do we think we want to go?

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00:24:00.000 --> 00:24:04.310

Jill Jacobs: What's the future? Possibly look like? And how are we gonna get there.

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00:24:05.060 --> 00:24:08.849

Jill Jacobs: So those videos were fantastic.

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00:24:08.950 --> 00:24:12.470

Jill Jacobs: very interesting, heartfelt. If I look a little

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00:24:12.640 --> 00:24:21.580

Jill Jacobs: whatever I don't know, it's because I got a little teary with the first one especially, because I felt like I was kinda

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00:24:21.740 --> 00:24:37.669

Jill Jacobs: kind of given a little tap in my memory gut, I guess, emotionally, because I saw Ginny Thornburgh on there. I worked with her way back so many years ago, when I was doing the FDR and the wheelchair stuff at the National Organization on Disability. And Ginny was there

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00:24:37.700 --> 00:24:48.929

Jill Jacobs: getting her programs off the ground around inclusivity in in a religious environment. And so we worked together then, and I was really

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00:24:49.330 --> 00:24:53.410

Jill Jacobs: pleased to see her face, and I loved hearing what Ginny had to say

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00:24:53.590 --> 00:25:01.540

Jill Jacobs: about the work they did around changing institutions, changing that the way things were in Pennsylvania.

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00:25:02.330 --> 00:25:07.610

Jill Jacobs: I also work with every day with a wonderful person called Nancy Thaler.

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00:25:07.730 --> 00:25:10.510

Jill Jacobs: and you all might know her there in Pennsylvania.

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00:25:10.670 --> 00:25:19.190

Jill Jacobs: She's worked very hard throughout her lifetime, and so I'm sure that that Ginny knows her, and many of you know of her.

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00:25:19.290 --> 00:25:21.639

Jill Jacobs: She's worked very hard on

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00:25:23.340 --> 00:25:35.480

Jill Jacobs: making change for people with disabilities in particular, people with intellectual and developmental disabilities. and she and I continue to work on that now today at the Administration for Community Living.

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00:25:35.690 --> 00:25:51.369

Jill Jacobs: so I want to talk today a little bit about where we come from, where we are, where we hope to go, and how the organization that I'm with, the Administration of Community Living and the Administration on Disabilities.

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00:25:51.590 --> 00:25:53.239

Jill Jacobs: how we

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00:25:53.610 --> 00:25:56.049

Jill Jacobs: We support change

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00:25:56.480 --> 00:26:00.000

Jill Jacobs: through our vast networks of programs and services.

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00:26:00.350 --> 00:26:08.919

Jill Jacobs: So a little bit about the Administration for Community Living. If you don't know what we do, we're under Health and Human Services in the federal government.

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00:26:09.600 --> 00:26:17.310

Jill Jacobs: and some of the programs at ACL are the Administration on Aging, the Center for innovation and Policy.

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00:26:17.980 --> 00:26:27.760

Jill Jacobs: NIDILR, which is, I can't even remember all the words that the that the acronym stands for. But it's the National Institute on

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00:26:27.990 --> 00:26:29.750

Jill Jacobs: Disability.

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00:26:29.850 --> 00:26:34.140

Jill Jacobs: Research. They are our research arm. Okay?

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00:26:34.860 --> 00:26:38.619

Jill Jacobs: And then the Administration on Disabilities where I'm the Commissioner.

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00:26:39.650 --> 00:26:45.100

Jill Jacobs: So at the Administration on Disabilities, we focus on

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00:26:45.230 --> 00:27:03.500

Jill Jacobs: particular segment of work. So we do. We have the Office of Independent Living Services, and OILS oversees all the centers for independent living across the country and all the state organizations that support those centers - the State Independent Living Councils.

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00:27:03.760 --> 00:27:12.700

Jill Jacobs: We've got about. I honestly don't know how many. I think maybe 500 centers for independent living across the country, a lot, a lot.

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00:27:12.930 --> 00:27:22.200



Jill Jacobs: That's one thing we do. And you may be familiar with the independent living movement because Judy Heumann is considered the mother of the independent living movement.

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00:27:22.670 --> 00:27:37.859

Jill Jacobs: We also oversee at the Administration on Disabilities the Developmental Disability Councils. So these are councils that are created by every governor. In every state, every territory. There's a council, a DD Council.

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00:27:38.020 --> 00:27:48.409

Jill Jacobs: And it's required that the people on the DD Councils are at least the majority of the Council is people with developmental disabilities.

148

00:27:48.550 --> 00:27:56.919

Jill Jacobs: And the Governor answers to this Council. They communicate regularly, and then we oversee and support them.

149

00:27:58.080 --> 00:28:01.239

Jill Jacobs: We have Protection and Advocacy under us.

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00:28:01.470 --> 00:28:04.229

Jill Jacobs: Protection and Advocacy. Well, we have

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00:28:04.900 --> 00:28:13.570

Jill Jacobs: I don't know. Maybe 67 or 70 Protection and Advocacies across the country, at least one in every State and Territory. Some there's some have more.

152

00:28:13.750 --> 00:28:18.199

Jill Jacobs: and that's a place where people with disabilities can go for free legal support,

153

00:28:18.210 --> 00:28:42.029

Jill Jacobs: call their Protection and Advocacy in their state and say, I have a problem. I need help. There's a problem, a systemic problem in my state. There, we feel like this is happening. We need help our school district. There's a systemic problem. They're doing this. So they're doing that instead of what they're supposed to do. You can call your Protection and Advocacy system about that. Protection and Advocacy systems are very helpful. During covid

154

00:28:42.440 --> 00:28:58.470

Jill Jacobs: I reached out to my P and A before I had this role and said, what the heck is going on? How come people with disabilities and their caregivers aren't at the front of the line? Do they not realize that caregivers for people with disabilities are frontline workers?

155

00:28:58.640 --> 00:29:02.939

Jill Jacobs: and the P and A helped us to make sure that in Virginia

156

00:29:03.040 --> 00:29:19.109

Jill Jacobs: we got to the front of the line, our caregivers got to the front of the line that we were recognized that we got, you know, the protective equipment that we needed. We got our vaccines, we were recognized and valued. They helped us advocate for changes in home and community services to make sure that

157

00:29:19.130 --> 00:29:22.450

Jill Jacobs: people, people whose caregivers had to quit.

158

00:29:22.930 --> 00:29:37.620

Jill Jacobs: you know, still had some kind of care. Their family members could care for them and get reimbursed for doing that care. So that's some of the things that the P and A does, some of the things the P and A does around advocacy, legal support. And some ways they've helped us recently.

159

00:29:39.320 --> 00:29:43.650

Jill Jacobs: We also have the UCEDDs

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00:29:44.210 --> 00:29:50.229

Jill Jacobs: And that stands for University Centers for Excellence in Developmental Disability services.

161

00:29:50.830 --> 00:30:05.279

Jill Jacobs: There are about 70 of those, too, and they are in every State and Territory. At every university. Not every university, but at least one university in every State and Territory has a UCEDD in it.

162

00:30:05.390 --> 00:30:09.199

Jill Jacobs: and they do all sorts of disability work. They're all unique.

163

00:30:10.110 --> 00:30:20.349

Jill Jacobs: They're all different. For example, we have one in Arizona that has many focuses, but one particular focus they have is around tribal services.

164

00:30:21.150 --> 00:30:28.769

Jill Jacobs: We have a UCEDD in Minnesota that works very hard on home and community-based services.

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00:30:29.330 --> 00:30:34.870

Jill Jacobs: I hope they'll forgive me that I don't remember their exact name

166

00:30:35.040 --> 00:30:44.640

Jill Jacobs: Center for Community Integration. I'm bad at names, and you all have one in Pennsylvania, too. So those are some of the services that we have.

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00:30:44.740 --> 00:30:57.120

Jill Jacobs: We also have something, and those are ongoing services. They exist. They are mandated to exist through you know, Federal laws, Federal acts, and they get ongoing funding every year.

168

00:30:57.820 --> 00:31:07.310

Jill Jacobs: and they'll continue to. Then we have something called Projects of National Significance or PNS. So PNS is what we call discretionary funds.

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00:31:07.490 --> 00:31:18.480

Jill Jacobs: and those funds. Every year we get to decide we've got this pile of money. What are we gonna do with this money? And so we really look at what is what's trending in disability.

170

00:31:18.530 --> 00:31:24.539

Jill Jacobs: What are? Where are the areas that we need to change, or what's trending in a positive way?  
We need to put some funds toward

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00:31:24.900 --> 00:31:28.959

Jill Jacobs: building that up even more, you know, really escalating it.

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00:31:29.120 --> 00:31:33.430

Jill Jacobs: so that's every year we do that. And then

173

00:31:34.800 --> 00:31:38.769

outside of those programs, those funding streams that we have.

174

00:31:39.360 --> 00:31:53.370

Jill Jacobs: We have a lot of. We've really worked hard on this in the past few years. For sure, I have to say that to build partnerships. So we have partnerships. We've really focused in the past few years on a number of partnerships. I'll highlight a few

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00:31:53.670 --> 00:32:13.989

Jill Jacobs: We've really worked hard on our partnership with the Department of Education with what's called OSERS Office of Special Eds. And Special Ed and rehabilitative services, and then under that, it's called RSA - Rehab Services Administration. Not that you all need all the detail, but so you get an idea.

176

00:32:14.230 --> 00:32:21.939

Jill Jacobs: And with them we've worked specifically around students with disabilities, young people with disabilities.

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00:32:21.960 --> 00:32:32.580

Jill Jacobs: transition helping people with students with disabilities and their families understand what it's going to look like to transition from school to adult life.

178

00:32:32.820 --> 00:32:38.090

Jill Jacobs: and how that can be improved, supported.

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00:32:38.100 --> 00:32:44.080

Jill Jacobs: How we can help young people with disabilities learn to advocate for themselves as individuals

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00:32:44.230 --> 00:32:51.839

Jill Jacobs: in small groups, with their friends locally around policy at the **State level, Federal level**. How can they do that?

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00:32:52.870 --> 00:33:05.300

Jill Jacobs: So we've partnered with Department of Ed in particular, last year I'm really working hard to put out funding. I think it was. It was a lot. I wanna say it was 200 million dollars or something like that worth **of** funding

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00:33:05.310 --> 00:33:18.029

Jill Jacobs: to get funds to States, and make sure we included our centers for independent living in that funding so that they could, they can work on these transition things. This transition issues with students.

183

00:33:18.580 --> 00:33:24.579

Jill Jacobs: We've partnered with FEMA a lot in the last year and a half around disaster relief and climate change

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00:33:24.760 --> 00:33:40.860

Jill Jacobs: How can we make sure that we get services to people with disabilities before disasters, during disasters and after disasters? And how can we make sure our voice is heard around climate change? How climate change affects people with disabilities?

185

00:33:41.010 --> 00:33:46.139

that's been a great partnership, and we are looking forward to more good things to come as we move forward.

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00:33:46.930 --> 00:33:48.220

Jill Jacobs: and I think

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00:33:48.320 --> 00:33:57.719

Jill Jacobs: a big partnership for us in the past year and a half or so, past 2 years, huge partnership, has been with CMS. The Centers for Medicaid and Medicare services.

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00:33:58.640 --> 00:34:10.389

Jill Jacobs: the space that we we've worked with CMS on a lot of things. But the space where we've really focused is home and community-based services. So when we talk about home and community-based services, many of us think of

189

00:34:10.420 --> 00:34:22.889

Jill Jacobs: 8 or HCBS. Many of us think of HCBS as our waiver. I have a Medicaid waiver. That Medicaid waiver helps me to live in the community and not live in an institution.

190

00:34:23.190 --> 00:34:29.050

Jill Jacobs: So the services that you saw in the video people were getting whatever they got in institutions

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00:34:29.510 --> 00:34:37.110

Jill Jacobs: that home, but home and community-based services ensures that those can be provided instead in the community. And

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00:34:38.040 --> 00:34:51.330

Jill Jacobs: what we've really worked with CMS on in the last year is called the Settings Rule. So the Settings Rule came about well, a while ago, like a dozen years ago, and it's taken a while to really institute it.

193

00:34:51.340 --> 00:35:05.579

Jill Jacobs: A lot of push, a lot of work, a lot of organizing, a lot of strategizing, lot of incremental policy change and programmatic change at the state level to identify, How is this gonna work here?

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00:35:06.200 --> 00:35:13.320



Jill Jacobs: The heart and soul of the Settings Rule is really about human rights, civil rights, basic rights.

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00:35:13.870 --> 00:35:33.849

Jill Jacobs: Because what we found is that well, home and community-based services, living in the community, is awesome and great, and it's what we all want. It can still be isolating. It can still, home and community-based services can still be set up in a way where providers kind of run things, and people with disabilities don't really have choices and options.

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00:35:34.600 --> 00:35:44.590

Jill Jacobs: It can be set up in a way where rules are made for people with disabilities. and in a way that isn't person-centered. So

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00:35:44.650 --> 00:35:55.420

Jill Jacobs: what the Settings Rule does is it changes that. And it requires that services are provided in a way that is person-centered. It focuses,

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00:35:55.630 --> 00:35:59.240

Jill Jacobs: it centers the person with a disability.

199

00:35:59.370 --> 00:36:02.070

Jill Jacobs: What's important to me as a disabled person?

200

00:36:03.090 --> 00:36:11.920

Jill Jacobs: What do I want in my life? How am I gonna get there. How are the services that are available to me gonna help me get there? What matters to me?

201

00:36:14.670 --> 00:36:16.350

Jill Jacobs: What matters for me?

202

00:36:16.410 --> 00:36:23.450

Jill Jacobs: What's my life going to look like right now and in the future, what? How am I? What is that about? It's about me.

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00:36:25.230 --> 00:36:32.120

Jill Jacobs: And so that's what the Settings Rule is about, and the Settings Rule does that with the leverage. And in the context of

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00:36:33.320 --> 00:36:38.719

Jill Jacobs: civil rights, human rights. So we, the Settings Rule, insists on

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00:36:38.800 --> 00:36:44.310

Jill Jacobs: several things, and some of the key things are really basic that you might not think

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00:36:45.070 --> 00:36:55.600

Jill Jacobs: that we would have to actually say on paper that we would have to actually say, this is a rule. this, but it turns out we do. And so we've said it. And we're enforcing it.

207

00:36:56.850 --> 00:37:01.190

Jill Jacobs: So some of those rules are things as

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00:37:01.240 --> 00:37:10.360

Jill Jacobs: basic as if I'm hungry, I should have access to food. If I'm thirsty, I should have access to drink.

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00:37:13.510 --> 00:37:20.739

Jill Jacobs: I have the right to see my family and my friends, I have the right not to see my family and friends if I don't want to.

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00:37:22.420 --> 00:37:29.529

Jill Jacobs: I have the right to have relationships, friendships, to try things just like anybody else.

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00:37:30.110 --> 00:37:34.720

Jill Jacobs: I have the right to try dating someone and see if that works, and if it doesn't

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00:37:35.590 --> 00:37:38.770

Jill Jacobs: to end it. I have the right to have

213

00:37:39.690 --> 00:37:47.919

Jill Jacobs: to express myself, my identity. If I'm gay or straight, or male or female, and enter into relationships as I choose.

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00:37:48.660 --> 00:37:56.000

Jill Jacobs: I have the right to have sex. I have the right to have friends come to my house and visit with me, real basic things.

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00:37:58.860 --> 00:38:03.519

Jill Jacobs: I have the right to live where I want to live. and when I live there

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00:38:04.610 --> 00:38:11.840

Jill Jacobs: the right to live there in the way that I choose to live there as long as I'm following the law, I should be able to do these things.

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00:38:11.850 --> 00:38:21.849

Jill Jacobs: And so that's kind of the basics of what the HCBS Settings Rule is about. And so at ACL, In the past few years we have worked extremely hard

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00:38:22.050 --> 00:38:24.189

Jill Jacobs: partnering with

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00:38:24.870 --> 00:38:27.439

Jill Jacobs: the Centers for Medicaid Medicare Services

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00:38:27.880 --> 00:38:31.940

Jill Jacobs: to make sure that rule is being followed

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00:38:32.320 --> 00:38:34.429

Jill Jacobs: in States. And so in the past

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00:38:34.790 --> 00:38:41.070

Jill Jacobs: year I've traveled myself to. I've literally lost count of how many states

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00:38:42.730 --> 00:38:55.530

Jill Jacobs: I've gone to with CMS. We've gone out and we've looked at States. We've looked at providers. And we've said, what's really happening here? Are you really implementing this rule, State?

224

00:38:55.570 --> 00:39:00.420

Jill Jacobs: Are you making sure your providers are really implementing this rule, State.

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00:39:01.550 --> 00:39:06.990

Jill Jacobs: And then we've let people know. Let the States know in written reports

226

00:39:07.480 --> 00:39:18.809

Jill Jacobs: what we found, what needs to be better. What needs to change, what's working awesome and we want more of, what's working there. So let's work on it. But it's a great idea

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00:39:19.500 --> 00:39:25.880

Jill Jacobs: we've let state **know**. and we've done that in a way that's public which has not happened in the past.

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00:39:26.280 --> 00:39:37.990

Jill Jacobs: We've made sure that all of these reports are public. You can go online and you can find them and see what happened in my State. What happened in that in Arizona or Texas or Alabama, wherever.

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00:39:38.720 --> 00:39:51.930

Jill Jacobs: So I think we've visited 17 or 18 states. We're going to continue doing that work. And the work is evolving as we learn. So it's not a static process. It's an iterative process. It's an evolving process.

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00:39:51.980 --> 00:39:59.669

Jill Jacobs: Every so often we say, okay, we finished this group of states. Let's take a look and see, what's what are we learning?

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00:39:59.770 --> 00:40:02.999

Jill Jacobs: And how are we gonna adjust our process as we move forward?

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00:40:04.340 --> 00:40:06.670

Jill Jacobs: So it has been

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00:40:06.690 --> 00:40:13.769

Jill Jacobs: a great opportunity to learn and to make change. And one of the key elements of that has been

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00:40:13.940 --> 00:40:24.280

Jill Jacobs: advocates, people with disabilities. And I'm hoping there's a lot of advocates in this room today, people with disabilities and people who love and care about them and for them.

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00:40:25.000 --> 00:40:30.379

Jill Jacobs: So what we've done at ACL is, we have reached out to our networks

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00:40:30.610 --> 00:40:44.470

Jill Jacobs: that I just talked about and said, Who's an advocate in your state? We know you all are advocates. We want you to help us identify more advocates who are the real trusted folks, you know. Who's that mom who everyone knows. It's gonna be like.

237

00:40:44.880 --> 00:41:09.020

Jill Jacobs: you know, she's gonna know, she's wise, she's been doing this a long time, throwing punches for a long time, making policy change, insisting on change for a long time. Who's that expert in your State? Who are? Who's the person with a disability, who is admired and revered, and who really knows how to get the message across? Who are your trusted spokespeople, and then we come together with our networks and trusted spokespeople.

238

00:41:09.140 --> 00:41:10.170

Jill Jacobs: and

239

00:41:10.740 --> 00:41:23.980

Jill Jacobs: they all speak to CMS. Which is unprecedented, and it's never been done before, and they directly tell CMS, here's what's working. Here's where there's a problem. Here's the rocks we need you to look under. Here's the red flags.

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00:41:24.630 --> 00:41:39.799

Jill Jacobs: so that when we go out to the States, we're armed, we're prepared. We have some. We have a real knowledge base about what people say. Not what program leaders say, not what providers say. We hear that stuff too sure.

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00:41:39.880 --> 00:41:42.389

Jill Jacobs: But we hear from the people.

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00:41:42.740 --> 00:41:50.709

Jill Jacobs: and we help bring that information to CMS, Who really needs to hear from the people and have never before heard from the people.

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00:41:51.760 --> 00:41:55.939

Jill Jacobs: So that's something we've worked really hard on. And we're really proud of at ACL.

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00:41:58.330 --> 00:42:04.289

Jill Jacobs: We've seen remarkable results with that. We've seen

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00:42:05.700 --> 00:42:11.879

Jill Jacobs: just a fresh, new, heartfelt, warm response

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00:42:13.420 --> 00:42:15.599

Jill Jacobs: from CMS.



247

00:42:16.110 --> 00:42:33.230

Jill Jacobs: And how you know a new. I think CMS has always understood, but they're able to display now and express now, and participate now in a different way in making sure these rights are happening for people with disabilities through this rule.

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00:42:34.010 --> 00:42:42.230

Jill Jacobs: So it's been wonderful. It's been a great opportunity. And you all are focused on history. And so are we.

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00:42:42.350 --> 00:42:51.540

Jill Jacobs: We love our history, we believe in our history, we honor and admire people like Judy Heumann and Ginny Thornburgh and

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00:42:51.860 --> 00:42:53.889

Jill Jacobs: my beloved Nancy Thaler.

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00:42:54.970 --> 00:42:58.500

Jill Jacobs: and we believe on making history

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00:43:00.000 --> 00:43:07.420

Jill Jacobs: so a little bit about me. Personally, I know I've been talking a minute, but I'll tell you that personally I have a disability.

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00:43:07.680 --> 00:43:10.749

Jill Jacobs: I grew up with a dad who had a disability.

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00:43:11.210 --> 00:43:15.690

Jill Jacobs: and my children have disabilities. 2 of my children have developmental disabilities

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00:43:16.910 --> 00:43:24.710

Jill Jacobs: and feel like this is kind of been my whole life experience, disability stuff. I don't didn't ever know anything different.

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00:43:24.790 --> 00:43:26.510

Jill Jacobs: I feel really lucky

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00:43:26.630 --> 00:43:37.099

Jill Jacobs: that my dad had a disability, because when I had my kids, I had so much knowledge and experience about what that is, what that means.

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00:43:37.400 --> 00:43:48.009

Jill Jacobs: how it impacts a human being and who they are as a person, and I so I was. I'm lucky cause I never, ever, from the time I had my kids thought

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00:43:48.620 --> 00:43:50.720

Jill Jacobs: there's something wrong with them.

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00:43:51.030 --> 00:43:58.909

Jill Jacobs: I just felt like this is who they are, and this is what I'm going to do to make sure they are able to be that person as best as they can be

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00:43:58.940 --> 00:44:01.220

Jill Jacobs: throughout their lives. They're 30 now.

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00:44:02.070 --> 00:44:11.209

Jill Jacobs: They, you know, have their own levels of independence. It's, you know, no 2 people with disabilities are the same, and neither are they.

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00:44:11.820 --> 00:44:17.040

Jill Jacobs: I'm proud of them. I'm impressed with them. and I love them.

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00:44:20.070 --> 00:44:30.679

Jill Jacobs: I'm very dedicated to home and community-based services. and it's a big reason of why I choose to be here in this position, and I choose to stay in this position.

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00:44:33.080 --> 00:44:44.749

Jill Jacobs: So I'll tell you story, personal story. And every time I say this, I don't say it every time I speak, but I'll say it here because we're talking about institutions, and it's the right context to do so.

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00:44:47.150 --> 00:44:49.229

Jill Jacobs: On my dad's side of the family.

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00:44:50.890 --> 00:44:54.420

Jill Jacobs: Every man in our lineage

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00:44:55.510 --> 00:44:57.850

Jill Jacobs: has lived and died in an institution.

269

00:44:59.930 --> 00:45:01.500

Jill Jacobs: My grandfather.

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00:45:02.150 --> 00:45:09.309

Jill Jacobs: my great-grandfather, and my great great grandfather, all lived and died in a place called Eastern State

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00:45:10.310 --> 00:45:13.399

Jill Jacobs: in East Feliciana Parish, Louisiana.

272

00:45:15.880 --> 00:45:17.390

Jill Jacobs: But my dad didn't.

273

00:45:18.880 --> 00:45:24.429

Jill Jacobs: even though he had a disability, too. He certainly was in and out of nursing homes. It was a challenge.

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00:45:26.730 --> 00:45:29.989

Jill Jacobs: but he died at home because he had home and community-based services.

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00:45:31.250 --> 00:45:34.240

Jill Jacobs: and he lived a great majority of his life at home.

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00:45:35.540 --> 00:45:40.469

Jill Jacobs: My children have never been in a nursing home or an institution, thankfully.

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00:45:42.790 --> 00:45:43.950

Jill Jacobs: and I hope

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00:45:44.400 --> 00:45:51.979

Jill Jacobs: they never will be. I hope none of our communities, our disability communities, children, will be.

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00:45:52.190 --> 00:45:54.380

Jill Jacobs: I hope none of us will have to be.

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00:45:57.130 --> 00:46:13.269

Jill Jacobs: and I respect and honor our legacy and our history. I respect and honor this moment. I've been gifted as to be in this position. I respect and honor every single one of you for the fights that you have every day, and the work that you do every day.

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00:46:16.240 --> 00:46:19.169

Jill Jacobs: and I thank you for letting me be here today and speak with you.

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00:46:19.370 --> 00:46:22.659

Jill Jacobs: Thank you. If you have questions, I'm happy to answer them.

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00:46:24.520 --> 00:46:32.090

Cindy Leonard: Jill, thank you for that. That I'm tearing up now, too. Thank you for sharing that personal story. That's

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00:46:32.150 --> 00:46:39.049

Cindy Leonard: that was very touching. So we do have a few a few questions in the Q & A.

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00:46:40.820 --> 00:46:48.569

Cindy Leonard: I'm going to take the, I'm not going to go in order. The first one, which I think is something that we may have to share

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00:46:48.830 --> 00:47:00.010

Cindy Leonard: after the fact, in the post follow-up, post-event follow-up email. Jan asks, can the link or website be shared that has the public reports for the Settings Rule?

287

00:47:00.720 --> 00:47:18.140

Jill Jacobs: Yes, I can get that for you and share it. I could send it to you, Cindy, so you can share it with everyone. Would that be okay?

Cindy Leonard: Absolutely.

Jill Jacobs: Thank you for asking. I really appreciate that you asking so that we can make sure everyone has that information.

288

00:47:18.450 --> 00:47:31.969

Cindy Leonard: Lucinda asks, Can you explain why ODP was unable to use 170 million Covid-era dollars. and why it was taken away in this year's budget? Where did those dollars go that were unused?

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00:47:32.940 --> 00:47:37.160

Jill Jacobs: I need you to interpret that acronym for me, please.

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00:47:37.850 --> 00:47:44.499

Cindy Leonard: Office of Developmental Programs, I believe.

Jill Jacobs: So that's a state office.

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00:47:46.780 --> 00:47:48.630

Jill Jacobs: I can't tell you that answer.

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00:47:48.750 --> 00:48:00.219

Cindy Leonard: and one of the panelists, I see, is actually typing in an answer. So somebody, considering that deputy secretary Ahrens says is typing in an answer. So there we go.

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00:48:00.520 --> 00:48:06.039

Cindy Leonard: and I'll read that answer for everyone once it's finished. The next question

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00:48:06.640 --> 00:48:10.489

Cindy Leonard: also from Lucinda says, personal-centered is great.

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00:48:10.610 --> 00:48:17.130

Cindy Leonard: but the regulations in residential, independent living are out of date with this and out of date.

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00:48:17.210 --> 00:48:23.019

Cindy Leonard: with a focus on, and this is capitalized, everyday lives. How is this being addressed?

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00:48:24.910 --> 00:48:31.160

Jill Jacobs: So I'm going to reflect back to you what the question is. So I understand what you're asking, if that's okay?

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00:48:31.260 --> 00:48:39.049

Jill Jacobs: so what I think you are asking is

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00:48:41.670 --> 00:48:46.009

Jill Jacobs: How are group homes

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00:48:47.150 --> 00:48:50.060

Jill Jacobs: made to

301

00:48:50.690 --> 00:49:01.300

Jill Jacobs: respond in the way that the HCBS Settings Rule says, in a person-centered way, is that correct?

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00:49:06.030 --> 00:49:22.030

Cindy Leonard: I suppose that interpretation makes sense.

Jill Jacobs: If the person who asked it is still here and wants to correct me, or, you know, add some information as I respond, please feel free to. I won't be offended at all if I'm on the wrong track.

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00:49:22.420 --> 00:49:24.210

Jill Jacobs: So

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00:49:26.790 --> 00:49:40.979

Jill Jacobs: I agree that there are many group homes or settings like that. So could also include places where people with disabilities work in a group

305

00:49:41.400 --> 00:49:55.150

Jill Jacobs: or on their own. It could also include day programs where people go during the day. And they're all they maybe their perspective is out of step.

306

00:49:57.100 --> 00:50:05.870

Jill Jacobs: I hear you. I don't disagree with you. and I would also say that

307

00:50:08.310 --> 00:50:12.429

Jill Jacobs: when we started moving people from institutions to community.

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00:50:13.600 --> 00:50:16.870

Jill Jacobs: it was a first step. And so

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00:50:17.490 --> 00:50:29.059

Jill Jacobs: group homes were the first version, you know, that's what we came up with what our community came up with in our, historically, right? We came up, get them out of institutions. Let's find something else.

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00:50:29.260 --> 00:50:30.200

Jill Jacobs: And

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00:50:30.370 --> 00:50:34.230

Jill Jacobs: they're wonderful in lots of ways, and yes.

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00:50:34.280 --> 00:50:39.290

Jill Jacobs: a lot of the practices that were that that were started

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00:50:39.530 --> 00:50:50.460

Jill Jacobs: way back when haven't really evolved that much. And so through the Settings Rule, we set these rules, and that's the way that we can make change.

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00:50:50.810 --> 00:51:00.159

Jill Jacobs: So if in your state, you're familiar with group homes that don't follow the Settings Rule. We would love to know that, we would love to hear about that.

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00:51:00.240 --> 00:51:03.480

Jill Jacobs: In fact. being in Pennsylvania.

316

00:51:03.520 --> 00:51:09.580

Jill Jacobs: we are gathering names of advocates now who would like to let CMS know how they feel.

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00:51:09.790 --> 00:51:19.419

Jill Jacobs: So if you can get your contact information, if you're interested in that, you can get your contact information, perhaps to Cindy. She can send me a list of people

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00:51:19.520 --> 00:51:26.760

Jill Jacobs: who'd like to be part of an advocacy group to let CMS know what you feel is happening in your state so that we can address that.

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00:51:27.100 --> 00:51:28.550

Jill Jacobs: I will tell you

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00:51:28.900 --> 00:51:39.690

Jill Jacobs: what we found. I told you we've evolved, right? We were doing things one way. But as we learn some things, we evolved to start doing it another way. So this next group of states, we're going to

321

00:51:40.070 --> 00:51:49.089

Jill Jacobs: where our focus is much more on what we found over the last 17 or 18 states. And what we found primarily is

322

00:51:49.220 --> 00:51:55.480

Jill Jacobs: case management. Isn't that great? We need to work on it. Every state needs to work on their case management.

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00:51:56.170 --> 00:51:58.820

Jill Jacobs: and that includes

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00:52:00.050 --> 00:52:02.140

Jill Jacobs: creating person-centered plans.

325

00:52:02.610 --> 00:52:05.570

Jill Jacobs: monitoring person centered plans.

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00:52:05.640 --> 00:52:16.739

Jill Jacobs: training to understand what that even means. And how can we accomplish it? Tools to help accomplish it. Maybe communities, groups that help

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00:52:17.070 --> 00:52:18.630

those things happen.

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00:52:19.210 --> 00:52:31.530

Jill Jacobs: person-centeredness is a problem, case management is a problem, service delivery can be a problem in terms of, you know,

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00:52:32.140 --> 00:52:47.259

Jill Jacobs: having enough providers, understanding what providers are out there. Maybe there's just a list of providers, but not really actual. They're not accepting anyone. These are some of the things that we're going to be working on as we move forward, meeting with States

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00:52:47.410 --> 00:53:04.010

Jill Jacobs: and saying, What can we do here? What's happening in your State? Show us what's happening in your State. So we need from advocates to tell us what problems they're encountering. So if you feel, I don't know who asked the question, if you feel that, you know, group homes in your State are problematic.

331

00:53:04.150 --> 00:53:24.720

Jill Jacobs: and they aren't really reflecting the HCBS Settings Rule. We would like to hear about it. Let Cindy know. And, Cindy, if you could pass on names of people who would like to get their voices heard, I would love that.

Cindy Leonard: There was a little follow-up commentary. I'm going to move on to the next question. But same questioner

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00:53:24.750 --> 00:53:34.779

Cindy Leonard: expanded to say that certain regulations do not allow for personal choice. If my son wants to have me work for him, which I currently do, I am not allowed to under present regulations.

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00:53:35.190 --> 00:53:50.429

Cindy Leonard: And Deputy Secretary Ahrens is also typing an answer to that question in the Q & A. So I'm going to go ahead and let her answer that. Going back to the first question that Deputy Secretary answered

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00:53:51.270 --> 00:54:00.069

Cindy Leonard: about ODP not being able to use 170 million covid-era dollars. The answer to that, so everybody can hear it

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00:54:00.400 --> 00:54:08.699

Cindy Leonard: Deputy Secretary Ahrens said there were no unspent Covid funds. The General Assembly passed a budget that included 170 million less than

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00:54:08.730 --> 00:54:24.710

Cindy Leonard: the Governor requested for ODP. The funds were not used due to under-utilization. Many ODP providers are still struggling to recover from the pandemic. This is mostly due to workforce shortages. So that was the answer to that question.

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00:54:24.980 --> 00:54:29.370

Cindy Leonard: the next question we have

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00:54:29.920 --> 00:54:39.949

Cindy Leonard: this is from John, he says. Can you talk a little more about relationship with Pennsylvania. John, if you could expand on what relationship do you mean?

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00:54:40.390 --> 00:54:43.610

Cindy Leonard: Ms. Jacobs' relationship with Pennsylvania or [her]

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00:54:43.870 --> 00:54:48.989

Cindy Leonard: department's relationship with Pennsylvania is most likely, I think, what he's saying

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00:54:49.920 --> 00:55:10.680

Jill Jacobs: So our relationship with Pennsylvania is the same relationship we have with any State or Territory. We oversee programs in those States, and the ones I mentioned, Independent Living, DD Councils, Protection and Advocacy, UCEDDs, Projects of National Significance

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00:55:11.120 --> 00:55:23.939

Jill Jacobs: in. In all of those in, in every State and Territory, and through our partnerships, we engage individuals in that state, around advocacy, around change-making, around

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00:55:24.190 --> 00:55:25.930

Jill Jacobs: all sorts of things.

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00:55:26.120 --> 00:55:35.660

Jill Jacobs: And we support the State of Pennsylvania in being successful, the best that they can be. We don't see

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00:55:35.790 --> 00:55:40.730

Jill Jacobs: States as our adversaries. We see them as our partners.

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00:55:40.830 --> 00:56:03.699

Jill Jacobs: You know, we wanna work together. I appreciate Deputy Secretary Ahrens' presence here today. We see, you know, states as we, we want to build partnerships and build relationships. And we want to facilitate partnerships and relationships between advocates, people with disabilities, their family members and state organizations. We we're about building bridges.

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00:56:04.410 --> 00:56:09.979

Jill Jacobs: So we build a bridge to you people in Pennsylvania. We hope you walk across and meet us in the middle.

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00:56:11.820 --> 00:56:15.079

Cindy Leonard: Thank you. And the next question is from Rose.

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00:56:15.190 --> 00:56:33.019

Cindy Leonard: how is the work you're doing with CMS making sure you're getting input from those who advocate for profoundly autistic individuals who are often excluded from community programs due to behaviors that require high staff ratios and more specialized supports.

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00:56:34.010 --> 00:56:36.430

Jill Jacobs: I really appreciate this question.

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00:56:36.700 --> 00:56:42.209

Jill Jacobs: and I appreciate you who asked this question. Do you know her name?

Cindy Leonard: Her name is Rose.

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00:56:42.280 --> 00:56:47.699

Jill Jacobs: Rose, appreciate that you asked this question. Are you a person who has autism?

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00:56:50.650 --> 00:56:52.909

Jill Jacobs: If you if you're comfortable sharing that.

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00:56:57.190 --> 00:57:08.499

Technology Moderator: Jill, I'll just share that participants in this can't come off mike. So Rose could maybe share in the chat, but she won't be able to speak with you directly.

Jill Jacobs: So, Rose, I appreciate you asking that question.

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00:57:08.550 --> 00:57:15.330

Jill Jacobs: For whatever reason you chose to ask. It's a good one. It's a valid one, and I think everyone needs to hear this distinction.

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00:57:16.360 --> 00:57:17.929

Jill Jacobs: There are people

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00:57:18.120 --> 00:57:21.390

Jill Jacobs: who struggle to participate in community

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00:57:22.050 --> 00:57:30.819

Jill Jacobs: in the ways that maybe you and I see community, right? The way I consider my community may not be the way that Cindy sees community

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00:57:30.840 --> 00:57:32.500

Jill Jacobs: for her. Right?

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00:57:32.670 --> 00:57:37.729

Jill Jacobs: So I was a military spouse for a long time. I still consider the army my community.

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00:57:38.090 --> 00:57:43.629

Jill Jacobs: I'm a member of the disability community. I consider that my community. I live in Northern Virginia.

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00:57:43.860 --> 00:57:53.949

Jill Jacobs: and, you know, I've got a little neighborhood I live in here. That's my community, my family's my community, for other people community might mean sports or schools, or my book club.

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00:57:54.530 --> 00:58:03.450

Jill Jacobs: It might mean my family and my support workers. What community is to me is not the same as what community might be to you.

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00:58:04.040 --> 00:58:07.470

Jill Jacobs: And so we rely on the person-centered plan.

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00:58:07.590 --> 00:58:19.329

Jill Jacobs: And we wanna make sure people understand how to create person centered plans, how to work with people with disabilities and their family members to make sure that person centered plan reflects what that

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00:58:19.360 --> 00:58:22.989

Jill Jacobs: person wants and needs, desires, believes in

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00:58:23.310 --> 00:58:29.980

Jill Jacobs: and what they see as their community. So if we can do that, if we can get better and better at that.

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00:58:30.580 --> 00:58:38.980

Jill Jacobs: it doesn't matter what you see as your community, my friends, it matters that we are getting you what you need in the community you see as yours.

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00:58:39.660 --> 00:58:52.130

Cindy Leonard: And Rose had a follow up. Her son is a person with autism.

Jill Jacobs: So thank you, Rose, I appreciate you asking.

Cindy Leonard: Okay, our next question. We've got time, for we've got some time for a few more.

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00:58:52.640 --> 00:58:59.529

Cindy Leonard: With the. This is from Jan, with the reality of direct care staffing crisis.

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00:58:59.700 --> 00:59:06.220

Cindy Leonard: What consideration is being given to further engage community members and supporting families

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00:59:06.240 --> 00:59:09.580

Cindy Leonard: in engaging supports outside of our systems.

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00:59:10.250 --> 00:59:15.870

Jill Jacobs: Thank you for asking that question. Man, everyone's on point today. Pow, pow, pow! I love it.

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00:59:16.120 --> 00:59:25.209

Jill Jacobs: so we have it. ACL, we have a project

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00:59:25.230 --> 00:59:35.939

Jill Jacobs: I guess we're gonna call a project. We are creating what we're calling in the National Center for Direct Care Workforce. So we're

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00:59:36.440 --> 00:59:41.309

Jill Jacobs: very focused on trying to figure out how to fix this

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00:59:41.840 --> 00:59:56.770

Jill Jacobs: caregiver crisis that we're in. It is extremely hard to find staff. It's extremely hard for agencies to find staff, for day programs to find staff, for people with disabilities who use consumer direction to find staff.

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00:59:57.310 --> 01:00:09.289

Jill Jacobs: It's a problem. We know, it's a problem. So we're creating this national center to explore that and to find ways to fix this problem. I'm not going to say that we're like, we know the solution. We're working on it.

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01:00:09.740 --> 01:00:13.480

Jill Jacobs: So in working on that, we put together

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01:00:13.650 --> 01:00:32.570

Jill Jacobs: a steering committee that includes people with disabilities who use these programs, their family members who work through these programs, that includes organizations, associations that support the States in running HCBS programs and includes provider associations.

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01:00:32.830 --> 01:00:51.649

Jill Jacobs: subject matter experts from universities, and who've done a lot of study and research. And again, we consider people with disabilities and their family members to be subject matter experts. So we they. We have those individuals on the steering committee, too, and we all are working together along with multiple

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01:00:51.730 --> 01:00:56.740

Jill Jacobs: expert organizations across the country to try to solve this problem.

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01:00:56.850 --> 01:01:01.869

Jill Jacobs: That's something we're doing right now. We are also partnering with our Federal

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01:01:02.120 --> 01:01:12.169

Jill Jacobs: partners, the Department of Labor. Others, you know, CMS, other HHS entities. We're partnering every way we can to fix this problem.

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01:01:12.590 --> 01:01:21.099

Jill Jacobs: We always want your input. We always want to hear from you. We know that it's a problem. We're working on it, my friends.

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01:01:22.840 --> 01:01:25.490

Cindy Leonard: Thank you. And

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01:01:26.140 --> 01:01:32.280

Cindy Leonard: another question. This is the last question in the chat. If anybody has any final questions.

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01:01:32.300 --> 01:01:41.839

Cindy Leonard: Not in the chat, but in the Q & A feature. If you have any other questions, we can take one or 2 more. So please put them in the Q & A if you have anything else

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01:01:41.970 --> 01:01:48.349

Cindy Leonard: the question I'm looking at is from John? And he asked, could you talk a little bit about

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01:01:48.380 --> 01:01:54.089

Cindy Leonard: your department's relationship with Aging and Disability Resource Centers.

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01:01:54.210 --> 01:01:58.830

Jill Jacobs: I sure can. So the project I just mentioned

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01:01:59.120 --> 01:02:04.460

Jill Jacobs: well, I don't know if you'll ever heard of silos. People talk about silos all the time.

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01:02:04.580 --> 01:02:06.960

Jill Jacobs: so you know,

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01:02:09.410 --> 01:02:14.650

Jill Jacobs: disability in the aging community has historically been a little separated, right?

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01:02:15.700 --> 01:02:29.839

Jill Jacobs: But the Administration on Aging which oversees the Aging [and Disability] Resource Centers is part of ACL - Administration for Community Living. And so are we, Administration on Disability. So we're all together under one roof.

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01:02:29.960 --> 01:02:32.419

Jill Jacobs: And we are working really hard.

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01:02:32.460 --> 01:02:35.189

Jill Jacobs: I'm partnering with AOA [Administration on Aging].

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01:02:36.500 --> 01:02:41.599

Jill Jacobs: One of the big things we're partnering on is the Administration on Aging is our partner



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01:02:41.640 --> 01:02:47.470

Jill Jacobs: in this caregiver project we're working on, the caregiver crisis.

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01:02:48.250 --> 01:02:51.059

Jill Jacobs: So if that project is

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01:02:52.320 --> 01:02:55.450

Jill Jacobs: run by the National Council on Aging

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01:02:55.660 --> 01:03:04.599

Jill Jacobs: and there are multiple partners that are disability partners. And so people on the committee have, you know, worked together

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01:03:04.750 --> 01:03:16.850

Jill Jacobs: To solve these problems in a way that includes people with disabilities, and includes people who are aging. And so what I like to say is, you can age with a disability.

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01:03:16.990 --> 01:03:27.049

Jill Jacobs: You can age into a disability. But either way, you're gonna get to disability. So we are again building a bridge between disability and aging

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01:03:27.110 --> 01:03:36.139

Jill Jacobs: in this way. We also have, so the Administration on Aging has, and I can make sure that Cindy gets a link to this also,

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01:03:36.170 --> 01:03:51.660

Jill Jacobs: has a National Family Caregiver strategy. And that's through our RAISE program. And so I would love to, the national strategy we presented to Congress this year, the end of last year

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01:03:51.990 --> 01:04:11.410

Jill Jacobs: we presented that to Congress and it was open for public comment for a while. We would love for all of you to take a look at that and see what you think about it. There's a real focus on family caregivers and what, you know what's happening. If you're a family caregiver, whether you're caring for someone who's aging or someone who's younger.

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01:04:11.510 --> 01:04:26.459

Jill Jacobs: we focus on that. So I'm like, I will make sure you get a link to that. I'll get a link to Cindy so you can learn more about that. And we're doing lots of programs with aging. I'll give you one more. One more I'll tell you about, and that is, we have something called the Bridging Aging and Disability Project.

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01:04:26.540 --> 01:04:55.209

Jill Jacobs: that is, goes through our Developmental Disability councils, and so in different states, so different States are doing different things around that but they're working on issues like guardianship and conservatorship. And how to make sure that people have choice around, that they get supported decision making. We're working on things like social security in one state or many different issues that those projects, bridging aging and disability projects are working on.

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01:04:58.780 --> 01:05:01.420

Jill Jacobs: I see your lips moving, Cindy, but you're on mute.

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01:05:02.530 --> 01:05:09.229

Cindy Leonard: Yes, I am. I cleared my throat and didn't want everybody to hear that. Are you up for 2 more questions?

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01:05:09.610 --> 01:05:27.010

Jill Jacobs: Of course, if you all don't mind the fact that my that there's people who've decided to work on the yard today while I'm on this. And if you don't mind that background noise, of course I'm up for more questions.

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01:05:27.140 --> 01:05:40.310

Cindy Leonard: This is anonymous. Oftentimes in the disability community we tend to silo, and there is a feeling that supporting another group takes away from your group. How does ACL promote that all disability

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01:05:41.140 --> 01:05:42.180

Cindy Leonard: groups

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01:05:42.190 --> 01:05:46.290

Cindy Leonard: can support each other without losing out for their own.

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01:05:47.070 --> 01:05:59.329

Jill Jacobs: My goodness! Crabs in a barrel, you know. I'm a big fan of coalition building at ACL We believe in coalition building. We believe in building bridges and crossing them.

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01:05:59.600 --> 01:06:12.140

Jill Jacobs: We get the people feel that way. I believe that that comes from the traditional funding streams. So funds for people with developmental disabilities were funded by the DD Act. Okay?

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01:06:12.150 --> 01:06:41.729

Jill Jacobs: **Rehab Act** funds, things for people who use independent living programs and maybe have more physical disabilities. Funds for people who are aging come through the **Older Americans Act**. Because those funding streams exist. This is my belief. Maybe other people would disagree. We've gotten into this mode of, this is the way we do things. And oh, if I want to share with this other person, I have to give up some of mine, right? If I want this other person to share with me, they gotta give up some of theirs.

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01:06:42.520 --> 01:06:59.400

Jill Jacobs: It's an unfortunate perspective. We work very hard to foster collaboration, to participate and model collaboration and to ask that collaboration exists elsewhere. I would like to comment, too, around equity.

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01:07:00.760 --> 01:07:04.040

Jill Jacobs: We work really hard to

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01:07:04.310 --> 01:07:07.560

Jill Jacobs: foster equitable collaboration.

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01:07:08.820 --> 01:07:13.340

Jill Jacobs: It's important that we remember that not everyone is the same as me.

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01:07:13.680 --> 01:07:31.160

Jill Jacobs: People come from all kinds of walks of life, have all kinds of experience, look all kinds of ways, believe all kinds of things, and one great thing about disability, and there are many great things about having a disability. But one great thing about our community, people with disabilities, is we exist everywhere.

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01:07:32.170 --> 01:07:46.710

Jill Jacobs: everywhere, in all the communities, in all the sections, and I hope that we will work together more in that way, and we foster that. And we model that at ACL, and we expect, and so does the President expect. He issued an equity

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01:07:46.730 --> 01:07:51.780

Jill Jacobs: an equity executive order. The Secretary of Health expects.

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01:07:53.380 --> 01:07:55.099

Jill Jacobs: ACL expects

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01:07:55.730 --> 01:08:02.220

Jill Jacobs: that we provide all of the services, and we work together in a way that is equitable.

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01:08:03.490 --> 01:08:14.550

Cindy Leonard: So we have time for one more quick question. And then we are gonna move onto the panel discussion. Another question that's not really much of a Q & A type of thing.

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01:08:14.780 --> 01:08:24.670

Cindy Leonard: An anonymous attendee wonders if contact information for you will be made available.

Jill Jacobs: My email address is Jill Dot Jacobs

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01:08:24.930 --> 01:08:41.930

Jill Jacobs: at Acl, Dot, HHS, Dot, Gov, and I will put it, can I? Can I type in the chat? Will people see if I put it in the chat?

Cindy Leonard: as long as everyone is selected. Yes. And I can also include that in the follow-up.

Jill Jacobs: I'm happy for everyone to take, get my email address. want to tell you the truth.

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01:08:42.560 --> 01:08:58.110

Jill Jacobs: Always happy for people to get my email address, I get a lot of email. So it's hard to respond to everyone. So you might email me, and I'll send you a short email back and loop in someone who can really directly give you, point to where you need to go.

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01:08:58.660 --> 01:09:00.550

Jill Jacobs: I'm happy to talk to you.

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01:09:01.180 --> 01:09:08.779

Cindy Leonard: Thank you for that. So this is the final question we're gonna take for this section. You. This is from Lee.

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01:09:09.240 --> 01:09:14.580

Cindy Leonard: and they ask, you mentioned that provider agencies are included on the steering committee. Does this include direct support professionals, or are they leadership of these agencies?

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01:09:14.790 --> 01:09:23.480

Jill Jacobs: It includes direct support professionals. Absolutely.

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01:09:24.279 --> 01:09:31.750

Jill Jacobs: We need to know the perspective of the actual people. Now, the center itself,

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01:09:32.840 --> 01:09:50.539

Jill Jacobs: at this time there, as we evolve, we definitely have an expectation things will change, but the center itself isn't intended at this moment to for direct support professionals to be able to reach directly and say, I need help with this. What can I do? It's intended to help

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01:09:50.670 --> 01:09:53.200

Jill Jacobs: States improve.

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01:09:53.439 --> 01:10:06.549

Jill Jacobs: and then through your States or Territories that then you can get support in that way. Right? So direct support professionals can reach out through whatever we're creating and so can people with disabilities.

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01:10:07.060 --> 01:10:12.019

Jill Jacobs: Even with that, though, as I said. the perspective of people with disabilities and

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01:10:12.030 --> 01:10:21.010

Jill Jacobs: and the family members, and I'm so sorry I didn't mention that initially, and I'm glad you asked the question for clarity and the support of direct support professionals.

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01:10:23.620 --> 01:10:26.930

Cindy Leonard: Great! That's all the time we have for today.

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01:10:27.200 --> 01:10:32.180

Cindy Leonard: Hey, Commissioner Jacobs. Thank you so much for talking and being here and

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01:10:32.210 --> 01:10:36.009

Cindy Leonard: patiently answering so many questions.

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01:10:36.050 --> 01:10:42.640

Cindy Leonard: We're grateful to you and for the work that you're doing. and we look forward to seeing

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01:10:42.750 --> 01:10:58.139

Cindy Leonard: the future progress that comes out of your department. So thank you.

Jill Jacobs: Thank you. And I am truly grateful for all of you, and the work you're doing. And you are the future. Thank you for having me.



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01:10:59.470 --> 01:11:12.060

Cindy Leonard: So. Next up we have our esteemed panel of disability experts which will be moderated by Pittsburgh's own Chaz Kellem. I almost feel like Chaz needs no introduction, but I'll do it anyway.

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01:11:12.070 --> 01:11:15.540

Cindy Leonard: Our moderator for the panel discussion, Chaz Kellem.

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01:11:15.710 --> 01:11:22.429

Cindy Leonard: currently serves as a program manager at Highmark Health, where he does work in diversity, equity, and inclusion.

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01:11:22.690 --> 01:11:33.179

Cindy Leonard: Chaz began his career at the Pittsburgh Pirates, where he spent 10 seasons, most of which in the Community and Public Affairs Department, as the manager of diversity initiatives.

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01:11:33.610 --> 01:11:44.950

Cindy Leonard: And we've got 3 panelists today. Our panelists are Deputy Secretary, Kristen Ahrens from the Pennsylvania's Office of Developmental Programs, ODP,

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01:11:45.100 --> 01:11:55.779

Cindy Leonard: within the Department of Human Services. Prior to her appointment as Deputy Secretary in 2018 Ms. Ahrens served as the director of the Bureau

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01:11:56.050 --> 01:12:07.630

Cindy Leonard: of Policy and Quality Management at ODP. Before joining ODP in 2016, Ms. Ahrens was the policy director for the Institute on Disabilities at Temple University,

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01:12:07.750 --> 01:12:14.409

Cindy Leonard: Pennsylvania's Federally Funded University Center for Excellence in Developmental Disabilities.

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01:12:14.740 --> 01:12:20.969

Cindy Leonard: Ms. Ahrens' 30 years of experience working with people with developmental disabilities.

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01:12:21.230 --> 01:12:34.729

Cindy Leonard: spans from advocacy and community education to providing supported living, family support and self-directed services, and includes development and management of several self-directed models.

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01:12:35.410 --> 01:12:40.609

Cindy Leonard: We also have Hope Dittmeier, the executive director for Mattingly Edge.

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01:12:40.710 --> 01:12:46.869

Cindy Leonard: Ms. Dittmeier holds a master's degree in rehabilitation counseling from the University of Kentucky.

459

01:12:47.070 --> 01:12:52.630

Cindy Leonard: She is also a Social Role Valorization (SRV) practitioner.

460

01:12:52.930 --> 01:13:03.889

Cindy Leonard: SRV training provides empirical knowledge on how to increase the chances people with disabilities will experience the good things in life many people take for granted.

461

01:13:04.210 --> 01:13:14.910

Cindy Leonard: She has also learned a great deal from her sister-in-law in terms of the perspective of a person with a disability. Our third panelist is Christopher Liuzzo,

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01:13:15.600 --> 01:13:25.200

Cindy Leonard: a consultant based in New York state, who is doing work grounded in values informed by social role valorization and person-centered practices.

463

01:13:25.540 --> 01:13:31.530

Cindy Leonard: He has held numerous advocacy and administrative leadership roles since the mid 1970s.

464

01:13:31.840 --> 01:13:39.269

Cindy Leonard: His work includes the co-founding of advocacy organizations dedicated to individualized supports.

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01:13:39.760 --> 01:14:03.349

Cindy Leonard: He retired from his role as associate executive director of the Arc of Rensselaer County, New York, where he led initiatives to downsize and close congregate living settings. He's now a

consultant to organizations especially interested in moving from congregate services to individualized support. And now going to pass the podium to Chaz. Welcome everybody

466

01:14:03.400 --> 01:14:05.730

Cindy Leonard: and let the discussion begin

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01:14:06.580 --> 01:14:20.080

Chaz Kellem (he/him/his): alright. Good morning, everyone, and thank you so much, Cindy, as mentioned. My name is Chaz Kellem. I use the he him his series of pronouns, and I'm honored to serve as today's moderator of this phenomenal

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01:14:20.080 --> 01:14:43.170

Chaz Kellem (he/him/his): panel, very much looking forward to it. Quick visual description. African American male, glasses. We're in a yellowish golden shirt, short hair and joining you today from the Fifth Avenue Place, the Highmark Health headquarters . Very much excited to jump right into our questions this morning. So our first question we know that

469

01:14:43.170 --> 01:14:58.020

Chaz Kellem (he/him/his): the 50-year trajectory from the institutional model to today's home and community-based models provides a sense of security and insurance to people with disabilities and families,

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01:14:58.080 --> 01:15:07.910

Chaz Kellem (he/him/his): even with today's threats of staff shortages, limited pool of staff for the future, and efforts towards segregation and congregation.

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01:15:08.370 --> 01:15:20.599

Chaz Kellem (he/him/his): What provides you with the hope for the future? Again, what provides you hope for the future? And I'm gonna ask Deputy Secretary to start us off with the response to that question.

472

01:15:22.730 --> 01:15:29.419

Kristin Ahrens: Yes, and good morning, everyone. Really glad to be here. Love seeing the video presentations and

473

01:15:29.810 --> 01:15:45.739

Kristin Ahrens: and hearing Commissioner Jacobs start us out. So before I talk about hope, I do want to be really clear that I have some, I have real concerns about threats to some of the progress that we have made.

474

01:15:45.980 --> 01:16:03.909

Kristin Ahrens: I think workforce shortages are one. And I want to be very specific about what some of those are. I think it is beyond just direct support professionals. This goes to Rose's question and comment earlier, I think one of the real challenges that we have in terms of

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01:16:04.040 --> 01:16:31.219

Kristin Ahrens: ensuring that home and community-based services are available to everyone is the clinical capacity within our home and community-based service system. And you know, when I look at the numbers coming out of the Centers for Disease Control related to autism and autism prevalence in 8-year olds right now, it's one in 36, 8-year olds in this country have autism, and a quarter of those are on

476

01:16:31.220 --> 01:16:40.129

Kristin Ahrens: the more severe end of the spectrum, and those young people will be adults, and many of them will be looking

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01:16:40.150 --> 01:17:00.679

Kristin Ahrens: to us to provide services. And so we really gotta be thinking about how our home and community-based services can deliver and deliver therapeutic restorative environments, structured environments for adults with autism and with dual diagnosis, which is another

478

01:17:00.910 --> 01:17:27.720

Kristin Ahrens: area that our system is significantly challenged with. So one of the other things I'll say, because I took a look at the attendee list, and I can see we have a lot of advocates on here. The other thing, I think, is a threat is that we do have some waning advocacy. The voices that you know, got us here today in terms of having less than 5% of people living in institutional settings.

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01:17:27.790 --> 01:17:39.790

Kristin Ahrens: I feel like to some degree people are a little bit resting on our laurels, and we think this is a done deal, and, you know, we're good. I don't think we can take our foot off the pedal, particularly when it comes to

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01:17:39.840 --> 01:17:57.129

Kristin Ahrens: making sure that the kind of support that people need to live in this home and community-based settings is available. So with that, now we'll talk about hope. Sorry for the downer portion of that. But I do want to be real about where I think some of the specific thoughts are there.

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01:17:57.280 --> 01:18:05.439

Kristin Ahrens: But in terms of hope. But you know, hope is that we've been on this trajectory in in Pennsylvania. We are down now.

482

01:18:05.670 --> 01:18:10.859

Kristin Ahrens: for IDD services. Less than 5% of people are living in institutional settings.

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01:18:11.000 --> 01:18:29.700

Kristin Ahrens: Even in the midst of the pandemic, we closed 2 of the 4 state-operated facilities right now, again, in the midst of this workforce crisis and all of the challenges. With the pandemic recovery, we're closing another institutional setting.

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01:18:29.710 --> 01:18:40.229

Kristin Ahrens: We are in the process of closing Woodhaven, which is a privately operated facility. In southeastern Pennsylvania. But we are actively working on that, and that should be closed

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01:18:40.280 --> 01:18:43.399

Kristin Ahrens: within the next 12 to 18 months.

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01:18:44.140 --> 01:19:04.569

Kristin Ahrens: Another thing that gives me hope is we've built some really great infrastructure. We have some very, very solid infrastructure to support home and community-based services in particular, in Pennsylvania. I think we have done a very good job of building up peer support models.

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01:19:04.590 --> 01:19:07.540

Kristin Ahrens: Our network of family advisors.

488

01:19:07.620 --> 01:19:23.509

Kristin Ahrens: Adopting a Life Course. To really think about people over the course of a lifespan. Those pieces are very much embedded in our system at this point. And it gives me a lot of hope that that will continue in spite of all of this threats.

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01:19:23.840 --> 01:19:27.790

Kristin Ahrens: That that we've got something solid that will continue.

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01:19:27.860 --> 01:19:34.459

Kristin Ahrens: And then the last thing I would say is that as part of the infrastructure, there's been a lot of provider transformation

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01:19:34.560 --> 01:19:38.020

Kristin Ahrens: that has happened. We have providers that have

492

01:19:38.410 --> 01:19:55.149

Kristin Ahrens: closed, you know, closed any facility-based services and are supporting people that really focus on employment. Our employment numbers are up tremendously from where they had been previously. Youth coming out of high school are now employed at a much higher rate than they used to be.

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01:19:55.280 --> 01:20:01.699

Kristin Ahrens: We have some nice, we have providers who have really been looking to move away from

494

01:20:01.840 --> 01:20:15.920



Kristin Ahrens: residential services and more towards supported living models. All of those things give me tremendous hope, and I think we've seen we've got some very good data to support that. those trends are occurring. So that's,

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01:20:16.040 --> 01:20:18.200

I think, lots of reason for hope. There.

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01:20:18.750 --> 01:20:46.449

Chaz Kellem (he/him/his): Thank you so much. Appreciate that that thoughtful response. Hope is so important to continue to talk about and express. So thank you for that response. I do wanna take a moment to acknowledge all the folks that are attendees to this morning. We do have a great pool of advocates of organization representatives, so I wanted to take a moment to thank and acknowledge all of you as attendees for joining for this very important conversation.

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01:20:46.650 --> 01:20:53.739

Chaz Kellem (he/him/his): So I'm gonna go to Christopher. Same question, what provides you with hope for the future?

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01:20:55.140 --> 01:20:58.429

Christopher Liuzzo: Well, hello, everybody! Chris Liuzzo

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01:20:58.610 --> 01:21:11.919

Christopher Liuzzo: from New York. I've had the great privilege of spending a fair amount of time in Western Pennsylvania, both on a social level and on a professional level. Shout out, Dorothy Gordon, I see you out there somewhere. So hi to you.

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01:21:12.540 --> 01:21:21.949

Christopher Liuzzo: I'm gonna, in some sense, echo the Deputy Secretary's concerns about threats. They're different than hers. But

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01:21:22.470 --> 01:21:25.499

Christopher Liuzzo: sort of the downers thing that you did.

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01:21:26.510 --> 01:21:30.970

On the positive note, you know that the first video started with Dr. King.

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01:21:31.650 --> 01:21:36.239

Christopher Liuzzo: And if there's anything that gives me hope, and there aren't many things,

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01:21:36.450 --> 01:21:43.379

Christopher Liuzzo: it's his famous quote, which I can only paraphrase. But it's that the arc of the moral universe is long

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01:21:43.690 --> 01:21:46.449

Christopher Liuzzo: but it bends toward justice.

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01:21:47.010 --> 01:21:52.069

Christopher Liuzzo: and our field is bending ever so slightly

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01:21:52.290 --> 01:21:57.100

Christopher Liuzzo: over the last 40, 50 years toward justice.

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01:21:58.160 --> 01:22:09.109

Christopher Liuzzo: Our good friend, I know a good colleague and friend and mentor of Hope Dittmeier's is one of mine, too. John O'Brien, some of you will know John.

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01:22:09.580 --> 01:22:11.730

He was once asked,

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01:22:12.450 --> 01:22:13.630

Christopher Liuzzo: what's our work?

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01:22:15.020 --> 01:22:19.539

Christopher Liuzzo: And John, ever thoughtful, said to make hope

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01:22:19.690 --> 01:22:27.360

Christopher Liuzzo: palpable to the people we support and to their families that they can feel something

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01:22:29.100 --> 01:22:31.420

Christopher Liuzzo: hopeful about their futures.

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01:22:32.680 --> 01:22:33.580

Christopher Liuzzo: So

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01:22:34.880 --> 01:22:40.450

Christopher Liuzzo: it makes me think that, what I hope happens,

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01:22:40.650 --> 01:22:45.809

Christopher Liuzzo: not that I hope that I believe will, necessarily, but I hope for

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01:22:45.930 --> 01:22:47.150

Christopher Liuzzo: is that

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01:22:47.290 --> 01:22:51.119

Christopher Liuzzo: people in our field, leaders, self-advocates.

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01:22:51.340 --> 01:22:56.460

Christopher Liuzzo: administrators, turn the beam of inquiry

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01:22:57.070 --> 01:23:01.680

Christopher Liuzzo: toward themselves, not outward, not blaming ODP or

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01:23:01.920 --> 01:23:13.049

Christopher Liuzzo: whoever, but what is going on in my life and in my organization? What am I doing to make hope palpable

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01:23:13.190 --> 01:23:22.670

Christopher Liuzzo: with the people we support? And Hope, we keep saying hope, but Hope Dittmeier, who you will hear from shortly,

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01:23:22.850 --> 01:23:24.610

she's one of those people.

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01:23:25.360 --> 01:23:32.619

Christopher Liuzzo: She runs an organization that didn't say, we're gonna change the State of Kentucky, which is where she's from.

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01:23:32.940 --> 01:23:38.610

Christopher Liuzzo: And there were another handful of organizations I know of around the country. What Hope Dittmeier did

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01:23:38.740 --> 01:23:44.700

Christopher Liuzzo: was say, what am I going to do in my organization, is it going to do.

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01:23:44.850 --> 01:23:54.370

Christopher Liuzzo: Here's what we're gonna do. We just drew a line in the sand. We're gonna stop doing that and only do this

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01:23:55.550 --> 01:23:58.630

Christopher Liuzzo: and we don't have to change the State of Kentucky

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01:23:58.850 --> 01:24:02.729

Christopher Liuzzo: or the association the administration on community living to do that.

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01:24:03.140 --> 01:24:07.469

Christopher Liuzzo: I can change Hope Dittmeier. Hope Dittmeier can change Hope Dittmeier.

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01:24:07.570 --> 01:24:11.850

Christopher Liuzzo: I can change my organization and stop doing that.

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01:24:12.810 --> 01:24:22.559

Christopher Liuzzo: So I hope that we have, I hope, 4 more leaders like Hope Dittmeier. who can develop the courage

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01:24:23.120 --> 01:24:26.790

Christopher Liuzzo: to do what needs to be done

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01:24:27.030 --> 01:24:29.990

Christopher Liuzzo: to develop

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01:24:30.820 --> 01:24:38.260

Christopher Liuzzo: the humility to recognize that what we've been doing ain't so good

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01:24:39.370 --> 01:24:41.760

Christopher Liuzzo: and the honesty to say that

537

01:24:42.640 --> 01:24:52.290

Christopher Liuzzo: and the courage to deal with the uncertainty, because, as you move along that line of supporting people to move from client hood to citizenry,

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01:24:52.640 --> 01:25:01.010

Christopher Liuzzo: the uncertainty goes up. You stick, stick with your group home, you know the rules, right? You know where the money comes from.

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01:25:01.140 --> 01:25:06.350

Christopher Liuzzo: You know how you're going to get in trouble. You know how you're going to stay out of trouble. But as you start to do

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01:25:06.390 --> 01:25:15.360

Christopher Liuzzo: more citizen-oriented things for the people you support, the uncertainty goes way up. Not quite sure how I'm going to pay for this.

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01:25:15.400 --> 01:25:23.239

Christopher Liuzzo: Not quite sure how the regulators are gonna respond to this. So what you need is a sense of

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01:25:23.440 --> 01:25:24.460

Christopher Liuzzo: courage

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01:25:25.080 --> 01:25:27.970

Christopher Liuzzo: to move in that direction.

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01:25:29.100 --> 01:25:31.920

Christopher Liuzzo: and I hope, I'll finish with this.

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01:25:32.380 --> 01:25:40.650

Christopher Liuzzo: I really enjoyed Jill Jacobs' talk, especially when she got down, told us her and her family story.

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01:25:40.830 --> 01:25:50.069

Christopher Liuzzo: but I got a kick out of, I don't think she's still with us though, but this focus on the rule, the Settings Rule.

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01:25:52.000 --> 01:25:54.229

I hope that we don't get fooled



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01:25:54.640 --> 01:25:56.260

Christopher Liuzzo: by compliance

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01:25:56.650 --> 01:26:08.920

Christopher Liuzzo: with a rule. The rule is really aspirational. It's giving people real lives. You can be at 1,000% compliance with that rule

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01:26:09.350 --> 01:26:10.230

Christopher Liuzzo: and

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01:26:10.610 --> 01:26:18.909

Christopher Liuzzo: not change one iota about what your organization does. Oh, I gave everybody a key,

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01:26:19.770 --> 01:26:21.380

Christopher Liuzzo: which is part of the rule.

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01:26:21.800 --> 01:26:25.900

Christopher Liuzzo: You have a key to your home. That doesn't mean it's your home,

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01:26:26.140 --> 01:26:27.339

Christopher Liuzzo: crying out loud.

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01:26:27.860 --> 01:26:33.210

Christopher Liuzzo: So I hope that most we begin to move in a direction

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01:26:33.280 --> 01:26:34.740

Christopher Liuzzo: away from

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01:26:34.810 --> 01:26:38.539

Christopher Liuzzo: I comply with the rule to I am giving people

558

01:26:38.830 --> 01:26:43.020

Christopher Liuzzo: the good life or the bestest life I know how to give people.

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01:26:44.180 --> 01:26:47.130

Christopher Liuzzo: So that's that on hope.

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01:26:47.380 --> 01:27:03.179

Chaz Kellem (he/him/his): Alright, thanks so much, Christopher. Appreciate it. And I would love to turn the same question over to Hope. Good morning, Hope. Thank you for joining us as we think about the future. We're curious as to what provides you hope for the future.

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01:27:04.010 --> 01:27:32.630

Hope Leet Dittmeier: Well, just like the other 2 speakers here. I think there's a lot to be concerned about. There's a whole lot to be concerned about, but as a service provider at Mattingly Edge, we provide only individualized, customized supports based on getting to know the person and what they want their lives to look like. And so my hope comes from, if I can share a quick story

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01:27:32.630 --> 01:27:35.450

Hope Leet Dittmeier: of work, the work being done.

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01:27:35.810 --> 01:27:55.160

Hope Leet Dittmeier: So one of the men that we support. Name is Robin, and, like many of the people we support, he came to our organization for support after living in congregated, segregated services. He lived in a building with about 16 other or 15 other people. Had done that his entire adult life

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01:27:55.160 --> 01:28:19.650

Hope Leet Dittmeier: and he came to was because during Covid, he couldn't live with the rules of the in that institution. And he and the family asked if we could help create something different for him. And so over the course of a couple of years, his family purchased a condominium in a wonderful, wonderful neighborhood, and we built a team of direct support folks around him. So

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01:28:19.650 --> 01:28:45.519

Hope Leet Dittmeier: our job was to understand what Robin was looking for in support workers, and to recruit and screen them. And then Robin and his family would interview and make decisions about hiring. And so he had a team of about 7, mostly men, 2 women and I think 5 men, who helped cover around the clock care because he'd come from an institutional setting.

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01:28:45.520 --> 01:29:01.600

Hope Leet Dittmeier: Folks said he needed 24/7 care. So in Kentucky, when in your plan of care each year the team has to decide how many hours a day you're allowed to be alone or unsupported, and Robin's team had always said, zero,

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01:29:01.790 --> 01:29:26.500

Hope Leet Dittmeier: he needed 70, 24 hours a day. So we started that with him he we helped him find this condominium. We helped him recruit a housemate who lives with, who lives with him, so that someone's there in the overnight sleeping hours. And so that roommate is not an employee of ours. It's an agreement that he has with Robin to live there for free in exchange for being there overnight

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01:29:26.500 --> 01:29:43.439

Hope Leet Dittmeier: for security purposes, and other than that, for 16 hours a day, Robin had a team. Well, up comes the terrible workforce problem, and we were just as we lost people on a team. We could not find replacements, and we were really, really struggling.

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01:29:43.440 --> 01:29:51.380

Hope Leet Dittmeier: And so we met with his family, as we did many, many families, and said, you know, here's the data. Here's the information.

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01:29:51.380 --> 01:30:03.770

Hope Leet Dittmeier: This is what's happening in the workforce crisis. Here's what we've done to try to address that we raised pay. We did the improved benefits, quickened our hiring process, did a number of things, but we were still having trouble.

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01:30:03.770 --> 01:30:28.189

Hope Leet Dittmeier: So we met with the family and said, What are we gonna do about this, so that Robin can stay safe in his home. And there were a couple of suggestions and ideas that we pursued. One of them was to test whether Robin could really be alone part of the day or not. Right? And we use

technology to do that. So Robin would have about an hour and 15 minutes of, in between 2 support workers,

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01:30:28.190 --> 01:30:32.869

that he'd be on his own. But he had a device that he could let

573

01:30:33.190 --> 01:30:59.039

Hope Leet Dittmeier: contact somebody. And actually, in the very first week, I believe he was even on camera with somebody, so that somebody wasn't physically present, but was watching them. That worked really well, and over time the team decided that Robin could, in fact, be alone up to 2 hours at a time by himself. Now we're an organization that has always believed in independence, right? And autonomy, and all those things. And yet

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01:30:59.040 --> 01:31:13.520

Hope Leet Dittmeier: this crisis is what took us to finally ask the question, is it really true that Robin has to have somebody attached on at all times? Right? But that's hopeful that that the idea that people might be able to prove themselves

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01:31:13.600 --> 01:31:30.440

Hope Leet Dittmeier: and not be over supported. I believe in Kentucky we have a lot of people who get no support, and a lot of people who are over-supported 24 hours a day. So that was a really good thing. The second question we ask is, who else could spend time with Robin.

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01:31:30.450 --> 01:31:47.139

Hope Leet Dittmeier: Right? And we did a meeting. We invited people in. We did a relationship map. And there was this uncle on the relationship map that I had heard Robin talk about forever, and he just retired. He retired last year, and we asked the question,

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01:31:47.760 --> 01:32:04.259

Hope Leet Dittmeier: Would he be interested in coming to Robin's for dinner on Monday nights. That's one of the times that we don't, you know, don't have support. We reached out to his uncle, his uncle said, you know, now I'm retired. I have the time to do it. I really haven't gotten to spend much time with Robin, and

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01:32:04.260 --> 01:32:28.800

Hope Leet Dittmeier: now he does spend, I believe, it's from 4 to 8 with Robin on Mondays. That's a great thing, right? Family pulling and attracting natural supports in as part of the solution. And then finally we said, Is there a way when Robin goes out, and can, he lives in a wonderful walkable neighborhood? Lots of things he can get to, restaurants, bars, grocery stores.

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01:32:28.800 --> 01:32:43.409

Hope Leet Dittmeier: pharmacy, so forth and so on. Could Robin access community by himself. He's a wheelchair user. But he drives his own wheelchair, and could he go to Kroger, his grocery store, right there where he goes 3, 4 times a week?

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01:32:43.410 --> 01:32:57.030

Hope Leet Dittmeier: Everybody, everybody there knows Robin, right? What would happen if Robin went to Kroger by himself, and so we worked it out where a support worker was gonna stay at a distance instead of being right with Robin. Right? Gonna be,

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01:32:57.170 --> 01:33:03.069

Hope Leet Dittmeier: you know, 20 yards or more away with hands-off support. What happens?

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01:33:03.300 --> 01:33:07.569

Hope Leet Dittmeier: And you know what happened? People pulled stuff off the shelf for him.

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01:33:08.160 --> 01:33:11.920

Hope Leet Dittmeier: People put his groceries on the on the

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01:33:12.670 --> 01:33:13.560

Hope Leet Dittmeier: that

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01:33:13.810 --> 01:33:18.809

Hope Leet Dittmeier: whatever where checkout line right? People did it, citizens did it.

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01:33:20.140 --> 01:33:44.079

Hope Leet Dittmeier: And so my hope is that we'll get really creative, and that creativity will lead us to goals we already had for the crisis central to our mission, and that is that people do as much for themselves as they can, because that increases autonomy and personal power, and all kinds of things less dependency, and that people rely on citizens

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01:33:44.420 --> 01:33:47.210

Hope Leet Dittmeier: for simple, everyday.

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01:33:47.250 --> 01:34:03.179

Hope Leet Dittmeier: common support, not personal care, but simple, everyday. People open the doors for us. People, do you know ladies, short in stature, asked me to get something off. I'm 5', 8", you know. Get something off of the top shelf that that we

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01:34:03.210 --> 01:34:09.099

Hope Leet Dittmeier: don't suffocate people with support services. But we find ways. And that's my hope

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01:34:09.150 --> 01:34:21.009

Hope Leet Dittmeier: that instead of just applying support to people that we use support to find ways that people will be less dependent on support because they have more people,

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01:34:21.030 --> 01:34:25.070

Hope Leet Dittmeier: they have more power, they have more ability.

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01:34:25.150 --> 01:34:32.869

Hope Leet Dittmeier: So that's the thing I'm hopeful about. And that is, by the way, directed very specifically on, you know, Chris's point.

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01:34:33.330 --> 01:34:47.299

Hope Leet Dittmeier: You know, one person that our organization is supporting. It's not fixing the problem in the whole system. But I think is an example of how we can capitalize on this workforce crisis. We have to.

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01:34:48.640 --> 01:35:02.730

Chaz Kellem (he/him/his): Thank you so much, Hope, appreciate that response. Wanted to remind folks, if you have questions for our esteemed panel to put those into the Q & A. Using the button on the bottom of your Zoom toolbar.



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01:35:02.730 --> 01:35:26.689

Chaz Kellem (he/him/his): As we jump into our second question here. Individuals with disabilities, and their families want choices and self-determination, and where they live as well as how they utilize their public funding for home and community-based services. What's on the horizon that provides a wider range of choices? Again, what's on the horizon

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01:35:26.690 --> 01:35:37.990

Christopher Liuzzo: that provides a wider range of choices? And I'm gonna start that question with Christopher. Christopher, any thoughts on that question?

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01:35:38.160 --> 01:35:40.039

Christopher Liuzzo: Yeah, I do have some thoughts on it.

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01:35:41.980 --> 01:35:49.950

Christopher Liuzzo: Certainly, one thing on the horizon is self-direction and I know you do get some of that in Pennsylvania. We do it here in New York.

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01:35:50.140 --> 01:35:54.339

Christopher Liuzzo: and I'm a huge fan of self-direction.

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01:35:56.140 --> 01:36:01.529

Christopher Liuzzo: and it's fairly large here in New York. We have about 160,000 people enrolled in our waiver

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01:36:01.690 --> 01:36:07.690

Christopher Liuzzo: and I think we're up to 27,000 of them are, have self-directed budgets.

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01:36:09.040 --> 01:36:12.180

Christopher Liuzzo: Just to caution again what we're finding

603

01:36:12.340 --> 01:36:24.219

Christopher Liuzzo: all over New York, and I'm guessing in other States, is that an awful lot of people are isolated. you know. It's like we give them your budget. You're on your own.

604

01:36:24.840 --> 01:36:26.670

Christopher Liuzzo: Send us the bill, and

605

01:36:26.720 --> 01:36:32.289

Christopher Liuzzo: I don't know what you call them in Pennsylvania, but here the bill payers are called fiscal intermediaries.

606

01:36:32.550 --> 01:36:35.759

Christopher Liuzzo: and you know we'll pay your bills. Have a good life.

607

01:36:36.330 --> 01:36:40.220

Christopher Liuzzo: So what we're hearing more and more is, you know,

608

01:36:40.690 --> 01:36:42.150

Christopher Liuzzo: people feeling

609

01:36:42.180 --> 01:36:53.320

Christopher Liuzzo: isolated. Yeah, I got my money. Yeah, I have this plan. But I'm all alone, and that's a big caution and worry.

610

01:36:53.710 --> 01:36:54.400

611

01:36:55.040 --> 01:36:59.620

Christopher Liuzzo: So while it's on the horizon, it's already here, right? The horizon is here.

612

01:36:59.860 --> 01:37:03.699

Christopher Liuzzo: It's got something. Question marks around it.

613

01:37:05.450 --> 01:37:08.140

Christopher Liuzzo: The horizon, in my view, is

614

01:37:08.450 --> 01:37:19.050

Christopher Liuzzo: the world is our horizon if we can stop thinking about buildings and programs and services and start thinking about, I think Hope just referenced this,

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01:37:19.840 --> 01:37:24.739

Christopher Liuzzo: use the world as our service delivery

616

01:37:24.920 --> 01:37:35.580

Christopher Liuzzo: model system. I was very disappointed earlier on in her opening remarks, Cindy Leonard said that we're closing. You guys are closing Polk.

617

01:37:36.530 --> 01:37:41.669

and there's some organization that's gonna develop or build 4 group homes.

618

01:37:42.110 --> 01:37:43.000

Christopher Liuzzo: Really?

619

01:37:44.340 --> 01:37:47.769

Christopher Liuzzo: Doing this now?

620

01:37:48.680 --> 01:37:59.480

Christopher Liuzzo: The world is out there, and you're going to develop 4 group homes which will, and even Jill Jacobs alluded to it, group homes are not in on themselves.

621

01:38:01.010 --> 01:38:03.709

Christopher Liuzzo: It's almost inevitable that they will do that.

622

01:38:04.940 --> 01:38:16.890

Christopher Liuzzo: My thumbnail career is, I spent 25 years developing group homes and 25 years picking them apart. The second half was a whole lot better and

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01:38:17.680 --> 01:38:19.660

a whole lot more difficult, but

624

01:38:19.980 --> 01:38:22.560

Christopher Liuzzo: learn to use the world

625

01:38:24.450 --> 01:38:28.769

Christopher Liuzzo: rather than programs and services. Get out of that human service language.

626

01:38:31.250 --> 01:38:36.699

Christopher Liuzzo: I think another thing that's on the horizon is, you know, we often ask, where's the money?

627

01:38:37.840 --> 01:38:43.849

Christopher Liuzzo: I was struck by in the first video, the old institution director, talking about the cage

628

01:38:44.350 --> 01:38:48.599

Christopher Liuzzo: and the institution director said, what, I don't have enough money.

629

01:38:48.820 --> 01:38:52.210

Christopher Liuzzo: I don't have enough staff, and the clinical people helping to do it

630

01:38:53.060 --> 01:38:54.020

Christopher Liuzzo: alright.

631

01:38:54.330 --> 01:39:01.199

Christopher Liuzzo: Go to some executive or CEO's office or office today and say, why, why are you doing that? And what will you hear?

632

01:39:03.160 --> 01:39:07.370

Christopher Liuzzo: I don't have enough money. I don't have enough staff, and my clinicians are on board.

633

01:39:09.570 --> 01:39:13.169

Christopher Liuzzo: When I was an administrator, I would think, I'm not poor.

634

01:39:13.430 --> 01:39:28.289

Christopher Liuzzo: I got all of this money locked up in my bricks and mortar and group services. I already have the money. We can bankroll innovation if we can learn to free the money we've already got

635

01:39:29.090 --> 01:39:38.399

Christopher Liuzzo: tied up in the bricks and mortar. How do we leverage the bricks and mortar money, and the program monies tied up in it, into innovation? The money

636

01:39:38.640 --> 01:39:47.869

Christopher Liuzzo: is here, you know. I learned a couple of years ago. Ireland, the country,

637

01:39:48.090 --> 01:39:56.759

Christopher Liuzzo: it's administration on with disability, I don't know what they call it, but they sent letters to their provider sector

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01:39:56.780 --> 01:40:00.769

Christopher Liuzzo: that said in organization by organization. Dear

639

01:40:01.200 --> 01:40:02.530

Christopher Liuzzo: Arc.

640

01:40:03.920 --> 01:40:14.060

Christopher Liuzzo: We've looked at your books. and we see that you own X millions of euros worth of property. free and clear

641

01:40:14.740 --> 01:40:21.539

Christopher Liuzzo: that was paid for by the Irish Government, probably by the people that live in those group homes, but with their benefits.

642

01:40:22.390 --> 01:40:27.589

Christopher Liuzzo: If you want to do anything more in this sector with our, with public money,

643

01:40:27.960 --> 01:40:31.510

Christopher Liuzzo: show us how you're going to free the money up from the bricks and mortar.

644

01:40:31.910 --> 01:40:37.229

Christopher Liuzzo: The Irish Government had some chutzpah to do that, but they understood where the money was.

645

01:40:38.720 --> 01:40:45.960

Christopher Liuzzo: Also on the horizon, I think, is, one of the videos, the narrator said, we are evolving

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01:40:46.940 --> 01:40:50.820

Christopher Liuzzo: slowly in our thinking about who belongs.

647

01:40:51.360 --> 01:40:55.860

Christopher Liuzzo: And as we continue to evolve this, get to that point that we all belong.

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01:40:56.100 --> 01:40:59.180

Christopher Liuzzo: That's on the horizon. And what's key to that

649

01:41:00.410 --> 01:41:04.930

Christopher Liuzzo: is, yeah, we toss around this phrase, person-centered planning

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01:41:05.620 --> 01:41:16.300

Christopher Liuzzo: and I don't know how you do it in Pennsylvania. But here in New York, the official form of person-centered planning, the one adopted by our State agency

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01:41:16.350 --> 01:41:17.859

Christopher Liuzzo: is a digital thing,

652

01:41:19.110 --> 01:41:25.620

Christopher Liuzzo: key in, they ask you the questions, you pop in the answers, and your life plan

653

01:41:25.810 --> 01:41:26.730

Christopher Liuzzo: pops out.

654

01:41:28.360 --> 01:41:36.479

Christopher Liuzzo: Don't be fooled by that, right? So I think I'm hoping, this is back to the hope question as well as the horizon question, is that

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01:41:36.700 --> 01:41:41.639

Christopher Liuzzo: we learn or accept that person-centered planning is not a form.

656

01:41:42.540 --> 01:41:47.850

Christopher Liuzzo: Its deep, deep listening. Again, to go to our friend John O'Brien,

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01:41:47.870 --> 01:41:54.260

Christopher Liuzzo: it's about developing relationship. And if you're just using a computer to tell you, here's your plan,

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01:41:54.850 --> 01:41:56.689

That's not gonna cut it.

659

01:41:56.760 --> 01:41:59.569

Christopher Liuzzo: So I'm hoping that on the horizon

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01:41:59.980 --> 01:42:10.589

Christopher Liuzzo: we learn that the plan that comes out of the computer is nothing more than something that tells you here's how much money we'll give you, but that the real planning is in

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01:42:12.070 --> 01:42:24.030

Christopher Liuzzo: deep listening. And again, John and our other good friend Beth Mount, people who created person-centered planning back in the early 80s. Even then,

662

01:42:24.270 --> 01:42:29.170

Christopher Liuzzo: they said, and they say to this day, person-centered planning

663

01:42:29.690 --> 01:42:33.150

Christopher Liuzzo: cannot be divorced from organizational change.

664

01:42:33.490 --> 01:42:36.139

Christopher Liuzzo: You can't do

665

01:42:36.150 --> 01:42:43.279

Christopher Liuzzo: authentic person-centered planning and learn, this is what so and so's good life looks like, and then not

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01:42:43.710 --> 01:42:48.789

Christopher Liuzzo: tinker around with your organization. So I'm hoping that on the horizon

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01:42:49.020 --> 01:42:57.050

Christopher Liuzzo: more and more leaders will learn, I have to change my organization in order to facilitate

668

01:42:57.540 --> 01:42:58.910

Christopher Liuzzo: who belongs.

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01:43:00.980 --> 01:43:11.400

Chaz Kellem (he/him/his): Alright. Thank you so much for that thoughtful response, Christopher. Deputy Secretary, anything to add on the horizon that provides a wider range of choices. Any thoughts?

670

01:43:11.850 --> 01:43:27.749

Kristin Ahrens: Yeah, I'd just add, in Pennsylvania we actually have pretty broad use of self-directed services. We've got a lot of different service types that people can self-direct, 2 different models they can use for the kind of fiscal intermediary.

671

01:43:27.810 --> 01:43:42.300

Kristin Ahrens: We have support brokers available to support people who need a little more assistance with self-direction. We have some work to do there in terms of expanding that, making sure there's true access to that service statewide. But the other thing,

672

01:43:42.360 --> 01:43:51.210

Kristin Ahrens: 2 things on the horizon that I think will really help with self-direction and affording more choices for people.

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01:43:51.270 --> 01:44:04.599

Kristin Ahrens: One, we've got a, we intend to move to selective contracting for supports coordination. I won't get into all the detail. But basically, what we're gonna do is change our agreement with the Federal Government that will

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01:44:04.670 --> 01:44:07.470

Kristin Ahrens: essentially allow us some more

675

01:44:07.550 --> 01:44:09.750

Kristin Ahrens: room in terms of

676

01:44:10.780 --> 01:44:20.210

Kristin Ahrens: working with our support coordination organizations to establish performance standards, not just compliance with rules. I know there's been a lot of discussion about rules and compliance.

677

01:44:20.280 --> 01:44:31.449

Kristin Ahrens: This would actually establish some quality standards that we would expect to see in supports coordination. We would also like to change the way we pay supports coordination so that we can really do some alignment

678

01:44:31.460 --> 01:44:34.549

Kristin Ahrens: with outcomes that we can be looking

679

01:44:34.630 --> 01:44:57.189

Kristin Ahrens: at what is occurring in individuals' lives in terms of outcomes. We can look at broader system outcomes that we're looking to achieve and can actually pay for that in terms of supports coordination. We have set, supports coordination is totally pivotal, right? These are the people that come out. They do the planning. They know the system. They're, you know, guiding and advising and

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01:44:57.190 --> 01:45:23.589

Kristin Ahrens: facilitating these planning meetings. And should be doing it in a true person-centered way. The skill of that supports coordinator is really critical. and we have set support coordination up in such a way that they are burdened phenomenally with a lot of administrative stuff that doesn't necessarily have a lot of value for the individual and the family. So we we've got a lot of cleanup to do there, and we are embarking on that now.

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01:45:23.810 --> 01:45:35.999

Kristin Ahrens: The other thing I would say is, and this actually came out of the closures of Polk and White Haven. There was in our fiscal code our legislature passed some language that said

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01:45:36.280 --> 01:45:48.410

Kristin Ahrens: the savings from those closures ,which is pretty significant, just this year it's a little over 10 million dollars, must go, it goes into a restricted fund that must go to housing,

683

01:45:48.530 --> 01:45:52.460

waiting lists or direct support professional quality.

684

01:45:52.500 --> 01:46:00.570

Kristin Ahrens: Our advisory committee currently is exploring the idea of doing some kind of housing subsidy.

685

01:46:00.930 --> 01:46:18.889

Kristin Ahrens: for individuals, not for residential settings. We already subsidize residential settings, group homes. The State already does that. This would be for people who are living in their own homes. And I think that that has the potential to be a game changer if we can figure out how to do that and pull that off.

686

01:46:19.070 --> 01:46:33.850

Kristin Ahrens: And we've seen other States. We've got a couple of models here in PA that are pretty encouraging. So that that's an area where I think if we can do that, it's going to be really significant change in terms of people's choices.

687

01:46:34.440 --> 01:46:36.390

Chaz Kellem (he/him/his): Thank you so much.

688

01:46:36.420 --> 01:46:52.509

Hope Leet Dittmeier: And I'm gonna ask Hope to respond. Hope we are gonna get to audience questions here next. Hope, anything to add on the horizon element in addition to what Kristin and Christopher have already said?

689

01:46:52.520 --> 01:46:59.180

Hope Leet Dittmeier: You know, I just think we have to be real with ourselves. We have to be honest, like person-centered planning in a congregate setting

690

01:46:59.590 --> 01:47:14.770

Hope Leet Dittmeier: is an oxymoron. It doesn't work. So the model itself is broken. If living in someone else's home, being a guest in someone else's home, or a tenant

691

01:47:14.960 --> 01:47:32.880

Hope Leet Dittmeier: limits, dramatically limits, not only your choices, but your autonomy. And so at Mattingly Edge, we believe, very, very strongly in separation of housing and supports. Your landlord should not be your service provider.

692

01:47:32.950 --> 01:47:52.550

Hope Leet Dittmeier: It doesn't make sense. The final rule tried to address some of that, like your landlord, has to give your key, right? Your landlord has to let you close your bedroom door. Your landlord has to, but you still have the landlord and the landlord is your service provider. So I think, on the horizon, the idea of housing,

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01:47:52.720 --> 01:48:08.589

Hope Leet Dittmeier: affordable accessible housing, is the linchpin to all of this, because if you live in your own home. the provider and the government do not have control, how you function and operate at home.

694

01:48:08.770 --> 01:48:16.720

Hope Leet Dittmeier: and so we believe very strongly in separation of housing. The other thing, I would say, is that

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01:48:17.220 --> 01:48:22.769

Hope Leet Dittmeier: there is a lot of money in the housing world

696

01:48:22.930 --> 01:48:24.580

Hope Leet Dittmeier: that we have not

697

01:48:24.670 --> 01:48:46.610

Hope Leet Dittmeier: worked to access. We started a project Mattingly Edge is getting ready to spin off. I'm really proud of it as its own nonprofit, that is called inclusive housing solutions, and it works to help people help increase the amount of affordable accessible housing in Louisville, but until that is solved. So right now we are spending money that's in our pots



698

01:48:47.150 --> 01:48:52.789

Hope Leet Dittmeier: for people to have housing when there's money, other places when people need help

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01:48:52.850 --> 01:49:03.050

Hope Leet Dittmeier: with housing. So in Kentucky, one of the things we did, and Kentucky doesn't do very many things right at all, but this we got right. In our Olmstead plan,

700

01:49:03.390 --> 01:49:06.839

Hope Leet Dittmeier: people with intellectual and developmental disabilities

701

01:49:07.510 --> 01:49:33.850

Hope Leet Dittmeier: get top priority to Section 8 vouchers. So yeah, it's part of the Olmstead plan. And so, if you have an intellectual or developmental disability, you go apply for section 8, voucher. You get a letter from them saying, Oh, your number 5,620 on our waiting list. You take that letter to the Independent Living Center, and you get a voucher.

702

01:49:34.370 --> 01:50:01.130

Hope Leet Dittmeier: You can get a voucher anywhere from 3 to within 3 to 6 months' time, which the average waiting list here is over 5 years. So we can use that process to help people find housing, but because we had so much trouble finding housing, we had to kind of invent this initiative to work on that. So I think you know the model's broken. We need, people need to have their own homes, because that's the only way they're gonna really have choice about how they live.

703

01:50:01.600 --> 01:50:03.610

Chaz Kellem (he/him/his): Thank you so much, Hope. I do want to

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01:50:03.680 --> 01:50:27.809

Chaz Kellem (he/him/his): get to some of the attendee questions. So I'm going to toss out a question, and any of our panelists not welcome for your response. We do have a few, and I want to try to get to as many as we can in our very little time remaining. So the first question I want to respond to is ODP looking at ways to include more of a local voice as the system develops?

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01:50:28.040 --> 01:50:30.810

Chaz Kellem (he/him/his): Any thoughts or response to that from our panelists?

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01:50:32.390 --> 01:50:43.219

Kristin Ahrens: Yeah, I'm happy to answer that. Certainly. So there, there are a couple of things. One, we have, in the last number of years, I don't know,

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01:50:43.230 --> 01:50:46.069

Kristin Ahrens: for people who aren't familiar with,

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01:50:46.200 --> 01:50:52.239

Kristin Ahrens: or deeply embedded in the knowledge of our system, one of the things that's

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01:50:52.310 --> 01:50:55.930

important about understanding how ODP works is,

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01:50:56.130 --> 01:51:06.180

Kristin Ahrens: we actually administer all of our services through -- almost all of our services, our institutional services are not administered this way -- but

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01:51:06.330 --> 01:51:12.349

Kristin Ahrens: the vast majority of our services are administered in partnership with local government, with

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01:51:12.520 --> 01:51:15.090

our counties. We have

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01:51:15.240 --> 01:51:17.320

Kristin Ahrens: 48 county joinders.

714

01:51:17.580 --> 01:51:39.989

Kristin Ahrens: So that that covers the entire State, where we have agreements with them, and they actually administer services at the local level on our behalf. So we delegate about half of our responsibilities that we have to the Federal Government are actually delegated at the county level. And we have been doing quite a bit of work to strengthen those relationships.

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01:51:40.340 --> 01:51:55.990

Kristin Ahrens: Because I think there was a time, there was a lot of push and pull. But Pennsylvania got in some trouble with the Federal Government for what they said, you have 67 different programs. And so we had to kind of make sure that we had more standardized operations.

716

01:51:56.210 --> 01:52:12.340

Kristin Ahrens: And I think we might have pulled that back a little bit too much. So we've been doing a lot of work to really strengthen the partnerships at the local levels. All those counties should have, based on a 1966 law, advisory groups that are providing input to the county plan.

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01:52:12.410 --> 01:52:33.360

Kristin Ahrens: Again, some of those are real strong. We've got, you know, very vocal advocates that participate in those, others where you know the voices of advocates aren't super active on those county boards. So certainly, for anybody who's interested in getting involved, you can go to your county ID office and

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01:52:33.360 --> 01:52:45.710

Kristin Ahrens: see if the County board is meeting, when it is, and if they have this seat available for you. But totally agree. I think particularly when we're talking about people who come to us

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01:52:45.760 --> 01:52:57.030

Kristin Ahrens: who may need services over the course of a lifetime, depending, you know, when they come to us in that lifespan, that local work is so important. We also have.

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01:52:57.570 --> 01:52:59.369

Kristin Ahrens: our Family Network.

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01:52:59.580 --> 01:53:18.900

Kristin Ahrens: and regional collaboratives that have been doing a lot of work around supporting families and using the life course framework which I'm happy to put in the chat if people aren't familiar with it.

That's another effort that we have really tried to put the locus of that at the local level, which is, is critical.

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01:53:19.830 --> 01:53:40.810

Chaz Kellem (he/him/his): Thank you so much for that. We do have a lot of questions to get to and apologize. Now we're running out of time here, gonna try to squeeze in one or 2 more here, really quick response, if anyone has one, what are the efforts that we're using to create, boost, and fund the next generation of change makers?

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01:53:40.920 --> 01:53:43.360

Chaz Kellem (he/him/his): Any initial thoughts on that question?

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01:53:45.870 --> 01:53:47.899

Christopher Liuzzo: Well, a little bit.

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01:53:49.450 --> 01:53:55.440

Christopher Liuzzo: Efforts that I know of around the country, and I know hope you know of these too,

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01:53:55.680 --> 01:54:00.299

Christopher Liuzzo: very progressive leaders, thought leaders,

727

01:54:00.540 --> 01:54:06.789

Christopher Liuzzo: leading learning institutions, which we call them of late,

728

01:54:07.060 --> 01:54:11.600

Christopher Liuzzo: really put people into a

729

01:54:13.010 --> 01:54:20.280

Christopher Liuzzo: "turn the beam of inquiry inward" kind of setting, like, what are you really thinking about the people you support?

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01:54:20.350 --> 01:54:22.240

Christopher Liuzzo: What are your assumptions?

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01:54:22.550 --> 01:54:33.600

Christopher Liuzzo: What is authentic, person-centered planning? And are you really doing it? And what capacities do you need to develop

732

01:54:33.960 --> 01:54:35.280

Christopher Liuzzo: to

733

01:54:36.770 --> 01:54:46.399

Christopher Liuzzo: increase your ability to listen deeply to the people you support? So these are not focused on budgeting or governance or risk management.

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01:54:46.540 --> 01:54:50.659

Christopher Liuzzo: These learning institutes are focused heavily on

735

01:54:51.880 --> 01:54:53.430

Christopher Liuzzo: personal development.

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01:54:53.440 --> 01:55:00.089

Christopher Liuzzo: And maybe if somebody wants information about them in your state or in other states, maybe

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01:55:00.220 --> 01:55:04.729

Christopher Liuzzo: you could send a note to Cindy, and Cindy could send it on to me, and I can get you the information.

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01:55:05.550 --> 01:55:32.139

Chaz Kellem (he/him/his): Thanks so much, Christopher. So I do wanna take a moment to thank all of our esteemed panelists for their time, their testimony. Really do appreciate it. I do recognize that we had some additional questions we weren't able to get to. We will work with Cindy and team to try to provide responses. We may explore possibly future events, bringing up some of those questions as well. So thank you very much to Deputy

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01:55:32.140 --> 01:55:56.999

Chaz Kellem (he/him/his): Secretary, Hope and Christopher for your feedback and your thoughtful responses. Before I turn her back over to Cindy, I do wanna make sure I acknowledge the all the amazing folks behind the scenes that have made today's event possible. We've got a great tech team on board thank you to our both of our sign language interpreters for their support for today. And as I turn it back over to Cindy, I do wanna thank Cindy.

740

01:56:15.480 --> 01:56:27.150

Cindy Leonard: And thank you again to Commissioner Jacobs, Chaz, Deputy Secretary Ahrens, Hope, Chris, Sierra, our partners at Heinz History Center, Temple Institute on Disabilities, and Achieva.

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01:56:27.250 --> 01:56:32.640

Cindy Leonard: And once again. We're grateful to AW Mellon Foundation for their role in making this event possible.

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01:56:32.910 --> 01:56:42.520

Cindy Leonard: And a second thank you to our wonderful ASL interpreters, Neve and Erica, and our apologies to everyone for the initial glitch that we had

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01:56:42.620 --> 01:56:46.190

Cindy Leonard: with the ASL interpreters. Video not showing up on the screen.

744

01:56:46.750 --> 01:56:53.390

Cindy Leonard: I'd also like to mention on a related note, there's a newly published book. I just finished reading this.

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01:56:53.460 --> 01:57:13.110

Cindy Leonard: It's related to the history of institutions in America, and it's called Public Hostage, Public Ransom: Ending Institutional America. The book is by William Bronston, MD. Who was a physician, practicing at Willowbrook State Hospital, or State School, rather, Staten Island, New York, in the 70s.

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01:57:13.380 --> 01:57:26.109



Cindy Leonard: In addition to the history and the conditions he battled during his work there he relays his journey in catalyzing a Federal class action lawsuit against the State of New York to close that institution.

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01:57:26.320 --> 01:57:32.289

Cindy Leonard: It's a really powerful and compelling book, like you can't put it down kind of reading.

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01:57:32.660 --> 01:57:40.300

Cindy Leonard: I am going to drop a link to the book website in the chat for anyone who's interested. I'll put it in the follow-up email as well.

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01:57:40.360 --> 01:57:48.750

Cindy Leonard: It's [WWW.publichostage.publicransom.org](http://WWW.publichostage.publicransom.org). There's that in the chat.

750

01:57:49.560 --> 01:57:59.539

Cindy Leonard: And finally, we urge you to get to know the Consortium. Our website, which is WPDHAC.org which is our acronym letters.

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01:57:59.550 --> 01:58:01.899

Cindy Leonard: I'll drop that in the chat as well.

752

01:58:03.540 --> 01:58:18.830

Cindy Leonard: is a central resource for the disability history of Western Pennsylvania, and when you visit, be sure to go down to the footer and sign up for our e-Newsletter. We're going to be launching a special program in the coming months, so you can join us

753

01:58:18.850 --> 01:58:30.509

Cindy Leonard: and become a part of our work and support our work more directly. Thank you again to everybody involved today and to our wonderful audience for being here. Enjoy the rest of your day, everyone.