

WEBVTT

00:03:29.456 --> 00:03:36.456

All right, I will now call to order this evening's study session of the Champaign County Developmental Disabilities Board

00:03:36.461 --> 00:03:43.461

And the Champaign County Mental Health Board. It is Wednesday, September 24th, 2025 at 545 p.m.

00:03:44.177 --> 00:03:48.177

In the Shields Carter Room of the Scott M. Bennett Administrative Center, Urbana, Illinois.

00:03:48.272 --> 00:03:50.272

May I have a roll call?

00:03:51.536 --> 00:03:53.536

Alejandro Gomez.

00:03:54.474 --> 00:03:56.474

Chris Miner? Here.

00:03:56.705 --> 00:03:58.705

Tony Nichols.

00:03:59.055 --> 00:04:01.055

Elaine Palencia?

00:04:01.592 --> 00:04:04.592

Here, Kyle Patterson. Here.

00:04:05.028 --> 00:04:07.028

Emily Rodriguez.

00:04:08.048 --> 00:04:10.048

Jane Sprandel.

00:04:10.048 --> 00:04:12.544

Here. Jon Paul Youakim.

00:04:12.739 --> 00:04:15.739

Here. Molly McLay? Here.

00:04:15.921 --> 00:04:17.921

Kim Fisher?

00:04:19.334 --> 00:04:21.334

Susan Fowler. Here.

00:04:21.348 --> 00:04:23.348

Jenny Lokshin?

00:04:25.494 --> 00:04:27.494
Anne Robin? Here.

00:04:27.457 --> 00:04:29.457
Neil Sharma?

00:04:30.734 --> 00:04:32.734
Vicki Niswander. Here.

00:04:33.115 --> 00:04:35.115
We have a quorum.

00:04:37.257 --> 00:04:44.257
Thank you very much. We can next move on to approve the agenda. Is there any discussion on the agenda or motions to approve?

00:04:51.568 --> 00:04:55.568
Alright, seeing no discussion. I will move to approve the agenda. May I have a second?

00:04:56.546 --> 00:05:00.546
I'll second. All right, we have a motion and a second. Any final discussion?

00:05:02.967 --> 00:05:09.967
All right, seeing none, all those in favor of approving the agenda as presented, say aye. Aye. Aye. All those opposed, same sign.

00:05:10.733 --> 00:05:12.733
The ayes have it, the agenda is approved.

00:05:14.020 --> 00:05:17.020
We will next move to public participation and agency input.

00:05:17.405 --> 00:05:25.405
As always, um, both boards are welcome individuals in the community to share their input with us.

00:05:25.896 --> 00:05:32.896
Um, while we may not be able to respond directly to public input, we do use it to inform future decisions.

00:05:33.423 --> 00:05:42.423
Um, there will be a lot of opportunities for discussion this evening, and I know some individuals who are in attendance have designated times that they might be speaking.

00:05:42.459 --> 00:05:50.459
But in terms of other public input, there will be time now and at the end of the meeting that you can provide it, and you can do so by approaching the podium,

00:05:50.611 --> 00:05:55.611

By filling out a slip of paper that's up there if you want to write your comment.

00:05:56.373 --> 00:06:01.373

You can also, if you're on Zoom, you can put something into the chat, or you can raise your hand.

00:06:02.673 --> 00:06:12.673

Um, for anybody who, um, may need to know this, um, please be aware of the Illinois Lobbyist Registration Act and take appropriate steps to be in compliance with the Act. If you're speaking with us.

00:06:13.590 --> 00:06:17.590

And we may limit individual time to 5 minutes and or total time to 20 minutes.

00:06:17.360 --> 00:06:19.360

That's a lot of information.

00:06:19.715 --> 00:06:26.715

seeing, uh, I guess, from there, is there anybody either online or in person, who would like to share public input at this time?

00:06:33.323 --> 00:06:35.323

Anyone online?

00:06:38.063 --> 00:06:42.063

Alright, seeing none, we can move on, and again, there will be time for public input.

00:06:42.799 --> 00:06:48.799

Later on. So, um, we will next move to the President's comments. So, we will first hear from

00:06:49.442 --> 00:06:51.442

The president of the Developmental Disabilities Board.

00:06:53.908 --> 00:07:01.908

Turn the microphone on. Okay, I am just so glad that we have the self-advocates back with us tonight. It's been a long time.

00:07:03.119 --> 00:07:08.119

We're looking forward to hearing you and listening to everything that you have to say to us.

00:07:08.119 --> 00:07:10.295

It's an honor to have you here.

00:07:10.967 --> 00:07:16.967

And we wish we could do more to, um, hear your voices throughout the course of the year, so thank you for coming.

00:07:16.967 --> 00:07:20.263

Thank you for spending the time to do this for us.

00:07:20.374 --> 00:07:22.374

We appreciate it.

00:07:23.405 --> 00:07:29.405

Thank you for your comments. Um, and I'm Molly McLay, the chair of the, um, Champaign County Mental Health Board.

00:07:29.273 --> 00:07:32.273

Um, and I just want to echo, um,

00:07:32.571 --> 00:07:37.571

those same comments, we are very, very excited to hear from everyone this evening.

00:07:38.038 --> 00:07:41.038

And are really grateful to have our advocates,

00:07:42.053 --> 00:07:49.053

Um, we have Engage Illinois, and we have also some information provided from the CCRPC Annual Preferences Survey.

00:07:49.053 --> 00:07:54.358

Um, and are very grateful to the entire staff for putting this together, especially Kim Bowdry, who will be

00:07:54.302 --> 00:07:57.302

Helping lead some of the questions this evening.

00:07:57.510 --> 00:07:59.510

Um, I also want to mention that

00:08:00.340 --> 00:08:10.340

This is... we've had a few study sessions for the Mental Health Board, um, and we will be having one on October 29th around immigrant and refugee mental health as well.

00:08:11.000 --> 00:08:15.000

Um, and we really welcome this opportunity to hear from members of our community.

00:08:14.985 --> 00:08:19.985

to better understand everybody's needs and figure out how we can best

00:08:20.924 --> 00:08:22.924

serve as our individual boards.

00:08:22.924 --> 00:08:24.993

So those are my comments for the evening.

00:08:24.993 --> 00:08:30.494

So, I will... we will next move to Executive Director's comments from Len Canfield.

00:08:32.843 --> 00:08:39.843

Hi, I was just thinking about deferring comments, but then I thought, maybe not. I want to encourage folks to sign in at the

00:08:40.441 --> 00:08:43.441

at the little sign-in sheet, and have a snack and a beverage.

00:08:43.859 --> 00:08:45.859

And also, um, welcome.

00:08:45.859 --> 00:08:50.860

Senator Rose, thank you for coming. I really appreciate you being here.

00:09:04.000 --> 00:09:07.000

But as most of you know, my wife actually works at DSC and also at Swahn.

00:09:08.474 --> 00:09:10.474

So, she and I hold...

00:09:17.191 --> 00:09:21.191

Would you... would you want to come to the microphone and... and share with us?

00:09:21.192 --> 00:09:25.024

I really appreciate these comments, and I think it's okay for me to defer

00:09:25.025 --> 00:09:26.987

comments to an honored guest.

00:09:26.986 --> 00:09:28.962

Okay.

00:09:30.300 --> 00:09:34.300

Oh, can you turn the microphone on, uh, so it shows up green? Perfect.

00:09:34.765 --> 00:09:36.765

Yeah, Chapin Rose, for the record, um...

00:09:37.519 --> 00:09:42.519

State Senator, 51st District, 12 counties, including most of, uh, Champaign, geographically, anyway.

00:09:43.149 --> 00:09:45.149

Uh, not Champaign-Urbana or savoy. Um...

00:09:46.176 --> 00:09:54.176

I was just mentioning that Wednesday night's reserved for my wife and her kids. We have a small group tonight, so I apologize, and nothing comes between us and that on Wednesday nights, but...

00:09:54.519 --> 00:09:59.519

Uh, I'll have to leave about 6.18. But I was mentioning to my wife, Camille, works at Swann Rehab.

00:10:00.722 --> 00:10:05.722

And also at DSC, and has spent her entire career as an occupational therapist, essentially dealing with

00:10:06.211 --> 00:10:09.211

Our wonderful friends and neighbors in the DD community. So,

00:10:10.002 --> 00:10:12.002

We have a big place in our heart for DD issues.

00:10:12.001 --> 00:10:14.136

Um, I think any of the, um...

00:10:14.636 --> 00:10:20.636

providers in the 12 counties that I represent know that I fight for them, um, every year when it comes to budget.

00:10:21.473 --> 00:10:24.473

And in fact, the last 3 budget speeches I closed with the DD community.

00:10:24.524 --> 00:10:33.524

Uh, as my closing on the Senate floor. So, anyway, I'll leave it at that. I just apologize greatly, I have to leave, but I do reserve Wednesday nights for my family, so...

00:10:34.451 --> 00:10:36.451

Uh, but happy to meet with you outside anytime, okay?

00:10:38.102 --> 00:10:48.102

Thank you for that, and you can... you can see the rest of this meeting online, because we record and post. Um, and also to the other honored guests sitting way in the back,

00:10:48.102 --> 00:10:52.046

There is room at the round table for folks, so if you want to

00:10:52.046 --> 00:10:56.278

come up and... it's okay if you're shy and don't want to, because we're over here being shy.

00:10:56.806 --> 00:11:04.806

So, we can... that's okay, too. Um, I do... one thing I did decide to say is that we had a developmental disabilities board meeting

00:11:05.203 --> 00:11:07.203

This morning, and I... it was...

00:11:07.364 --> 00:11:12.364

really quite emotional, and I'm really still feeling that, which is why I would like to

00:11:12.868 --> 00:11:16.868

defer any other comments and get on with the show, and we are...

00:11:16.869 --> 00:11:19.072

Um, Kim Bowdry's gonna skip

00:11:20.026 --> 00:11:22.026

Her plan, because we have, um,

00:11:22.570 --> 00:11:29.570

Kelli Martin is going to introduce the speakers and share about how they organized what they're going to say to us today.

00:11:30.962 --> 00:11:33.962

So, is that alright? Of course, that sounds great.

00:11:37.111 --> 00:11:44.111

All right, well, like she said, let's get this show on the road. So, um, again, my name is Kelli Martin, I work at DSC, and um...

00:11:45.191 --> 00:11:48.191

helped with folks from Community Choices to...

00:11:49.075 --> 00:11:54.075

um... get things kind of going with the advocates, and when we were asked to

00:11:54.300 --> 00:11:56.300

present information

00:11:56.929 --> 00:12:02.929

We got about 3 questions, like, what's going well? What could be going better? What else do you want to share with us?

00:12:03.539 --> 00:12:09.539

And we all got together, and Community Choices and DSC Advocates

00:12:09.834 --> 00:12:16.834

decided that they wanted to create a survey, and instead of just sharing their own personal experiences,

00:12:16.834 --> 00:12:21.820

They wanted to see what other people, their friends and peers, might say.

00:12:21.822 --> 00:12:28.046

So they, um, created the survey and distributed that to other advocates,

00:12:28.576 --> 00:12:32.576

And the survey focused on identifying what is going well,

00:12:33.102 --> 00:12:36.102

And where there are challenges in the following areas.

00:12:36.554 --> 00:12:39.554

Health, work, transportation,

00:12:40.411 --> 00:12:43.411

Recreation and leisure, housing and advocacy.

00:12:43.741 --> 00:12:49.741

We did receive about 22 responses, and then the advocates met as a group together,

00:12:49.815 --> 00:12:54.815

to discuss common themes that they saw throughout the survey responses.

00:12:54.815 --> 00:13:04.400

And so the advocates are going to present those survey results for what's working well and what could be working better in regards to these 6 advocates.

00:13:04.960 --> 00:13:09.960

And then at the end, they will be open to taking any questions that you might have. And I

00:13:09.960 --> 00:13:19.832

Believe you have their bios in the packet, and then each of them will introduce themselves as they get ready to tell you about their designated area, so...

00:13:19.832 --> 00:13:21.917

Eric, take it away.

00:13:23.159 --> 00:13:28.159

Hi, my name is Eric Beasley. I'm going to talk to you about the... if we're working at Categories.

00:13:29.246 --> 00:13:38.246

Here is the some... here is some of the things that I could see that shared for good... that is going well, and, uh, at their work is why

00:13:38.891 --> 00:13:48.891

Advocacy, or are you getting paid and earning money. They reported that they like their co-workers, their bosses.

00:13:49.796 --> 00:13:54.796

Uh, this is the biggest difference for people to certify instead of a...

00:13:56.344 --> 00:13:58.344

certification at work.

00:13:58.505 --> 00:14:03.505

Many also reported that they are enjoying their work schedule.

00:14:03.893 --> 00:14:07.893

that people are getting the schedules that are a bit of the...

00:14:08.863 --> 00:14:12.863

accommodated their fire had deeds.

00:14:12.735 --> 00:14:17.735

Uh, ages, uh, report, uh, enjoyed, uh, the work, uh, they do.

00:14:18.632 --> 00:14:25.632

Yeah, yeah, here are some things that are reported that it could be a bit better of the work.

00:14:26.394 --> 00:14:29.394

It is, uh, it is harder to balance benefits, uh...

00:14:29.933 --> 00:14:33.933

at the worker, because we wanted it to... we're working because...

00:14:33.933 --> 00:14:37.439

But we don't want to lose our benefits.

00:14:38.463 --> 00:14:41.463

The paperwork can be complicated.

00:14:41.562 --> 00:14:46.562

there are often a lot of, uh, hoops that it drops us through.

00:14:46.698 --> 00:14:51.698

Some of the administrators' responsibilities, uh, it can be hard.

00:14:52.853 --> 00:14:55.853

Some of the jobs, uh, you need to be more accessible,

00:14:56.589 --> 00:15:02.589

Peter on your feet, uh, for a long time, and it's challenging at some jobs.

00:15:02.935 --> 00:15:10.935

There, there should be more opportunities for those with a physical disabilities, uh, who is needed to sit down often.

00:15:11.296 --> 00:15:16.296

Some of the people that had reported wanting more money.

00:15:16.202 --> 00:15:21.202

more hours, and more work outside of, uh, outside of the seasonal jobs.

00:15:21.318 --> 00:15:26.318

The others, uh, also mentioned that they needed it more than the job training.

00:15:30.973 --> 00:15:35.973

Hi, my name is Jen Buoy, and I'm going to talk about the health category.

00:15:35.974 --> 00:15:44.170

I'll start with what is going well with people's health. Advocates reported being able to see doctors they like.

00:15:45.183 --> 00:15:48.183

Many reported getting the care and medication they need.

00:15:49.097 --> 00:15:55.097

Advocates are feeling healthy and are focusing on eating healthy, drinking water, and exercising.

00:15:55.748 --> 00:16:00.748

Here are some things that were reported that could be better with people's health.

00:16:01.128 --> 00:16:04.128

Some people have a lot of appointments.

00:16:04.998 --> 00:16:07.998

Others reported taking too much medication.

00:16:08.323 --> 00:16:17.323

Long waiting times that appointments are frustrating and inconvenient. Individuals who use wheelchairs

00:16:18.324 --> 00:16:22.324

say they need to get a new wheelchair faster?

00:16:23.435 --> 00:16:28.435

Some people reported that they would like to work on being...

00:16:28.415 --> 00:16:33.415

on the same page with family about what is good for their health.

00:16:35.330 --> 00:16:39.330

Some spoke about wanting to lose weight and be more active.

00:16:40.431 --> 00:16:47.431

Others mentioned the need for cheaper options for services that insurance doesn't cover.

00:16:48.505 --> 00:16:52.505

Mental health is also a topic of improvement that was mentioned.

00:16:59.129 --> 00:17:02.129

Hi, my name's Dori, and I'm going to talk ab-

00:17:03.601 --> 00:17:05.601

about recreation leisure.

00:17:06.493 --> 00:17:11.493

In short, and things going to be people, responsibility, and they are

00:17:12.362 --> 00:17:15.362

They are attending different special e...

00:17:15.872 --> 00:17:19.872

events, groups, organization, such as CUR,

00:17:19.872 --> 00:17:26.071

Community Choices, DSC, people responsible for having good friends, good churches,

00:17:26.177 --> 00:17:28.177
at the state by playing...

00:17:28.973 --> 00:17:35.973
Games and family, friends, housemates, and online. Many also have individually...

00:17:36.720 --> 00:17:38.720
with hobbies and instructs Cut.

00:17:38.706 --> 00:17:40.706
Mom, cubs? I mean...

00:17:40.716 --> 00:17:42.716
clubs, such as...

00:17:44.772 --> 00:17:47.772
Mingle as exercise and bowling.

00:17:48.729 --> 00:17:50.729
Here's are some things that are

00:17:50.982 --> 00:17:54.982
Repent that that could be better with...

00:17:54.981 --> 00:17:59.198
people. Recreation and leisure, it is...

00:17:59.818 --> 00:18:03.818
Stressful, and haven't... and keep friends and can.

00:18:03.818 --> 00:18:06.264
come up, and for many, also.

00:18:06.571 --> 00:18:09.571
How hard to make friends, and some, or repeat not.

00:18:10.283 --> 00:18:19.283
Haven't enough money or paid. Hobbies, transportation, and fun activities around the community. We're waiting more to do more.

00:18:22.514 --> 00:18:24.514
opportunity free?

00:18:24.896 --> 00:18:28.896
advance more victims' activities, weekends, transportation help.

00:18:28.895 --> 00:18:33.761
People to travel and expense more. Sometimes...

00:18:34.423 --> 00:18:36.423

People... .. people place...

00:18:36.665 --> 00:18:38.665
Events are not always...

00:18:38.777 --> 00:18:40.777
Advanced one.

00:18:46.880 --> 00:18:48.880
I did it.

00:18:52.402 --> 00:18:55.402
Yeah.

00:18:56.084 --> 00:18:58.084
I guess...

00:19:01.182 --> 00:19:03.182
My name is Danielle.

00:19:04.041 --> 00:19:07.041
And I am going...

00:19:07.603 --> 00:19:09.603
to talk about.

00:19:09.582 --> 00:19:11.582
The...

00:19:12.028 --> 00:19:14.028
How's already?

00:19:13.972 --> 00:19:15.972
Health...

00:19:15.953 --> 00:19:17.953
category...

00:19:19.705 --> 00:19:21.705
I start with...

00:19:22.835 --> 00:19:25.835
Things going well.

00:19:26.108 --> 00:19:28.108
8...

00:19:28.538 --> 00:19:31.538
Aflacine?

00:19:32.445 --> 00:19:34.445
Repeat. Appeared.

00:19:34.526 --> 00:19:36.526

Speaking.

00:19:36.740 --> 00:19:38.740
Happy, happy. Happy.

00:19:39.126 --> 00:19:42.126
Where? Where. They.

00:19:42.230 --> 00:19:44.230
Live...

00:19:45.132 --> 00:19:48.132
Some are living

00:19:49.174 --> 00:19:51.174
On. On.

00:19:52.051 --> 00:19:54.051
There... on.

00:19:54.026 --> 00:19:56.026
On... no.

00:19:56.573 --> 00:19:58.573
That one? Only.

00:19:58.673 --> 00:20:00.673
O-W-N. Own.

00:20:01.200 --> 00:20:03.200
Oh, who?

00:20:05.789 --> 00:20:07.789
And, like...

00:20:07.759 --> 00:20:09.759
Independent. Independent.

00:20:10.216 --> 00:20:13.216
Some are living...

00:20:14.084 --> 00:20:16.084
In an Apartment

00:20:16.374 --> 00:20:18.374
So...

00:20:19.813 --> 00:20:21.813
are living?

00:20:23.029 --> 00:20:25.029
with family...

00:20:25.590 --> 00:20:28.590

And...

00:20:29.841 --> 00:20:31.841
are living in...

00:20:32.612 --> 00:20:35.612
Group. Homes.

00:20:35.874 --> 00:20:37.874
And light...

00:20:38.882 --> 00:20:40.882
There...

00:20:41.634 --> 00:20:46.634
Don't ask me. Housemate?

00:20:47.977 --> 00:20:49.977
People that never.

00:20:49.940 --> 00:20:51.940
Feel safe.

00:20:54.075 --> 00:20:56.075
They... like...

00:20:58.652 --> 00:21:01.652
Location. Location...

00:21:02.227 --> 00:21:04.227
Oh, no...

00:21:05.387 --> 00:21:07.387
Housing, housing...

00:21:07.611 --> 00:21:09.611
so have.

00:21:09.589 --> 00:21:11.589
New... partner.

00:21:11.743 --> 00:21:13.743
Places. Places.

00:21:13.755 --> 00:21:15.755
And like...

00:21:15.724 --> 00:21:17.724
So, so...

00:21:18.345 --> 00:21:20.345
Many, like...

00:21:21.954 --> 00:21:24.954

Laundry, that is...

00:21:24.993 --> 00:21:28.993
On... City... Fit. Fit.

00:21:29.406 --> 00:21:31.406
Here are...

00:21:31.807 --> 00:21:33.807
Something...

00:21:34.242 --> 00:21:36.242
That, or her...

00:21:40.276 --> 00:21:42.276
The. Vac.

00:21:43.019 --> 00:21:45.019
could. Be.

00:21:45.802 --> 00:21:47.802
This meeting is being recorded.

00:21:48.311 --> 00:21:50.311
Better...

00:21:51.112 --> 00:21:53.112
with people...

00:21:53.658 --> 00:21:55.658
housing...

00:21:56.923 --> 00:21:58.923
Housing. E...

00:21:59.023 --> 00:22:01.023
experience. Experience?

00:22:02.910 --> 00:22:04.910
It's expenses. Expenses.

00:22:04.910 --> 00:22:07.221
So, people...

00:22:07.403 --> 00:22:09.403
Where...

00:22:09.354 --> 00:22:11.354
No. Now?

00:22:11.744 --> 00:22:13.744
How? Who?

00:22:15.298 --> 00:22:17.298

More. More? More?

00:22:17.602 --> 00:22:19.602
of your...

00:22:20.157 --> 00:22:22.157
town? Yeah.

00:22:24.308 --> 00:22:26.308
Space, space, or...

00:22:26.873 --> 00:22:28.873
Just. Want.

00:22:29.175 --> 00:22:31.175
more.

00:22:33.264 --> 00:22:36.264
Players. Lears.

00:22:36.878 --> 00:22:38.878
Staff?

00:22:39.350 --> 00:22:41.350
Terminal. Terminal in...

00:22:42.101 --> 00:22:45.101
Loopong.

00:22:50.014 --> 00:22:52.014
other...

00:22:53.558 --> 00:22:56.558
Respond. Respond.

00:22:56.781 --> 00:22:58.781
in there...

00:22:59.000 --> 00:23:02.000
They... need...

00:23:03.064 --> 00:23:07.064
Learn. Learn. More.

00:23:07.336 --> 00:23:09.336
Away...

00:23:10.147 --> 00:23:12.147
Healing a long...

00:23:12.374 --> 00:23:14.374
Along, so...

00:23:14.593 --> 00:23:16.593

Talking, talk.

00:23:17.990 --> 00:23:19.990
About...

00:23:20.626 --> 00:23:23.626
4? Yeah. Four. Fair.

00:23:23.574 --> 00:23:25.574
Uh, there.

00:23:25.837 --> 00:23:28.837
Future. Future.

00:23:29.768 --> 00:23:31.768
And the needs...

00:23:32.286 --> 00:23:34.286
4...

00:23:35.006 --> 00:23:38.006
Future... plan...

00:23:38.474 --> 00:23:40.474
E? Plan D.

00:23:41.482 --> 00:23:44.482
So, they know that.

00:23:45.018 --> 00:23:47.018
For Housing...

00:23:48.161 --> 00:23:50.161
Plan are

00:23:50.872 --> 00:23:53.872
And... Parents. Parents.

00:23:55.141 --> 00:23:58.141
Give only. Order. Order.

00:24:09.074 --> 00:24:14.074
All right. Hello, my name is Toby, and I'm going to talk about trans...

00:24:14.074 --> 00:24:16.252
About the, uh, transportation category.

00:24:16.709 --> 00:24:19.709
I'll start with things going well.

00:24:20.091 --> 00:24:24.091
Our community has a lot of options for transportation, including
community choices

00:24:24.561 --> 00:24:26.561

Transportation program, Lyft,

00:24:26.878 --> 00:24:30.878

Uber, MTD buses, ADA, and family and friends.

00:24:31.824 --> 00:24:33.824

The MTD buses are accessible

00:24:33.825 --> 00:24:36.719

And... easy to get around.

00:24:38.204 --> 00:24:42.204

MTD also provides free dash passes for people with disabilities.

00:24:43.249 --> 00:24:45.249

Many like that live.

00:24:45.379 --> 00:24:49.379

close to easy access to buses, advocates,

00:24:49.691 --> 00:24:52.691

report having family, uh, strong family support.

00:24:53.310 --> 00:24:58.310

Some advocates have their driver's licenses, and I really like this.

00:24:58.888 --> 00:25:00.888

Here are some of the things that we...

00:25:01.598 --> 00:25:03.598

that we, uh, were reported.

00:25:05.127 --> 00:25:09.127

That could be better with transportation. Advocates reporting needing more...

00:25:10.345 --> 00:25:12.345

ride options that go outside of...

00:25:13.280 --> 00:25:15.280

Champaign-Urbana to other nearby towns.

00:25:16.382 --> 00:25:18.382

And weekend options. Some reported...

00:25:18.502 --> 00:25:22.502

They needed more accessible options for people in wheelchairs.

00:25:23.494 --> 00:25:25.494

The MTD charging...

00:25:25.691 --> 00:25:31.691

route, MTD changing routes in the summertime is a point of frustration for some.

00:25:32.962 --> 00:25:35.962

The MTD ADA has poor communications at times.

00:25:36.522 --> 00:25:41.522

for drivers, gas prices, and affordability is a concern.

00:25:41.749 --> 00:25:44.749

Also, some spoke of the fact that they have...

00:25:44.943 --> 00:25:50.943

to get rides from other people, like PSWs, which could be hard and not always...

00:25:52.155 --> 00:25:54.155

reliable. Okay, Dora?

00:25:55.684 --> 00:25:57.684

I'm buying it for DAR. Okay.

00:25:59.006 --> 00:26:03.006

Uh, so here I am again.

00:26:03.007 --> 00:26:07.708

What I'm gonna talk to them about is that advocacy, uh, the category.

00:26:08.627 --> 00:26:14.627

I like that with the things that are going well. Speak up, speak out of the... what's it, the success, uh, this year.

00:26:15.256 --> 00:26:23.256

Many have reported that they've been, like, they've been a part of the Advocacy group from the Community Choices and DSC, eh?

00:26:23.566 --> 00:26:29.566

As someone have enjoyed their experience at Advocacy here with the politicians in Springfield.

00:26:29.923 --> 00:26:36.923

Community Choice has made a health guide a few years ago, back at the fact that there's been...

00:26:36.923 --> 00:26:38.928

Very helpful for some.

00:26:39.998 --> 00:26:43.998

And another person that reported that a joint, uh...

00:26:43.997 --> 00:26:47.953

being, uh, being on a computer choice is a board of directors.

00:26:47.954 --> 00:26:53.309

Here are some things that were reported that it would be better for the advocacy.

00:26:54.138 --> 00:27:00.138

advocacy, yep. Uh, people don't, uh, always, uh, feel sane or heard.

00:27:01.280 --> 00:27:06.280

we want to... the culture to change and be more welcoming and welcoming.

00:27:06.447 --> 00:27:08.447

And then the last said judgmental.

00:27:09.081 --> 00:27:13.081

The... something to think of their... their third deets are...

00:27:13.091 --> 00:27:20.091

to be a more public awareness about the disabilities in other organizations.

00:27:20.759 --> 00:27:27.759

Some are actually for more opportunities to advocacy, or more events, uh, to share their stories.

00:27:27.770 --> 00:27:30.770

agarism, so they're...

00:27:31.549 --> 00:27:34.549

are also looking for more to get called...

00:27:35.734 --> 00:27:41.734

collaboration between groups. They want to see organizations working together to advocate.

00:27:46.087 --> 00:27:49.087

Uh, okay, anything else for the board?

00:27:49.931 --> 00:27:54.931

Some of the people are worried about people that they have to...

00:27:54.932 --> 00:27:57.860

they do have visibility, but are not...

00:27:58.495 --> 00:28:02.495

disabled enough to qualify for the disability services and benefits.

00:28:04.477 --> 00:28:12.477

And people with disabilities are still smart. Many still want to work. Some people need a combination.

00:28:12.684 --> 00:28:14.684

It's hard to find jobs.

00:28:15.685 --> 00:28:20.685

Organizations should use funds for what they are meant for.

00:28:40.703 --> 00:28:42.703
I...

00:28:43.706 --> 00:28:45.706
Uh-oh, other device...

00:28:46.776 --> 00:28:49.776
accurately agree on Champaign County needs focus on

00:28:49.708 --> 00:28:54.708
Finding the more access sidewalks, public transportation, business,

00:28:54.799 --> 00:28:56.799
layout to help make

00:28:57.223 --> 00:29:03.223
recent activities for launching for our friends in wheelchairs. Please
don't... please do not put them

00:29:03.548 --> 00:29:05.548
on this... on the back burner.

00:29:08.904 --> 00:29:10.904
Thank you. Many...

00:29:10.904 --> 00:29:13.538
people are...

00:29:13.537 --> 00:29:16.537
Lonely.

00:29:16.838 --> 00:29:19.838
And are looking...

00:29:19.777 --> 00:29:21.777
for a wave.

00:29:21.768 --> 00:29:23.768
to make...

00:29:24.527 --> 00:29:26.527
The correct connection.

00:29:26.488 --> 00:29:28.488
Connected with...

00:29:29.024 --> 00:29:31.024
of other people.

00:29:34.236 --> 00:29:36.236
Thank you all for sharing that.

00:29:38.375 --> 00:29:43.375

If there are questions from board members, uh, now's the time.

00:29:52.779 --> 00:29:54.779

Can you say more about, um...

00:29:55.711 --> 00:29:58.711

how we can help people develop friendships.

00:29:59.968 --> 00:30:02.968

Perhaps we need to be working more outside of...

00:30:03.533 --> 00:30:05.533

DSC, Community Choices.

00:30:06.001 --> 00:30:08.001

So that the friendships come from...

00:30:08.536 --> 00:30:10.536

Others in the community,

00:30:10.686 --> 00:30:12.686

Do you have suggestions?

00:30:14.215 --> 00:30:17.215

Or how to facilitate more...

00:30:17.725 --> 00:30:19.725

friendship. Yes.

00:30:20.382 --> 00:30:22.382

Um, there's other...

00:30:23.436 --> 00:30:28.436

organizations, and I know friendships for the U of I.

00:30:28.965 --> 00:30:35.965

have paired up with people with disabilities as students for Best Buddies.

00:30:36.934 --> 00:30:39.934

We need some more, like, more programs.

00:30:40.655 --> 00:30:44.655

Um, and I know they are trying to expand

00:30:45.085 --> 00:30:47.085

their age group, I mean...

00:30:47.348 --> 00:30:49.348

it, um...

00:30:50.105 --> 00:30:55.105

would help, but you need more social opportunities, probably would...

00:30:55.420 --> 00:31:00.420

Be because not all non-profit organizations are...

00:31:00.515 --> 00:31:02.515

offering, um...

00:31:03.698 --> 00:31:05.698

you know, social opportunities.

00:31:07.784 --> 00:31:12.784

So, for a ton... many don't have, like, all that funding, so...

00:31:12.755 --> 00:31:14.755

It's, um...

00:31:16.147 --> 00:31:21.147

Yeah, it would help, and for some people don't know about any...

00:31:21.614 --> 00:31:25.614

somebody to help them learn what is the difference between...

00:31:26.609 --> 00:31:30.609

a friendship, and just being an acquaintance.

00:31:31.661 --> 00:31:37.661

A lot of people don't know the difference between an acquaintance and friendships, so people need to learn

00:31:38.389 --> 00:31:41.389

The difference in, like, a staff member, or...

00:31:41.800 --> 00:31:44.800

somebody just have, like, uh...

00:31:45.016 --> 00:31:47.016

a program to help them learn.

00:31:48.169 --> 00:31:51.169

And what are the steps she needs to do to take more to...

00:31:51.896 --> 00:31:53.896

Make friends. How do you...

00:31:53.894 --> 00:31:55.877

do that. People...

00:31:56.187 --> 00:31:58.187

Like, Michelle, um...

00:31:58.476 --> 00:32:02.476

My parents didn't teach me that much, you know, about how to make...

00:32:02.857 --> 00:32:08.857

Friends, all I knew was mainly about for acquaintances, but what a friendship

00:32:10.742 --> 00:32:12.742
is, is, um, not... and...

00:32:13.372 --> 00:32:16.372
it's still... it takes a long time.

00:32:17.808 --> 00:32:22.808
Or no, I didn't have... when you don't have the opportunity because I had a learning disability,

00:32:23.588 --> 00:32:26.588
In school, I spent all my time on my homework.

00:32:26.783 --> 00:32:31.783
doing that, so I didn't have the opportunity to go for social events.

00:32:32.040 --> 00:32:36.040
to make friends, because I spent twice as much...

00:32:36.887 --> 00:32:43.887
time doing... I spend all my time doing my homework, and I didn't have the opportunity for when people don't have those...

00:32:43.887 --> 00:32:45.917
social opportunities,

00:32:45.917 --> 00:32:50.017
When they're in school, it hurts, and you fall right...

00:32:50.017 --> 00:32:51.928
behind in life, it's...

00:32:51.928 --> 00:32:53.894
not helping.

00:32:54.522 --> 00:32:56.522
Thank you very much, that's very helpful.

00:32:59.158 --> 00:33:02.158
Well, I would say friendships are very important.

00:33:02.159 --> 00:33:11.900
Because in my past, when I was in high school, I had many friends back in my time. When I was in the small town of a small town of high school.

00:33:13.157 --> 00:33:15.157
And also, we've known each other since elementary.

00:33:15.661 --> 00:33:19.661
And also, there's been contests at each and here and there, but...

00:33:20.249 --> 00:33:25.249

to me, uh, to me, I had, uh, I went to a hoc football, American football, here.

00:33:25.066 --> 00:33:28.066

And so I connected with the boys.

00:33:28.534 --> 00:33:30.534

You know, made a lot of friends there. Eh.

00:33:31.018 --> 00:33:36.018

And, uh, of course, I've been to Hallmarks, and also I gotta be straights.

00:33:37.193 --> 00:33:40.193

And I got bullied about 3 times, but...

00:33:40.866 --> 00:33:44.866

Still, those kind of boys has been through a harder time than I have.

00:33:57.247 --> 00:34:00.247

What helps you make friends? What would help you?

00:34:01.087 --> 00:34:04.087

what would help me make friends?

00:34:06.006 --> 00:34:08.006

Just branching out and...

00:34:08.280 --> 00:34:12.280

meeting more people, I guess, more groups, and things of that nature.

00:34:19.920 --> 00:34:24.920

Yes, money can be a barrier, depending on what... how much and how much is needed.

00:34:28.002 --> 00:34:30.002

Especially going out to eat, you know.

00:34:30.031 --> 00:34:33.031

And now those times, people don't have them.

00:34:33.318 --> 00:34:36.318

And for fun activities, they're...

00:34:37.796 --> 00:34:42.796

expensive sometimes, like, you find those at the Virginia Theater. There could be, or...

00:34:43.657 --> 00:34:46.657

football, basketball, and sports games.

00:34:46.580 --> 00:34:48.580

can be expensive.

00:34:54.847 --> 00:35:10.847

Um, so I have a question that might, um, be answered better by our staff, but obviously, if any of our advocates can weigh in on this. Um, so, like, I have a sister who's in her early 40s with some disabilities, and I don't recall as she was going through the school system,

00:35:10.846 --> 00:35:18.831

per se, having, like, life skill classes, where I feel like that's where you would kind of teach and nurture friendships and things like that.

00:35:18.831 --> 00:35:32.679

Is that something, through the years, has gotten better, or are we still seeing young adults, maybe college-age students, still coming in and not really having those skills? Because I... I recognize we have a lot to teach

00:35:32.924 --> 00:35:38.924

any child in a school, but I was just wondering if, you know, through studies and experience, if we've learned

00:35:38.925 --> 00:35:43.993

We need to start in kindergarten showing people how to communicate better with people.

00:35:43.993 --> 00:35:47.519

And I like the idea of acquaintances versus friends.

00:35:48.148 --> 00:35:54.148

Because unfortunately, I'm sure you guys have experienced people who you thought were your friends, and they were kind of using you.

00:35:55.030 --> 00:36:01.030

So, I don't know if anyone has any feedback on that, or if you kind of understand what I'm asking, but...

00:36:01.029 --> 00:36:02.856

Please.

00:36:02.856 --> 00:36:07.989

Well, I do agree with you on that. For the classes, so for special education.

00:36:07.990 --> 00:36:21.735

But with the software in the back of my time, we did have special education class, but it was not disability. There were kids falling back at grades, there were kids that fall back at...

00:36:21.476 --> 00:36:23.476

Uh, fall back over homework.

00:36:23.961 --> 00:36:27.961

And I made a few friends in there, and also everyone got along with me.

00:36:28.322 --> 00:36:36.322

But all of a sudden, about a few years later, when I was... actually, Jen and I were volunteering the... one of the elementary schools to...

00:36:37.202 --> 00:36:42.202

And also, when I was in there, in there, I see, where's the connection to those kids?

00:36:43.235 --> 00:36:46.235

I was, like, blocking everything, huh?

00:36:46.774 --> 00:36:50.774

And also, another dimension, we just don't look like we exist anymore.

00:36:51.205 --> 00:36:54.205

I just felt like, where are they now?

00:36:55.368 --> 00:36:57.368

Eric, were you ever taught, like,

00:36:57.792 --> 00:37:04.792

the difference between relationships? Did you have any guidance in school about life skills like that? Like, how to make friends, or...?

00:37:05.461 --> 00:37:09.461

I would say... I would say... I would say life skills is very challenging.

00:37:10.266 --> 00:37:12.266

The life skills, they could be very mysterious.

00:37:13.263 --> 00:37:20.263

And also... and also, it could be many possibilities to what kind of the abilities we have out there during school times.

00:37:20.728 --> 00:37:23.728

We have to find strength and weaknesses in each one of us.

00:37:24.805 --> 00:37:27.805

And all... and very ears, all the above.

00:37:28.372 --> 00:37:33.372

Eh, don't be... you'll be surprised how many friends you can make in that school.

00:37:37.030 --> 00:37:43.030

Yes, um, we were mentors at... I think it was at the middle school for Jefferson,

00:37:43.030 --> 00:37:44.823

But it was...

00:37:44.824 --> 00:37:50.891

But there's not... there weren't even... there isn't any that much for mentoring, even.

00:37:51.756 --> 00:37:54.756

For... now, but also for...

00:37:55.789 --> 00:37:59.789

There isn't. I don't feel like enough life skills groups, um...

00:38:00.821 --> 00:38:02.821

out there for organizations, like...

00:38:02.821 --> 00:38:05.584

Helping, but I know, um...

00:38:06.246 --> 00:38:09.246

PACE, a Center for Independent Living, is helping...

00:38:10.260 --> 00:38:15.260

was trying to get youth kids for transition, and...

00:38:16.277 --> 00:38:19.277

to that, if mark in my time, those weren't...

00:38:20.030 --> 00:38:25.030

I mean, I didn't know and wasn't available. That's really what you need, is a slow...

00:38:25.346 --> 00:38:29.346

transition, and we can't just learn everything all at once.

00:38:30.368 --> 00:38:33.368

How are you gonna learn everything at once? There's too much to handle.

00:38:33.738 --> 00:38:37.738

All at once, and you can't concentrate, and I was like...

00:38:38.692 --> 00:38:44.692

you gotta do a little bit so you can concentrate, and then work your... just take small steps.

00:38:44.906 --> 00:38:46.906

And it needs to...

00:38:46.897 --> 00:38:48.897

To be... I think I...

00:38:48.898 --> 00:38:54.716

You gotta do it a little bit at a time, but it... it will... it would help if...

00:38:55.459 --> 00:38:57.459

You had, um...

00:38:57.465 --> 00:38:59.465

some more groups and, like,

00:39:00.150 --> 00:39:02.150
different levels, like, for...

00:39:03.910 --> 00:39:05.910
learning, learning skills, and...

00:39:05.917 --> 00:39:07.917
That's what would, uh...

00:39:08.975 --> 00:39:13.975
really, um... I think help would also affordable housing is...

00:39:15.798 --> 00:39:22.798
people to be able to afford apartments, that's why a lot of people are
living with family, or...

00:39:23.206 --> 00:39:25.206
Group homes are...

00:39:26.172 --> 00:39:28.172
It's just trying to be able to

00:39:29.151 --> 00:39:31.151
be able to afford...

00:39:37.491 --> 00:39:39.491
And, uh, well, trans...

00:39:41.624 --> 00:39:43.624
transportation, but also it's, like,

00:39:44.309 --> 00:39:52.309
You get to make your own choices. Some people would rather be able to
cook their... be able to cook their own food instead of having to be...

00:39:53.118 --> 00:39:59.118
And the assistant living or group homes, but so they could get better.

00:39:59.118 --> 00:40:00.755
Cooking skills, or...

00:40:00.737 --> 00:40:02.737
stuff to live, um...

00:40:02.972 --> 00:40:04.972
Instead of having...

00:40:05.279 --> 00:40:08.279
And... try to learn...

00:40:08.801 --> 00:40:12.801
To cook for a variety of healthy foods.

00:40:13.981 --> 00:40:15.981

So, um, to do a...

00:40:15.980 --> 00:40:17.798

Meal planning...

00:40:17.982 --> 00:40:20.982

A lot of people are different based on their blood types.

00:40:24.748 --> 00:40:27.748

I'd like to add, uh, to your question, Jane.

00:40:28.647 --> 00:40:31.647

Um, we'll add some information as an answer to your question.

00:40:32.223 --> 00:40:34.223

Um, I think that...

00:40:35.628 --> 00:40:40.628

I think that maybe kids might be coming out of school with some more skills for building friendships now.

00:40:40.549 --> 00:40:52.549

However, when you transition out of school, some people are going into college, where then those friends are still readily available, or people are readily available, and when you don't kind of have that...

00:40:53.248 --> 00:40:56.248

um... kind of everyday...

00:40:57.366 --> 00:41:00.366

you know, uh, exposure to people, like, all of a sudden you're sitting at home.

00:41:01.144 --> 00:41:05.144

I think then some of those skills and things that you've learned, then, um...

00:41:05.522 --> 00:41:07.522

you know, like, all of us kind of get forgotten.

00:41:07.668 --> 00:41:09.668

And so...

00:41:10.064 --> 00:41:17.064

We have offered some different, like, we call them personal development classes through Community Choices, so things like Jen's mentioned, like cooking skills,

00:41:17.964 --> 00:41:27.964

We've, um, offered classes on, um, what it means to be a friend and some of those unwritten rules of friendship, like talking about acquaintances versus friends versus staff, versus people you...

00:41:28.043 --> 00:41:32.043

may pay to be in your lives, like the person who cuts your hair, like we all do, right?

00:41:32.220 --> 00:41:35.220
Um, but I think that without...

00:41:36.933 --> 00:41:45.933
There we go. I think that without having more, um, opportunities to practice those skills, it can be really hard to, um, continue to develop them.

00:41:45.934 --> 00:41:47.866
Just like it is for any of us.

00:41:52.443 --> 00:41:57.443
Can I actually add a couple of words as a parent of a young man with disabilities?

00:41:58.332 --> 00:42:00.332
If we didn't have home-based

00:42:00.878 --> 00:42:04.878
services, or the PSW availability,

00:42:05.880 --> 00:42:10.880
I finally figured out, as did my son, that the best use of his PSWs

00:42:11.411 --> 00:42:16.411
work to get him out into the community, to exercise at the Y with him.

00:42:16.823 --> 00:42:19.823
to interact with him and become...

00:42:20.548 --> 00:42:25.548
You know, quasi-buddies, at least, to play games with him so they felt more comfortable.

00:42:25.844 --> 00:42:30.844
And most recently, you know, to cook with him, go to the store with him. So,

00:42:30.844 --> 00:42:36.263
You know, not everybody has the flexibility, perhaps, to use their PSWs.

00:42:36.971 --> 00:42:41.971
Plus, it took us maybe 5 or 6 years to find the right kind of PSWs.

00:42:43.376 --> 00:42:47.376
And so... and they don't last, because they're young adults and they move on.

00:42:47.944 --> 00:42:51.944
So it's, you know, I think there's a systemic challenge, even when we can...

00:42:52.589 --> 00:42:54.589

So to speak, pay

00:42:55.058 --> 00:42:57.058

For companions and friends.

00:42:57.536 --> 00:43:01.536

And they really are friends, and they've maintained communication beyond

00:43:01.543 --> 00:43:03.543

Staying in town.

00:43:03.760 --> 00:43:05.760

But it's...

00:43:06.852 --> 00:43:10.852

I'm just very concerned that if we ever lose the funds for PSWs,

00:43:10.852 --> 00:43:12.659

We're going to have more lonely.

00:43:12.772 --> 00:43:14.772

Adults.

00:43:15.977 --> 00:43:21.977

I think you're right. Yeah, if you lose the funding, people will not just loaning us, but...

00:43:22.142 --> 00:43:24.142

we will be out.

00:43:24.339 --> 00:43:26.339

how much less help they...

00:43:26.498 --> 00:43:28.498

You don't realize how much...

00:43:29.537 --> 00:43:31.537

It's just, like, doing activities.

00:43:32.347 --> 00:43:35.347

you know, going for, like you said, for exercise, going...

00:43:35.440 --> 00:43:37.440

to do fun recreation.

00:43:38.300 --> 00:43:41.300

activities helping you do stuff at home and...

00:43:41.984 --> 00:43:43.984

exercising and going out in the community.

00:43:43.985 --> 00:43:49.559

how much it's lost, just like at COVID, when people had to be at home.

00:43:50.150 --> 00:43:54.150

I mean, you could see the effects for them and all.

00:43:54.517 --> 00:43:58.517

And how much lonely... it's, like, not being able to get out and about.

00:43:59.279 --> 00:44:01.279

makes a huge...

00:44:01.998 --> 00:44:05.998

difference, yep. It's gonna make a huge difference if you can't...

00:44:06.375 --> 00:44:10.375

If you don't have that, and don't have the money to go out and...

00:44:10.913 --> 00:44:15.913

do it, and people are ready for the food, the SNAP, you know, is...

00:44:17.297 --> 00:44:21.297

Well, because... so, even if you don't get that much...

00:44:22.549 --> 00:44:24.549

They only base that on your rent.

00:44:24.605 --> 00:44:27.605

And... near utilities.

00:44:28.244 --> 00:44:33.244

It won't matter anything else, whether you had a ton of other bills or not.

00:44:34.324 --> 00:44:36.324

Um, and...

00:44:36.374 --> 00:44:39.374

I guess the requirements...

00:44:40.237 --> 00:44:44.237

And, uh, the rules are a little bit changing, you know, they're for...

00:44:45.921 --> 00:44:48.921

But... hopefully, um...

00:44:50.330 --> 00:44:54.330

we can advocate better and help them get them back on track for that.

00:44:57.050 --> 00:45:08.050

Well, truth is, uh, on the personal, the support worker, you said it, you said that they leave all the time, but truth is, in my part, I have the worst luck on personal support workers, the worst luck.

00:45:09.087 --> 00:45:14.087

Because they all last only a month, they always take advantage of you.

00:45:14.882 --> 00:45:18.882

And I'll say... and also, they're just here for the money, eh?

00:45:19.218 --> 00:45:23.218

And also back of the Pass, uh, because of the pass, we do papers all the time, heh.

00:45:23.793 --> 00:45:28.793

And then all of a sudden, I got one guy who... when I signed my name on it, that didn't even see the times.

00:45:29.768 --> 00:45:33.768

And he was freeloading the whole entire time. The... all those... the hours.

00:45:34.158 --> 00:45:44.158

Amy... I had another one, another one, we... we got along very well on that one, but I also discovered her... discovered her. She was doing her 13 hours straight week.

00:45:44.903 --> 00:45:46.903

Uh, that's under \$10 an hour.

00:45:47.654 --> 00:45:51.654

Man, they took advantage of all that money, and also we fired her for that one.

00:45:51.844 --> 00:45:54.844

So it didn't last very long and gotten in trouble, eh?

00:45:54.844 --> 00:46:00.097

Which I... well, we didn't have the heart for it, because, uh, because she just had a kid,

00:46:00.776 --> 00:46:04.776

So, we didn't... so, I think she got lucky for that one.

00:46:04.749 --> 00:46:06.749

Anyway, he...

00:46:06.727 --> 00:46:08.727

I would say...

00:46:09.516 --> 00:46:12.516

To be, uh, the personal support workers are just a waste of skin.

00:46:14.029 --> 00:46:21.029

Can I respond briefly? I would agree sometimes with that, because we went through some similar situations.

00:46:22.193 --> 00:46:26.193

I mean, it really took referral from referral from referral.

00:46:26.785 --> 00:46:31.785

And people who are truly interested in individuals with disabilities to get

00:46:32.705 --> 00:46:36.705

the right support workers, and those are hard to find. You don't find them on Indeed.

00:46:37.156 --> 00:46:39.156

It's, you know...

00:46:43.456 --> 00:46:45.456

I got one. Uh...

00:46:46.207 --> 00:46:48.207

Lori and then was talking to me today.

00:46:48.833 --> 00:46:53.833

after they came over yesterday, they talked to me about benefits.

00:46:55.273 --> 00:46:58.273

Then kind of give me benefits better, and...

00:46:58.920 --> 00:47:00.920

working with Addis.

00:47:01.313 --> 00:47:04.313

my home care, and I said,

00:47:04.609 --> 00:47:08.609

Well, I want that choice, I want to do...

00:47:09.114 --> 00:47:12.114

do it, because I got a person

00:47:13.007 --> 00:47:16.007

comes in Monday through Friday to help me out.

00:47:17.034 --> 00:47:19.034

And I can do some things.

00:47:19.300 --> 00:47:24.300

And some things I could do everything for myself, and some things...

00:47:25.108 --> 00:47:29.108

I just want her to help me to do a lot of stuff for me.

00:47:29.108 --> 00:47:33.824

And I... and I sit in there, looking at her, she said,

00:47:33.824 --> 00:47:36.992

I guess you're... come on to help.

00:47:36.992 --> 00:47:38.964

me to do stuff.

00:47:38.963 --> 00:47:44.434

And she asked me, well, one for dinner? And I said, what you want for dinner?

00:47:45.071 --> 00:47:48.071

And she said, it's your wanting soup?

00:47:49.016 --> 00:47:52.016

Or something like that. For me, and I ate it.

00:47:52.800 --> 00:47:54.800

And she said, the soup is too hot.

00:47:55.328 --> 00:48:00.328

Just let it cool down first, and then you can eat it, and then I was sitting there watching TV,

00:48:01.483 --> 00:48:05.483

And we had her sit there and talk together, and...

00:48:06.430 --> 00:48:08.430

She asked me, you ready, huh?

00:48:08.832 --> 00:48:15.832

She was doing everything what you want to do. She went outside, and then she went home a minute, and...

00:48:15.730 --> 00:48:17.730

I said, what are you going to?

00:48:18.178 --> 00:48:23.178

She went home with medical care to do something at home a minute. Then she came back,

00:48:23.952 --> 00:48:25.952

Yeah, I mean, we're ready to take a shower.

00:48:25.951 --> 00:48:28.164

And I got a shower chair.

00:48:28.322 --> 00:48:30.322

She...

00:48:30.689 --> 00:48:33.689

helped me get undressed and stuff like that, and...

00:48:33.960 --> 00:48:37.960

I walked in my shower chair by myself, and sitting down.

00:48:39.054 --> 00:48:42.054

And she helped me and all that stuff, and then...

00:48:42.959 --> 00:48:45.959

I'll call her neighbor, tell her to come back in, tell the

00:48:46.758 --> 00:48:50.758

bathroom with me, because I don't want to fall down, I got a chair there.

00:48:51.162 --> 00:48:56.162

And I got my alert right there, because it told me the alert is sitting right there.

00:48:57.133 --> 00:48:59.133

If you fall down, something like that, that speak.

00:48:59.815 --> 00:49:01.815

include your alert on.

00:49:01.816 --> 00:49:04.500

And the come in to help me.

00:49:05.129 --> 00:49:09.129

get back up off the floor, because I don't want to hurt myself, and I don't want to hurt...

00:49:09.731 --> 00:49:12.731

her to read my... if I may be...

00:49:12.749 --> 00:49:14.749

They don't right by me.

00:49:14.780 --> 00:49:18.780

I don't want to fall down, hurt my head, or bump my head on the floor.

00:49:19.369 --> 00:49:21.369

The floor is hard like a brick.

00:49:23.303 --> 00:49:25.303

And I don't want to fall down and hurt myself.

00:49:26.098 --> 00:49:32.098

And we'll all sit down and talk, and Lori came up talking to me about it.

00:49:32.210 --> 00:49:38.210

And Talisha came in, and I talked to her more about it.

00:49:39.045 --> 00:49:42.045

to get PL, and I said, well, I said, Lori,

00:49:42.507 --> 00:49:47.507

I will lose my... all my benefits, and she said, no, you're not losing your benefits.

00:49:47.887 --> 00:49:49.887

But you might lose...

00:49:50.746 --> 00:49:53.746
you're... not your home care, you'll be losing

00:49:53.742 --> 00:49:57.742
the crane... the people at the...

00:49:57.930 --> 00:50:01.930
put name, and I said, I don't want that no more, I want to...

00:50:02.629 --> 00:50:10.629
the more... do more for myself, and she could come on in and help me out more.

00:50:11.772 --> 00:50:13.772
Because Wonderful Friday.

00:50:13.537 --> 00:50:18.537
She comes in at 4 o'clock, okay, 4 o'clock comes up.

00:50:19.297 --> 00:50:24.297
I said there was you with her in all that stuff, and then after that...

00:50:24.531 --> 00:50:29.531
She asked me, uh, what I want to have for dinner, and she...

00:50:29.875 --> 00:50:31.875
Tell me, you got a lot of food here.

00:50:33.207 --> 00:50:35.207
what will you want.

00:50:35.492 --> 00:50:38.492
You want soup and I said, yes, I want some soup.

00:50:39.132 --> 00:50:42.132
And then, uh, today, she came over and...

00:50:42.109 --> 00:50:44.109
Help me a little while.

00:50:44.216 --> 00:50:49.216
And she said, dang, I want to get this place cleaned up with more, get the...

00:50:50.150 --> 00:50:55.150
the stuff of the cow and all that stuff, I left everything on the couch, and I said,

00:50:55.405 --> 00:50:58.405
pick up the stuff and put it away.

00:50:58.939 --> 00:51:01.939
could I have my Bible and all that stuff on there, and...

00:51:02.381 --> 00:51:08.381
Looking for a sitting there looking if they were gonna scare me for, uh...

00:51:08.875 --> 00:51:12.875
arrive for going to work. MC don't pay, I mean...

00:51:13.565 --> 00:51:15.565
And the...

00:51:15.588 --> 00:51:18.588
All don't pay me that long, right?

00:51:18.783 --> 00:51:21.783
And... and I asked him...

00:51:22.331 --> 00:51:25.331
I want more hours, but then said...

00:51:25.965 --> 00:51:30.965
They said there is not the morale for me.

00:51:30.965 --> 00:51:33.527
It's only 1.30 to 4.30.

00:51:34.155 --> 00:51:36.155
And I left this at 4.30...

00:51:36.008 --> 00:51:38.008
More than 43!

00:51:38.341 --> 00:51:41.341
And no more hour for me yet. And I said...

00:51:41.410 --> 00:51:44.410
Come on, people, I want more hours on Saturday.

00:51:45.293 --> 00:51:48.293
I sitting at home, be bored all the time.

00:51:49.221 --> 00:51:52.221
And everybody asked me, why you be bored on...

00:51:52.365 --> 00:51:57.365
Saturday for. And I said, I am bored now, I ain't not working.

00:51:57.728 --> 00:52:01.728
Here's my schedule has now popped up. Hey, Danielle.

00:52:02.244 --> 00:52:05.244
That was a perfect segue into something I wanted to share.

00:52:06.321 --> 00:52:14.321
Okay, so it sounded like you were talking a lot about you like your personal support worker, and you want to have her, and you have...

00:52:15.211 --> 00:52:19.211

other people that support her, and Susan was asking about, like,

00:52:19.211 --> 00:52:27.151

other friends or other natural supports, and, like, your friends at your church, and that sort of thing.

00:52:27.696 --> 00:52:32.696

Um, but you mentioned that sometimes you're bored on Saturdays. Yes, I am. And so...

00:52:33.209 --> 00:52:41.209

One of the kind of life skills, social connection thing that we try to do, um, we have a group at DSC that's called Employment Plus, and so...

00:52:41.210 --> 00:52:48.242

you have an opportunity to go out with other people that have jobs within the community, but the goal of that is to try to

00:52:49.273 --> 00:52:55.273

make those connections with each other so that then you guys can be friends and have really figured out how to...

00:52:55.473 --> 00:52:57.473

like, connect with each other,

00:52:58.248 --> 00:53:08.248

outside of DSC helping with that, or Community Choices helping with that. And then we also do something similar with people that live in their own apartments, because we recognize that

00:53:08.505 --> 00:53:19.505

Sometimes it's hard to figure out what to do when staff aren't directing it, and so this has really, like, individuals and people that are in there are trying to figure out what they're gonna do

00:53:20.096 --> 00:53:27.096

And maintaining that friendship, and some of them are getting together outside of structured events and activities, which is...

00:53:27.132 --> 00:53:33.132

really, really cool. So, thank you all for sharing that. Do we have some other questions from the board?

00:53:51.477 --> 00:53:54.477

Well, I think we lost Molly here for a minute, but um...

00:53:55.193 --> 00:54:00.193

I want to thank the group for doing such a nice job. You are a very articulate and smart group

00:54:00.648 --> 00:54:02.648

people, and we have learned a lot tonight.

00:54:02.968 --> 00:54:04.968

From all of you. Thank you.

00:54:12.826 --> 00:54:15.826

Well, should I go ahead and introduce... okay.

00:54:15.827 --> 00:54:22.898

So we're going to go to the next, um, segment of our meeting tonight, which is a little, um, discussion of...

00:54:22.897 --> 00:54:28.573

a group that we've been discussing in our CCVVB meetings for...

00:54:29.409 --> 00:54:31.409

quite a few months, Engage Illinois.

00:54:32.290 --> 00:54:35.290

Which is really looking toward, uh, moving Illinois toward

00:54:36.458 --> 00:54:41.458

giving people with disabilities better supports and services, much better than

00:54:42.084 --> 00:54:44.084

what is currently offered. So,

00:54:44.083 --> 00:54:49.620

In that... to that end, we have our guest with us, Sharon Costabile, who is the...

00:54:50.440 --> 00:54:55.440

the queen of Engage Illinois. I would call her son an official

00:54:55.404 --> 00:55:00.404

organization quite yet, but, um, Sharon has been doing a boatload of work.

00:55:01.224 --> 00:55:04.224

to connect people, and she's gonna tell you about that tonight.

00:55:06.623 --> 00:55:09.623

And you need that. I think I need a microphone.

00:55:10.847 --> 00:55:14.847

The very first thing that I would want to say is, Jen...

00:55:16.074 --> 00:55:18.074

Uh, Eric, Toby?

00:55:19.333 --> 00:55:21.333

Theodora and Danielle.

00:55:21.757 --> 00:55:23.757

I am so grateful.

00:55:25.106 --> 00:55:29.106

to hear everything that you have shared tonight. I just want you to know...

00:55:29.106 --> 00:55:31.417

How important you are.

00:55:31.549 --> 00:55:35.549

to change. Thank you very much for sharing.

00:55:37.648 --> 00:55:40.648

Second thing, my name is Sharon Costabile.

00:55:41.378 --> 00:55:46.378

I have a daughter with Down syndrome. She's 39 years old. Her name is Rachel.

00:55:47.521 --> 00:55:52.521

Um, and she is living in, uh, her own place.

00:55:53.344 --> 00:55:57.344

for going on 4 years now with a couple of

00:55:57.952 --> 00:56:00.952

Friends. I'm going to tell you a little bit about their story.

00:56:01.355 --> 00:56:05.355

Um, but first, I'd like to know who I'm speaking to.

00:56:06.495 --> 00:56:10.495

This is kind of new for me, so I... I hope that you'll bear with me.

00:56:10.868 --> 00:56:13.868

Um, you folks are all living

00:56:14.634 --> 00:56:16.634

in your own places,

00:56:16.766 --> 00:56:20.766

Or, no, I see a head shake. Maybe I should ask,

00:56:20.745 --> 00:56:22.745

Where do you guys live?

00:56:24.534 --> 00:56:29.534

I live with my, uh, mother in a duplex in...

00:56:30.052 --> 00:56:32.052

Champagne, so...

00:56:32.866 --> 00:56:41.866

There's because of the affordability, you know, for affordable housing, that is the number one issue why I am with my mother, because...

00:56:42.050 --> 00:56:44.050
It... I just...

00:56:44.128 --> 00:56:47.128
cannot seem to afford it.

00:56:47.841 --> 00:56:49.841
Or for... to find a place?

00:56:49.841 --> 00:56:56.786
Mm-hmm. That wouldn't... that's affordable, that meets my needs. When I've got insomnia, and I...

00:56:57.329 --> 00:56:59.329
I just can't...

00:56:59.693 --> 00:57:06.693
handle and to find something, and for somebody to do a housing voucher when you can't, or...

00:57:06.830 --> 00:57:10.830
Find a roommate, it's... And do you have home-based support?

00:57:10.830 --> 00:57:17.446
I have the home-based support, like she said, the PSW. Right. Yes.

00:57:17.355 --> 00:57:19.355
Now, yeah.

00:57:19.443 --> 00:57:21.443
So... Thank you.

00:57:21.503 --> 00:57:27.503
Eric? Well, I used to live in by myself, uh, by myself, because...

00:57:28.355 --> 00:57:35.355
Well, the thing is, the reason why I got that by myself years ago, because when I was first established when I was 18,

00:57:36.159 --> 00:57:43.159
And also, all they did was kind of like a Wheel of Fortune they used to, kind of like to pick a... pick a spot. Like, the biggest is group home.

00:57:43.140 --> 00:57:48.140
The bear, the son, the roommate, but guess how many bigot is, on with yourself.

00:57:48.278 --> 00:57:56.278
That's small. Yeah, because weren't they routed? I got it for a loan, they were right there, and they said, you got lucky on that one. Okay.

00:57:56.436 --> 00:57:58.436
So you live by yourself now?

00:57:58.905 --> 00:58:07.905

Well, I, uh, truth is, uh, truth is, I moved up here, because I just, uh, had to do a roommate, which is my mother. Okay.

00:58:07.905 --> 00:58:13.806

And she had to... she had to... she had to get out of the town, because it was getting rougher now. Okay.

00:58:14.180 --> 00:58:20.180

And also, we use Section 8 housing. It saved up a lot of money for both of us.

00:58:20.628 --> 00:58:26.628

And, uh, and all of a sudden, my grandfather, since my grandmother passed away two years ago,

00:58:26.916 --> 00:58:33.916

And he was getting pretty lonely, so it took all three of us to get a house, so all three of us can live in there.

00:58:33.916 --> 00:58:38.594

And so, I've been living there for 2 years, uh, on the house.

00:58:38.926 --> 00:58:40.926

Got a good deal on the bus drives.

00:58:41.655 --> 00:58:44.655

And... and are you on home-based support as well?

00:58:45.563 --> 00:58:58.563

You have a PSW? Well, my mother is working on it, being a PSW. Okay. So she is, so we... so we can have a little extra money to get through, to get through. Gotcha.

00:58:58.855 --> 00:59:00.855

And, uh, Toby?

00:59:01.709 --> 00:59:04.709

Are you on home-based, or do you live on your own?

00:59:04.861 --> 00:59:06.861

Uh, I live with my parents.

00:59:08.097 --> 00:59:10.097

Thank you. And how about you, Theodora?

00:59:12.166 --> 00:59:14.166

I live in a group home. In a group home?

00:59:14.805 --> 00:59:16.805

Danielle? A little...

00:59:18.128 --> 00:59:20.128

I live at 16 East Square.

00:59:20.719 --> 00:59:22.719

At a group home? No. No.

00:59:23.310 --> 00:59:25.310

I'm sorry, I misunderstood what you said.

00:59:27.117 --> 00:59:29.117

A little bit...

00:59:29.523 --> 00:59:31.523

I see. But I do...

00:59:32.805 --> 00:59:34.805

An apartment? I see. Apartment. Okay.

00:59:35.072 --> 00:59:39.072

Very cool. And does, um, if a little show of hands,

00:59:39.974 --> 00:59:43.974

of those who have an individual with a disability in their life.

00:59:47.691 --> 00:59:52.691

Thank you very much. I can't see behind me, but I know there's a few of you.

00:59:53.075 --> 01:00:00.075

Yeah, okay. Um, what I'd like to talk about is, um, a friend of mine, and her name is Ashley.

01:00:01.931 --> 01:00:08.931

This is Ashley. Ashley usually comes with me to do presentations. She's just fabulous.

01:00:08.932 --> 01:00:20.576

Uh, young lady, Down syndrome is her disability. Um, her abilities are incredible. She's a marketing genius, um, she's very chatty.

01:00:20.877 --> 01:00:22.877

And, um...

01:00:23.824 --> 01:00:25.824

A couple of years back,

01:00:25.824 --> 01:00:31.401

she found herself in a crisis. Her parents both passed away.

01:00:33.145 --> 01:00:37.145

Um, her dad had already been gone, her mom passed away,

01:00:37.736 --> 01:00:42.736

And she was very scared. She wasn't quite sure where she was going to end up, where she was gonna live,

01:00:43.673 --> 01:00:55.673

And it was suggested to her, um, at that point that she move possibly to Springfield. Now, where she was from the, uh, north area in, um,

01:00:55.726 --> 01:01:00.726

The northern suburbs of Chicago. So, somewhat farther away from you guys.

01:01:01.218 --> 01:01:06.218

Um, she was... it was suggested that she move to Springfield.

01:01:07.436 --> 01:01:11.436

to a state-operated developmental center, an institution.

01:01:12.573 --> 01:01:14.573

And...

01:01:15.963 --> 01:01:18.963

That was the default placement that was talked about.

01:01:19.771 --> 01:01:23.771

Ashley was very, very nervous about that. She didn't like the idea.

01:01:25.037 --> 01:01:33.037

But Ashley was very fortunate in that her mom had developed a lot of close relationships. She has two brothers.

01:01:33.038 --> 01:01:37.759

They don't live real close to her, but they are her support system.

01:01:38.360 --> 01:01:45.360

And mom made lots of friends, um, as she was growing up, and those friends came to...

01:01:45.940 --> 01:01:49.940

Um, develop a circle of support around Ashley.

01:01:52.989 --> 01:02:01.989

And the friend said, no way, Ashley's not going to, uh, you know, southern Illinois. Everybody she knows is up here. All her friends.

01:02:01.989 --> 01:02:05.180

You know, we talk about friendships, and she had developed quite a few.

01:02:06.221 --> 01:02:12.221

So, together, uh, the friends and some of Ashley's new champions, one of

01:02:12.106 --> 01:02:14.106

whom is sitting next to me.

01:02:14.498 --> 01:02:20.498

Vicki, and, um, some other individuals, Nancy and Chris and Anna,

01:02:20.549 --> 01:02:25.549

And they all said, we can help you think about a new future, Ashley.

01:02:25.846 --> 01:02:27.846
And we'll be there to guide you.

01:02:29.192 --> 01:02:31.192
So, Ashley learned how to dream.

01:02:31.181 --> 01:02:36.181
Again. And a new chapter began to unfold.

01:02:36.307 --> 01:02:38.307
For her.

01:02:41.534 --> 01:02:43.534
When one of those champions

01:02:43.859 --> 01:02:49.859
came to me and told me about Ashley, a friend of mine named Nancy,

01:02:50.118 --> 01:02:57.118
I told Nancy, well, Rachel just raised her hand and said she wanted to move out. Maybe we should get the girls together.

01:02:58.178 --> 01:03:00.178
Lo and behold, that's what happened.

01:03:00.556 --> 01:03:02.556
The girls came together.

01:03:03.038 --> 01:03:07.038
And Ashley and Rachel moved into their own place.

01:03:07.037 --> 01:03:09.508
12, 12 of 21.

01:03:10.142 --> 01:03:15.142
Their own place was a, uh, one floor in a two-flat.

01:03:15.422 --> 01:03:18.422
that my husband and I had purchased

01:03:18.586 --> 01:03:20.586
25 years ago.

01:03:21.080 --> 01:03:23.080
With the thinking that

01:03:23.261 --> 01:03:26.261
Someday, Rach might want to be on her own.

01:03:27.326 --> 01:03:31.326
So, as... as I was thinking about...

01:03:31.425 --> 01:03:36.425

why we needed to develop our supports around that,

01:03:37.643 --> 01:03:42.643

Um, and what those supports would be... I looked at what we had in Illinois.

01:03:43.495 --> 01:03:52.495

And many of you may already know this, we have, really, two choices other than, um, SODCs, and that is either Box A, which is

01:03:52.290 --> 01:03:54.290

providers managed.

01:03:54.993 --> 01:03:56.993

Agency-managed group pumps.

01:03:56.993 --> 01:04:00.289

Or, we have box B, which is what some of

01:04:00.508 --> 01:04:03.508

you guys are familiar with, which is home-based support.

01:04:04.592 --> 01:04:11.592

What I knew is that Rachel really needed some of these other things that you see over here.

01:04:11.858 --> 01:04:31.858

She needed a person-centered plan. She needed flexibility, because she likes to make plans. She carries around a little plaque that says, the girl who likes to make plans everywhere with her. She sets it. It's one of these. She sets it on her desk, no matter where she is. I like to make plans. So we knew this girl was going to need some flexibility.

01:04:32.569 --> 01:04:41.569

Um, we knew she wanted to be in the community. She likes to walk to the library. She likes to volunteer at Feed My Starving Children. She's...

01:04:42.350 --> 01:04:49.350

Um, involved also in church, Danielle. So, she likes going to, um, some type of a service.

01:04:49.544 --> 01:04:53.544

Um, we knew that was really important.

01:04:54.855 --> 01:04:56.855

But I think the most important thing

01:04:56.856 --> 01:05:03.351

is that she needed something that would be sustainable. And the reason I say that is because

01:05:03.696 --> 01:05:05.696

We all die, and...

01:05:06.120 --> 01:05:08.120
I'm getting older, and...

01:05:08.582 --> 01:05:13.582
About 80% of our folks, um, are finding them...

01:05:14.188 --> 01:05:19.188
Living at home with aging parents. I'm sorry, 70% are living at home with aging parents.

01:05:19.588 --> 01:05:22.588
And 25% of those parents are over...

01:05:23.301 --> 01:05:25.301
60. And that's me.

01:05:26.102 --> 01:05:29.102
So I knew sustainability was what I needed to see.

01:05:29.100 --> 01:05:30.937
for Rachel.

01:05:32.339 --> 01:05:36.339
So what we're looking at is something called a supported life.

01:05:36.369 --> 01:05:43.369
How can we support folks so that they can have all those wonderful things, and what is supported living?

01:05:44.079 --> 01:05:48.079
So if you look at the left side of the screen, for those of you who can see it,

01:05:48.080 --> 01:05:52.375
Creating a life for someone based on the person's preferences,

01:05:53.303 --> 01:05:58.303
interests, needs, and choice. Building the scaffolding that they need. Scaffolding meaning

01:05:59.046 --> 01:06:03.046
you know, all the things that they need to do what they want to do, and...

01:06:03.721 --> 01:06:10.721
To take a shower, like Danielle. Fine. You know, all kinds of things to help that person be as independent as possible.

01:06:11.435 --> 01:06:17.435
Having the opportunity to live in the community, that's what supported living is. The ability to decide if

01:06:17.693 --> 01:06:21.693
They want to live alone or with someone else, a roommate.

01:06:22.741 --> 01:06:31.741

John O'Brien, some of you may be, um, familiar with him. He just passed away recently. He wrote an article called Supported Living, What's the Difference?

01:06:32.519 --> 01:06:36.519

And he wrote that article in the early 1990s.

01:06:37.118 --> 01:06:39.118

It is his definition

01:06:39.262 --> 01:06:46.262

It is helpful to define the edges of supported living by saying as clearly as possible what it is not.

01:06:47.699 --> 01:06:53.699

And on the right side, you'll see a whole... a whole big circle of things that supported living is not.

01:06:54.429 --> 01:07:00.429

And if we read some of those, which... they're a little bit small, so I'm gonna read a couple of them to you.

01:07:01.694 --> 01:07:05.694

Um, some examples of what supported living is not.

01:07:06.669 --> 01:07:10.669

It's not a program to fix someone or change someone.

01:07:10.960 --> 01:07:16.960

It's not, um, being isolated or being lonely because you are on your own.

01:07:17.149 --> 01:07:19.149

or bored.

01:07:20.012 --> 01:07:24.012

Um, it's a test. Uh, it's not a test to see if you can live

01:07:24.149 --> 01:07:26.149

With no problems.

01:07:27.472 --> 01:07:29.472

It's just getting an apartment?

01:07:29.939 --> 01:07:32.939

to live in? That's not supported living.

01:07:32.939 --> 01:07:36.066

It's not a set of uniform requirements.

01:07:36.100 --> 01:07:43.100

and procedures. It's not compatible with services and congregate... that are congregate and control people.

01:07:43.673 --> 01:07:45.673

But what is supported living?

01:07:45.886 --> 01:07:47.886

If you look in the center there,

01:07:47.887 --> 01:07:54.111

It's a focus, and it's... and it really clarifies what we all need as people.

01:07:55.083 --> 01:08:00.083

Not just individuals with disabilities. We all need a supported life. We need a church.

01:08:00.401 --> 01:08:03.401

We need, uh, if we're faith-based, we need,

01:08:03.593 --> 01:08:13.593

Um, members that live near us that can support us in case of an emergency, a neighbor that has my key to open the door if I get locked out. Those kinds of things.

01:08:14.424 --> 01:08:16.424

So John O'Brien says it is a safe

01:08:16.607 --> 01:08:20.607

And decent home of your choice, with personalized assistance,

01:08:21.390 --> 01:08:24.390

Support from others who care about you and respect you.

01:08:26.163 --> 01:08:34.163

And if we look at what supported living really is, it's dignity and choice and equity, where you move from...

01:08:34.163 --> 01:08:44.266

Being isolated, out into the community, and you can be spread apart. You can... there can be multiple places to go, multiple landlords, you could be...

01:08:45.079 --> 01:08:50.079

in control of your life. Those are the kinds of things that we know supported living is about.

01:08:52.917 --> 01:08:56.917

These guys needed a flexible and innovative supported living model.

01:08:58.111 --> 01:09:00.111

With just a dollop of everything.

01:09:01.040 --> 01:09:03.040

some dreaming, some fun choices,

01:09:03.274 --> 01:09:08.274

Some routines, friendships, outings, working, community.

01:09:09.691 --> 01:09:11.691

This is Rachel in the middle.

01:09:12.029 --> 01:09:14.029

And Ashley on the right.

01:09:14.335 --> 01:09:16.335

And they're, um...

01:09:16.282 --> 01:09:21.282

third roommate that was added a year after they moved in together, and her name is Ruth.

01:09:21.567 --> 01:09:24.567

Ruth likes the Where's Waldo costume.

01:09:27.758 --> 01:09:30.758

So, of course, as the girls, um,

01:09:31.028 --> 01:09:39.028

developed, uh, they began to understand what you all have done such a wonderful job of doing, which is advocating for yourself.

01:09:39.658 --> 01:09:45.658

Rachel, um, has shared some of the things that she likes to do in the recent Speak Up, Speak Out.

01:09:46.675 --> 01:09:52.675

Um, event, uh, all three of the girls presented there on how to create your own

01:09:53.132 --> 01:09:55.132

your own, uh, micro-business.

01:09:56.186 --> 01:10:00.186

And one of the things that Rachel liked to do was to make plans.

01:10:00.588 --> 01:10:02.588

Um, to have, uh,

01:10:04.367 --> 01:10:06.367

I'm blocked from reading my own screen, sorry.

01:10:06.786 --> 01:10:11.786

to search for recipes, for trying out new foods.

01:10:11.929 --> 01:10:15.929

Um, she talked about looking for pictures of foods that she could cook.

01:10:15.929 --> 01:10:19.112

finding new desserts, sharing with family and friends.

01:10:19.628 --> 01:10:21.628
And... Ruth...

01:10:21.707 --> 01:10:23.707
also spoke.

01:10:24.687 --> 01:10:26.687
She likes to test out new recipes.

01:10:27.596 --> 01:10:33.596
She likes to take cookbooks to places to sell them. They published a cookbook with the help of our support team.

01:10:34.557 --> 01:10:40.557
Uh, Ruth likes to travel, and they, uh, also like to take business trips together.

01:10:43.815 --> 01:10:45.815
They wanted to start their own business.

01:10:45.815 --> 01:10:48.585
And with our staff, they did just that.

01:10:48.966 --> 01:10:54.966
Um, if you happen to be in the Naperville area, they're doing an open house in the month of

01:10:54.967 --> 01:11:00.681
Three open houses in the month of November, so that folks can come and see what supported living

01:11:01.333 --> 01:11:04.333
looks like, and they're selling their merchandise there.

01:11:07.286 --> 01:11:09.286
Supported living is doing all of these things.

01:11:10.069 --> 01:11:12.069
It's advocating to live your life, which...

01:11:12.431 --> 01:11:16.431
I am so pleased to see all of you folks doing so beautifully.

01:11:16.952 --> 01:11:21.952
Um, on the bottom right, the girls were in a march to...

01:11:22.896 --> 01:11:24.896
Um, fight against the cuts in Medicaid.

01:11:24.897 --> 01:11:32.992
On the bottom left, the girls did a video for, uh, Rev Up Illinois, encouraging all folks with disabilities to vote.

01:11:33.846 --> 01:11:38.846

And in the top, um, they were honored by our representative, Janet Yang Rohrer,

01:11:38.847 --> 01:11:47.944

for the work they are doing, um, as a micro-business, and that Illinois is in support of folks with disabilities starting their own businesses.

01:11:51.484 --> 01:11:54.484

Life at the 209 home, which is what we call where they live,

01:11:54.618 --> 01:11:56.618

It jump-started change.

01:11:57.175 --> 01:12:03.175

So, in 2023, um, several of us family members and our folks with disabilities

01:12:03.939 --> 01:12:06.939

came together and created something called the Creative Housing Network.

01:12:07.369 --> 01:12:12.369

Um, families led the initiative to make some changes.

01:12:12.452 --> 01:12:16.452

in Illinois, I wrote a letter to Governor Pritzker.

01:12:16.430 --> 01:12:24.430

An 11-page letter, um, which had lots of great statistics in it about what we're not doing in Illinois.

01:12:24.606 --> 01:12:27.606

And lo and behold, I got a call.

01:12:28.399 --> 01:12:32.399

From the tall gentleman in the back there, his name is Ryan Croak.

01:12:33.260 --> 01:12:35.260

Uh, not in the back of the room, on the screen.

01:12:37.192 --> 01:12:44.192

That's so cute. Um, yeah, so Ryan Croak, as Governor Pritzker's Senior Advisor on Disability Services,

01:12:44.492 --> 01:12:50.492

And he is also a deputy to Grace Howe, who is Secretary of Grace Howe standing next to him in the picture.

01:12:51.129 --> 01:12:56.129

And then you have, uh, the director of the Division of Developmental Disabilities on the right, Tanya.

01:12:56.105 --> 01:12:58.105

Um, PHOF.

01:12:59.052 --> 01:13:05.052
all of these folks joined us as we, um, initiated a strategic planning meeting,

01:13:05.052 --> 01:13:08.367
And, um, Vicki was also there, and Lynn.

01:13:08.435 --> 01:13:13.435
And we talked about what needs to change in Illinois.

01:13:13.778 --> 01:13:18.778
Um, together, this incredible group of about 70 folks

01:13:19.301 --> 01:13:22.301
a variety of individuals with disabilities joined us.

01:13:22.611 --> 01:13:25.611
um, families, we had allies, we had

01:13:25.945 --> 01:13:27.945
people from the administration, we had...

01:13:27.946 --> 01:13:29.936
just all the right people.

01:13:29.935 --> 01:13:34.209
Together, we established something called the

01:13:34.534 --> 01:13:36.534
North Star Plan.

01:13:36.817 --> 01:13:40.817
And in the North Star plan, the first goal was to develop

01:13:41.517 --> 01:13:43.517
a coalition.

01:13:43.717 --> 01:13:45.717
to help move forward

01:13:46.235 --> 01:13:49.235
the ideas that were presented.

01:13:49.351 --> 01:13:51.351
for folks with disabilities to live

01:13:51.629 --> 01:13:53.629
better lives in Illinois.

01:13:55.907 --> 01:14:01.907
And so, we were given a grant by the Coleman Foundation to begin Engage Illinois.

01:14:01.907 --> 01:14:08.568

Our vision is that individuals with disabilities design lives in the communities of their choice.

01:14:10.740 --> 01:14:16.740

The mission? Uniting individuals and family voices for equity, dignity, and choice.

01:14:17.248 --> 01:14:19.248

Equity, meaning...

01:14:19.882 --> 01:14:25.882

We need to distribute the funding that is available for folks with disabilities across

01:14:26.396 --> 01:14:28.396

all folks with disabilities.

01:14:29.132 --> 01:14:33.132

not just some, or more to some and less to others.

01:14:33.416 --> 01:14:38.416

And we needed, based on their needs, not just a stipend, which we'll see.

01:14:38.615 --> 01:14:40.615

A little bit of history here.

01:14:40.786 --> 01:14:47.786

The federal government developed institutions to educate people with disabilities to become productive.

01:14:48.474 --> 01:14:51.474

Members of, of, um, society.

01:14:52.054 --> 01:14:54.054

over the years, excuse me.

01:14:55.049 --> 01:14:57.049

Um, the institutions...

01:14:58.018 --> 01:15:00.018

I might as well go back so that you can see what I'm seeing.

01:15:01.106 --> 01:15:03.106

Or not? Or not.

01:15:03.268 --> 01:15:07.268

Um, huh? If you're going back, can you stay up there.

01:15:07.361 --> 01:15:09.361

The up arrow? Uh-huh.

01:15:10.625 --> 01:15:12.625

Mine doesn't want to do anything. Meh.

01:15:16.126 --> 01:15:18.126
Thank you, thank you, thank you.

01:15:18.690 --> 01:15:25.690
Um, over the years, institutions shifted from education to custodial services.

01:15:26.050 --> 01:15:29.050
And they functioned as the medical model.

01:15:29.585 --> 01:15:35.585
Um, where people were getting care in congregate settings. And that's kind of where we got stuck.

01:15:39.552 --> 01:15:46.552
Illinois compared to other states, we know there's a disproportionate amount of allocated money going to bricks and mortar.

01:15:47.395 --> 01:15:53.395
in Illinois, not to the services in the community. Illinois still has 7 institutions.

01:15:54.685 --> 01:16:00.685
Um, and the institutions are the default placement in Illinois. So, as we saw with Ashley,

01:16:01.578 --> 01:16:05.578
If... if... thank you very much. Goodbye, everybody over there.

01:16:06.216 --> 01:16:15.216
Thank you. Um, that if you... if you are in crisis and don't have someplace else to go, the institution is what is funded federally.

01:16:15.365 --> 01:16:18.365
And so, in Illinois, that's the way it works.

01:16:20.698 --> 01:16:30.698
Um, this shows you a little bit about the funding models that we currently have. Obviously, the federally funded default being on the left, the institutions, and um...

01:16:31.152 --> 01:16:34.152
And ICFDDs are the Intermediate Care Facilities.

01:16:35.271 --> 01:16:40.271
Uh, in the middle, we have the waiver programs, which we're all familiar with, um, Box A, Scylla.

01:16:40.316 --> 01:16:43.316
Group Homes, or Box B home-based program.

01:16:44.100 --> 01:16:47.100
What we're... what we're looking for is

01:16:47.100 --> 01:16:56.250

more progressive options, something more, um, supported, like supported living in the community. We don't really have a name for it yet.

01:16:56.689 --> 01:17:00.689

Um, some folks would like to say, hey, let's start a whole new waiver.

01:17:01.271 --> 01:17:07.271

We don't know that that's necessarily the way to go, but we know for sure that we need more flexibility.

01:17:09.007 --> 01:17:15.007

Um, the federally funded models, this is what's interesting when we talk about equity.

01:17:15.007 --> 01:17:20.344

The federally funded models, where individuals go into developmental centers

01:17:20.921 --> 01:17:25.921

Each person costs the federal government \$350,000.

01:17:27.031 --> 01:17:30.031

If they go into an intermediate care facility,

01:17:30.031 --> 01:17:35.337

The annual cost is \$150,000 approximately per person.

01:17:37.283 --> 01:17:42.283

Then we look at the waiver programs. Um, I know we have, uh, some providers that,

01:17:42.260 --> 01:17:44.260

are here, and we know that

01:17:44.823 --> 01:17:54.823

Uh, this model, uh, this community integrated living arrangement was established in 1981, and the model has not really changed much.

01:17:55.343 --> 01:18:00.343

in 40 years. So, it's needs-based, but it's not person-centered.

01:18:01.297 --> 01:18:07.297

Group homes are run by licensed providers, and the estimated average annual cost is

01:18:07.444 --> 01:18:12.444

Um, on the bell curve, right in the middle there, 80 to 100,000.

01:18:12.578 --> 01:18:15.578

higher needs individuals obviously cost more.

01:18:16.279 --> 01:18:18.279

And those with lower needs, um,

01:18:19.231 --> 01:18:21.231
are funded for less money.

01:18:21.536 --> 01:18:25.536
Rules and regulations have also not been updated for about 40 years.

01:18:26.843 --> 01:18:36.843
The home-based program, which we're all familiar with here, is a stipend of 3 times SSI, approximately \$34,000 a year.

01:18:36.843 --> 01:18:38.822
So, over here...

01:18:38.822 --> 01:18:44.774
And over here. What we see is, it's not equitable. It's not based on need.

01:18:45.156 --> 01:18:50.156
Um, in the home-based program, and that is something that is a serious problem.

01:18:50.828 --> 01:18:58.828
And especially because we see that right now, 80% of our families are selecting home-based.

01:18:59.565 --> 01:19:01.565
They're selecting home-based because

01:19:02.479 --> 01:19:05.479
There's not a lot of capacity for other options.

01:19:06.108 --> 01:19:10.108
They're also selecting home-based because they want more flexibility.

01:19:10.507 --> 01:19:12.507
Um, and so...

01:19:12.336 --> 01:19:17.336
With that happening, if we don't find ways for families to...

01:19:18.085 --> 01:19:34.085
Find a sustainable solution as we age to help our loved ones to be sustained in community. We're going to have, and are already seeing, some severe problems with capacity, with places for folks to live.

01:19:34.469 --> 01:19:37.469
And many folks are moving back in with families.

01:19:38.251 --> 01:19:42.251
Um, and when parents die, we know where the default is.

01:19:45.708 --> 01:19:53.708

So we're advocating for more flexibility, uh, for more personalized programs, and this... this slide shows the comparison.

01:19:54.658 --> 01:20:00.658

between a home-based program, which currently has case management provided by

01:20:00.843 --> 01:20:02.843

the individual

01:20:03.896 --> 01:20:08.896

Service Coordinator, your caseworker. Um, they have large loads, caseloads.

01:20:08.896 --> 01:20:15.053

Our... we met with our case manager yesterday, and she has 60 people on her caseload.

01:20:15.314 --> 01:20:17.314

That's an awful lot of people.

01:20:18.021 --> 01:20:26.021

Um, meetings are usually once a quarter, personal support workers are generally family members, or individuals can be hired.

01:20:26.021 --> 01:20:37.706

But again, difficult to find good folks. Um, and the monthly allotment of \$2,900 provides about 4 to 6 hours of support a day for 5 days a week.

01:20:38.483 --> 01:20:41.483

A new program. This is... this is what...

01:20:42.891 --> 01:20:49.891

Well, there you go. If you can spend it, that's a good point. I don't have to put that one in there.

01:20:50.319 --> 01:20:53.319

Um, I'm... I'm sorry.

01:20:53.657 --> 01:20:55.657

can't read the right side of my screen.

01:20:55.878 --> 01:20:58.878

Um, a new program would include

01:20:58.878 --> 01:21:01.896

robust wraparound services.

01:21:02.313 --> 01:21:05.313

Um, and it would be based, again, on...

01:21:05.790 --> 01:21:10.790

the person's needs, that we could actually implement what we write.

01:21:11.701 --> 01:21:19.701

in the plans. Wouldn't that be wonderful? That we allow and encourage our folks with disabilities to dream big.

01:21:20.430 --> 01:21:27.430

to think about what their interests and where they want to go, and what they want to do, but yet we can't really implement all of those things.

01:21:28.412 --> 01:21:32.412

Um, and also, being able to find and hire.

01:21:33.132 --> 01:21:37.132

Personal support workers as part of the case management. So important.

01:21:38.263 --> 01:21:40.263

A new program should be needs-based.

01:21:40.551 --> 01:21:45.551

And considerable multiple times throughout the day when support is required.

01:21:45.966 --> 01:21:50.966

So it shouldn't be just a couple of hours here and there. It should be across the day.

01:21:52.518 --> 01:21:58.518

Um, transportation, these are the services that are available on Homebase. Transportation.

01:21:59.345 --> 01:22:05.345

Nursing, emergency and employment support all have to come from the same monthly allotment.

01:22:05.543 --> 01:22:13.543

There's no funding available for flexible programming during the day. Nobody can go to a, you know, an SRA special rec

01:22:14.315 --> 01:22:17.315

program and get that paid for, or a YMCA and get that paid for.

01:22:18.385 --> 01:22:24.385

There's none of that. It's all self-directed, but only... you can only do so much.

01:22:24.692 --> 01:22:28.692

A new program would allow for more flexibility,

01:22:29.461 --> 01:22:34.461

It would be needs-based as, uh, part of the overall needs-based funding program.

01:22:34.519 --> 01:22:37.519

Individuals could be able to choose.

01:22:38.222 --> 01:22:43.222

choice, what they want, the activities they want, in the community, what they want.

01:22:43.727 --> 01:22:45.727

classes they want to take.

01:22:46.536 --> 01:22:48.536

what they want to attend, where, and when.

01:22:50.099 --> 01:22:53.099

So we need a strong parent voice, and the current

01:22:53.544 --> 01:22:57.544

strongest unified voice is in opposition.

01:22:57.665 --> 01:23:02.665

moving away from... of moving away from institutional and congregate settings.

01:23:02.907 --> 01:23:10.907

Which is the most expensive option. They're in opposition for a variety of reasons. Fear probably being one of the biggest.

01:23:11.412 --> 01:23:13.412

Because families don't know what to expect.

01:23:13.522 --> 01:23:18.522

If their loved one were to move out of an institution, they don't know what

01:23:18.671 --> 01:23:23.671

that other option is. We don't have a good other option in some ways.

01:23:24.508 --> 01:23:29.508

Um, so we need to advocate with louder voices for community-based programs that

01:23:29.918 --> 01:23:32.918

yield evidence-based positive outcomes.

01:23:34.130 --> 01:23:41.130

We need a strong family voice in Springfield, representing the demand for better community-based options.

01:23:42.759 --> 01:23:45.759

And we need thousands of voters.

01:23:45.839 --> 01:23:51.839

We need everyone to come to the governor's office together, and if we can raise our voices together,

01:23:52.162 --> 01:23:54.162

We can make some changes.

01:23:56.375 --> 01:23:58.375
Together, we have the power.

01:23:59.311 --> 01:24:01.311
Um, to create equity, dignity, and choice.

01:24:02.268 --> 01:24:06.268
Sometimes, the path that we have to take is not the easiest path.

01:24:07.512 --> 01:24:09.512
But what we do know is it's the right path.

01:24:11.113 --> 01:24:14.113
And so, I would ask you to join us.

01:24:14.969 --> 01:24:20.969
Um, you can join us at no cost. Uh, we are all volunteered.

01:24:21.910 --> 01:24:25.910
Certainly, if there's someone who would like to donate any money so that we can...

01:24:26.768 --> 01:24:31.768
travel and do these kinds of talks and expand the reach.

01:24:32.028 --> 01:24:38.028
were thrilled, and of course, if you have anyone that you would like to network,

01:24:38.222 --> 01:24:47.222
us too, so that we can go and spread the word. Or, if anyone would like to... I'm gonna... I'm gonna open it up to you in one second, Jen.

01:24:47.432 --> 01:24:53.432
Thank you. On page 30 are the QR codes that you see up on the screen.

01:24:53.562 --> 01:24:56.562
You can, um, scan with your phone and

01:24:56.519 --> 01:25:05.519
put your name in, and then we can take those names to the governor and say, look at all these folks that want something more.

01:25:05.856 --> 01:25:07.856
So please join us.

01:25:07.856 --> 01:25:10.003
Yes, Jen.

01:25:10.585 --> 01:25:17.585
Yes, um, to go to Springfield, like you say, so I don't think even enough, like, organizations, like,

01:25:18.990 --> 01:25:21.990

Um, to have enough money to fund to go.

01:25:21.990 --> 01:25:24.843

And to drive, you know, or...

01:25:25.547 --> 01:25:29.547

To take people with disabilities to carpool, to even have the money.

01:25:30.312 --> 01:25:34.312

To do that, to go up there... And use your voice.

01:25:34.522 --> 01:25:38.522

So, yeah, that's right, so enough, that's why I've asked, um,

01:25:39.182 --> 01:25:45.182

pace a long time ago that when they had, but now they don't have the funds anymore. When people...

01:25:45.411 --> 01:25:48.411

don't have enough funding and the time,

01:25:48.688 --> 01:25:50.688

to go up there and...

01:25:50.682 --> 01:25:55.682

take people, I mean, up there to get enough funds to drive people

01:25:55.790 --> 01:26:00.790

And to do those, speak up, speak out, going home, rallies, um...

01:26:01.342 --> 01:26:03.342

all kinds. It would...

01:26:04.203 --> 01:26:08.203

This is where we're talking about, like, a lot of people... we know it...

01:26:09.529 --> 01:26:14.529

It costs money, yeah, for people wanting to be reimbursed for gas, and for...

01:26:14.444 --> 01:26:16.444

a lot to drive.

01:26:16.582 --> 01:26:20.582

So, that's where it's going...

01:26:20.692 --> 01:26:22.692

to cost, but I know, um...

01:26:23.988 --> 01:26:31.988

Uh, if you also wanna ask, um, Center for Independent Living, located in Lincoln Square on the second floor.

01:26:32.806 --> 01:26:34.806

Um, I'm sure they would...

01:26:35.014 --> 01:26:37.014

be happy to, to, um...

01:26:37.971 --> 01:26:41.971

do this too, I mean, because they have... What about us together?

01:26:43.256 --> 01:26:47.256

They would do. They got an advocacy group for people with disabilities. There you go.

01:26:47.618 --> 01:26:51.618

And they... and... which Armen involved that meets once.

01:26:52.717 --> 01:26:54.717

a month, usually on the...

01:26:55.612 --> 01:26:58.612

First Wednesday of the month, so, um...

01:26:58.825 --> 01:27:00.825

If you ever, um...

01:27:02.029 --> 01:27:05.029

Warren, you can, uh, call, I can ask for...

01:27:05.720 --> 01:27:09.720

Probably, uh, Mel, and she would be happy, or...

01:27:09.807 --> 01:27:12.807

to arrange a time for...

01:27:13.862 --> 01:27:23.862

is, um, they do it hard work. They talk to people? Yeah, to go online, it's a hybrid. You can go online or come in person, like you do tonight. They have their meetings, you know.

01:27:23.861 --> 01:27:27.791

So... That's a great, a great referral. Thank you, Jen. Thank you.

01:27:28.462 --> 01:27:34.462

It's a great suggestion. Um, I know that, uh, this is probably later than you typically go. Is this later?

01:27:34.853 --> 01:27:36.853

I see tired people.

01:27:37.448 --> 01:27:44.448

Um, so I don't want to belabor the time. Um, if there are any burning questions, feel free to ask, or

01:27:44.732 --> 01:27:49.732

Uh, email me, you certainly have my contact information there, and um...

01:27:49.737 --> 01:27:51.737

Please join us.

01:27:52.539 --> 01:27:57.539

I feel that this is something that, uh, is important for both agencies,

01:27:57.683 --> 01:28:02.683

providers, we have lots of allies up by us, um,

01:28:02.738 --> 01:28:08.738

What's important is that the agencies and the providers are the ones that are going to help us.

01:28:09.422 --> 01:28:16.422

They're going to provide those services in terms of supports, and we need to collaborate and team

01:28:16.326 --> 01:28:18.326

Because together,

01:28:18.806 --> 01:28:20.806

were better. Alone.

01:28:21.262 --> 01:28:23.262

We can't accomplish much.

01:28:23.482 --> 01:28:25.482

Helen Keller said it so well.

01:28:26.257 --> 01:28:28.257

Thank you very much, everyone.

01:28:33.329 --> 01:28:37.329

Uh, it... it should be, could be, but I have cards.

01:28:38.408 --> 01:28:40.408

It should be, could be?

01:28:41.753 --> 01:28:44.753

We will find a way to provide the contact info.

01:28:44.577 --> 01:28:46.577

Um, I do have...

01:28:47.821 --> 01:28:49.821

I did remember to pick cards.

01:28:50.016 --> 01:28:52.016

So, please.

01:28:53.645 --> 01:28:58.645

Yeah, no, I'll just get a safety strategy.

01:28:59.091 --> 01:29:01.091

Thank you, and I'm so sorry that everyone was so...

01:29:01.798 --> 01:29:03.798

Here so late. It's totally true.

01:29:06.112 --> 01:29:13.112

We have our... we have had a few meetings that have gone longer than this recently, so we... we have... we have done that, but um...

01:29:14.126 --> 01:29:19.126

Are there any questions from board members or anyone else, um,

01:29:19.824 --> 01:29:21.824

For our presenter.

01:29:22.782 --> 01:29:28.782

Oh, you know, there's, uh... you talk about supportive living, you know, to what you said.

01:29:29.333 --> 01:29:33.333

But you have, like, the eating supporter of living, but it's not what you...

01:29:34.167 --> 01:29:39.167

you know, set up there. What they think versus what you think are two different...

01:29:40.999 --> 01:29:44.999

And if they call... people call themselves as a supportive living, or...

01:29:45.755 --> 01:29:55.755

You make a really... you make a really good point, and something that we are working on is helping people to understand the difference between supportive

01:29:56.398 --> 01:29:59.398

housing and support ed living.

01:29:59.737 --> 01:30:06.737

supportive housing is what you see those large apartment buildings with some help with services on-site.

01:30:06.983 --> 01:30:13.983

And folks have their own apartments, and maybe they're mixed-use apartments, so you have some folks with disabilities, some seniors.

01:30:13.984 --> 01:30:19.027

Some of those... that typically started from people who were unhomed.

01:30:19.027 --> 01:30:24.247

So, it was intended originally as an affordable living option.

01:30:24.842 --> 01:30:30.842

But it has morphed into other things, actually, and the definition is very, very cloudy.

01:30:31.559 --> 01:30:34.559

supported living is not about bricks and mortar.

01:30:35.421 --> 01:30:44.421

It's only about services. And you could take those services with you wherever you go. You could live in an apartment and get supported services, you can...

01:30:44.982 --> 01:30:59.982

rent a house. You can rent an apartment. You can own a condo. You can live with your friends, or you can live alone. It's how you get those services, so it's not about the bricks and mortar, it's about the service.

01:31:00.615 --> 01:31:02.615

Thanks for asking that question.

01:31:03.783 --> 01:31:05.783

Anybody else?

01:31:08.195 --> 01:31:14.195

Yes, ma'am. I'm just gonna repeat how very, very important for the 80% or 70% of

01:31:14.835 --> 01:31:17.835

People who default into home base. Homebase is...

01:31:18.774 --> 01:31:22.774

minimally successful for many families, and it's minimally successful

01:31:22.834 --> 01:31:28.834

Because the agencies that are SDA, state-designated agencies, they're wonderful,

01:31:28.834 --> 01:31:32.807

In terms of their caring and desire to help.

01:31:33.084 --> 01:31:38.084

They are not able, at this point, to help identify PSWs

01:31:38.318 --> 01:31:45.318

Yeah, that's so true. And more than process the paperwork, and it takes a month to process the paperwork. It's not their fault.

01:31:46.508 --> 01:31:55.508

But you can lose PSWs in the month that it takes to be... That's a good point. ...approved, you know, get your fingerprints taken, pay for some of this stuff.

01:31:56.128 --> 01:31:58.128

And then it's entirely up

01:31:58.344 --> 01:32:00.344
to the family,

01:32:00.685 --> 01:32:04.685
To train the PSW. Yeah. And to monitor the PSW.

01:32:05.083 --> 01:32:15.083
Yeah, and those are the things that we need to bring voice to when it comes to creating a new program. We need a program that addresses that.

01:32:15.083 --> 01:32:23.427
You know, how do we find support workers if it's a self-directed program? And the self-direction gives you the flexibility

01:32:23.607 --> 01:32:27.607
But it doesn't give you the help that you need in finding staffing.

01:32:28.363 --> 01:32:37.363
Uh, I have been very, very fortunate in finding the folks that we have at the home where the girls live. We have, um,

01:32:38.372 --> 01:32:40.372
3.5 people.

01:32:40.430 --> 01:32:48.430
Um, and the home is staffed 24-7. It, uh, I manage it, so it's not... it's a family-managed...

01:32:49.207 --> 01:32:54.207
um, home, I do payroll. It's not easily replicable for most folks.

01:32:54.858 --> 01:32:58.858
So we need something like what we're doing that's a hybrid.

01:32:59.075 --> 01:33:02.075
That is... it could be self-directed,

01:33:02.460 --> 01:33:09.460
If people are so inclined, but it... hopefully, it could be either. You know, if you need help from an agency,

01:33:10.139 --> 01:33:17.139
then you need help from an agency. I mean, when I die, my husband says, I don't know who's gonna do all this stuff that you're doing.

01:33:17.139 --> 01:33:23.614
payroll. He says, I'm not gonna do that. So, we don't have a sustainable solution, even though we have a fairly...

01:33:23.891 --> 01:33:26.891
cool situation for the girls.

01:33:26.891 --> 01:33:31.872

it's just not sustainable. We need to get our voices really, really loud.

01:33:32.723 --> 01:33:34.723

And any help that we can get.

01:33:34.767 --> 01:33:36.767

from everyone

01:33:38.153 --> 01:33:40.153

who we affiliate with is important.

01:33:41.186 --> 01:33:48.186

Thanks for bringing that up. Home-based was, uh, according to Director Pihoff, who I've had many conversations with now,

01:33:49.195 --> 01:33:52.195

Home-based was originally intended as an interim.

01:33:53.449 --> 01:33:56.449

It was not intended as the main choice.

01:33:56.492 --> 01:34:03.492

But it has shifted to the main choice, and so it leads people to believe that

01:34:03.961 --> 01:34:14.961

you know, Illinois is doing so good, look at all the people taking home-based. We should, you know, get off of the Ligus consent decree, because we're servicing all the people. When that's really not the case.

01:34:16.022 --> 01:34:19.022

Folks are taking it because they don't have a lot of other choice.

01:34:22.194 --> 01:34:27.194

Um, so last year, when we did another study session like this, um,

01:34:27.844 --> 01:34:34.844

you know, there were some things brought up by our advocates, and I said, you know, legislation, legislation, legislation.

01:34:34.845 --> 01:34:40.357

And, um, I'm so thankful I got to meet you tonight, Sharon. Um, as I said earlier, I have a

01:34:40.422 --> 01:34:43.422

Um, sister, who is, what, 44?

01:34:43.503 --> 01:34:45.503

I have a dad who's 7

01:34:46.246 --> 01:34:50.246

Um, so I am working my darndest to plan ahead for the future.

01:34:50.243 --> 01:34:52.243
But pretty much, I'm being told

01:34:52.289 --> 01:34:58.289
When you have a crisis, we'll be happy to help you. I cannot get her approved for disability, because she's still choosing to work.

01:34:59.381 --> 01:35:01.381
And I'm like, what?

01:35:01.979 --> 01:35:03.979
I know people in disability who are far...

01:35:03.979 --> 01:35:06.247
better off than my sister. And so...

01:35:06.817 --> 01:35:15.817
Um, maybe I need to help become one of those voices, because I like to talk, so... I would love that. So maybe you and I... and maybe you can...

01:35:16.003 --> 01:35:18.003
um, direct me, but, um...

01:35:19.158 --> 01:35:22.158
Again, there's so much going on in this world, but in this state,

01:35:22.736 --> 01:35:28.736
And again, sometimes we have to be the squeaky wheel to these legislators, and I was so thankful that Chapin Rose was here tonight.

01:35:28.811 --> 01:35:33.811
Um, I totally respect him, that this is family and God Night.

01:35:34.528 --> 01:35:38.528
Um, but believe me, his name is on my list to also say, hey.

01:35:39.439 --> 01:35:50.439
I want to partner with you. Are you willing to listen? Now, granted, my sister's in Iroquois County, but you know what? She's in the state of Illinois. Right. Yep. And I appreciate you bringing up the legislative piece.

01:35:51.260 --> 01:35:56.260
Um, one of our counterparts, um, on the steering committee for Engage Illinois, her name is Susan Mack,

01:35:56.644 --> 01:36:02.644
And she has met with, um, we're probably talking about 25 or so legislators.

01:36:03.105 --> 01:36:07.105
Um, uh, from the House of Representatives and Senators.

01:36:08.026 --> 01:36:10.026

Um, and what we're finding is

01:36:10.219 --> 01:36:16.219

They're saying, let's see if you can do this through the division. If you can get these changes

01:36:16.480 --> 01:36:20.480

you know, get them interested in helping to make these changes.

01:36:20.559 --> 01:36:26.559

And we'll stand behind you. We have lots of legislators saying they will stand behind Engage Illinois.

01:36:26.995 --> 01:36:36.995

So, as we... as we grow our coalition, that's the most important thing right now, is to grow the coalition so that we can come up and say, hey,

01:36:38.166 --> 01:36:43.166

You know, we're representing a huge portion. We know that on home-based alone,

01:36:43.166 --> 01:36:51.829

There are over 12,000 people that are on home-based. There's another 11,000 that are on, um, in Silis, in group homes.

01:36:51.829 --> 01:37:07.069

And then there are 16,000 on the puns list. So, why should those that have folks in, um, state-operated developmental centers have a louder voice than those of us who have larger numbers?

01:37:07.452 --> 01:37:10.452

So, let's even the playing field.

01:37:11.379 --> 01:37:17.379

You know, they didn't even include in a GuideHouse study for rates in the state of Illinois. They did not even include

01:37:17.974 --> 01:37:23.974

home-based. They only included the rates that are affiliated with, um,

01:37:23.974 --> 01:37:27.101

the providers. So, we have...

01:37:27.097 --> 01:37:31.097

a stipend, \$34,000 that, you know,

01:37:31.644 --> 01:37:37.644

Who can live on \$34,000? Not that we want the state to support everything, but let's do it equitably.

01:37:38.682 --> 01:37:43.682

You know, if we have a bucket of money, let's make sure that we're spreading that bucket out.

01:37:44.223 --> 01:37:46.223
Based on need across all folks.

01:37:47.815 --> 01:37:52.815
thinks I... I... I just... I wanted to make a really quick comment, just to affirm

01:37:52.816 --> 01:38:02.649
The strategy of... this is actually about numbers right now. The more people who are filing witness slips, the more... the longer the list of names

01:38:03.179 --> 01:38:08.179
that you can claim, support these ideas, that's really gonna matter. I mean, this is... I...

01:38:09.254 --> 01:38:11.254
you know, I don't like to bring up politics, but

01:38:11.910 --> 01:38:17.910
This is actually in the state of Illinois, there is such a big political interest

01:38:17.910 --> 01:38:20.636
Behind maintaining the large institutions.

01:38:20.819 --> 01:38:27.819
And, right, and like, I think everybody who knows the right thing to do is the community-based services, but unless there are, like,

01:38:27.819 --> 01:38:33.939
High numbers of witness slips, and these are easy things to do. The conversation about changing the...

01:38:34.917 --> 01:38:38.917
rules, changing the service categories, which are funded through Medicaid waivers,

01:38:38.917 --> 01:38:44.315
That's different. I think that you're right, what you just said about legislators are ready, as long as...

01:38:44.801 --> 01:38:50.801
State agency staff have the time and the support to do those redesigns. I think this is...

01:38:51.468 --> 01:38:59.468
That part is ready, it's just, you need a long list of people now. We have very... a very receptive administration right now.

01:39:00.245 --> 01:39:07.245
And we need to take advantage of that opportunity. Um, we have receptive folks in the Division of Developmental Disabilities.

01:39:07.738 --> 01:39:13.738

You know, we have lots of folks, allies, including, you know, county boards, that

01:39:14.381 --> 01:39:23.381

We're speaking to county boards, we're speaking to, um, Centers for independent living, we're talking to the boards, uh, directors of all of the SILs.

01:39:23.629 --> 01:39:32.629

So, people are receptive. We just need to... I think what's happened over the years is there have been siloed groups of

01:39:33.183 --> 01:39:39.183

Advocacy organizations. In many states, those all come together under one

01:39:40.104 --> 01:39:42.104

People's Choice type group.

01:39:42.103 --> 01:39:51.167

Illinois does not have that. We have the Arc of Illinois, which does a wonderful job of educating folks and helping to understand

01:39:51.957 --> 01:40:01.957

This complicated mess that we have here, but the system's broken, and we need to push to get it fixed while the fire is hot.

01:40:01.958 --> 01:40:06.152

Despite the fact that there's going to be cutbacks in federal funding.

01:40:07.022 --> 01:40:11.022

We still have people that need services. I'm sorry, we have to... whether it's

01:40:11.022 --> 01:40:13.223

public-private collaboration,

01:40:13.205 --> 01:40:18.205

County boards can help in some ways. I mean, we need to find ways

01:40:19.282 --> 01:40:22.282

to be innovative and creative with what we have.

01:40:23.193 --> 01:40:25.193

Thank you.

01:40:25.173 --> 01:40:27.173

Thank you, Lynn.

01:40:27.382 --> 01:40:29.382

Any other questions or comments?

01:40:31.352 --> 01:40:33.352

You're right, for the...

01:40:33.660 --> 01:40:39.660

How's... I mean, it's like, but to be able to... for not people to be homeless, I mean...

01:40:39.754 --> 01:40:42.754

That's why people can't afford it, but it's...

01:40:44.364 --> 01:40:46.364

Then, to find...

01:40:46.642 --> 01:40:53.642

to be able to have stuff more affordable, it's for... Absolutely. I mean...

01:40:53.662 --> 01:40:58.662

Her property were the highest in the country for property taxes.

01:40:59.169 --> 01:41:01.169

I think that's one of the reasons...

01:41:01.659 --> 01:41:09.659

why we don't want any... people don't want to buy the housing, then you can't find enough places to rent that's affordable.

01:41:09.812 --> 01:41:11.812

It's... all comes...

01:41:12.474 --> 01:41:17.474

And... utilities are high, but the...

01:41:17.459 --> 01:41:20.459

why he has gone downhill.

01:41:21.147 --> 01:41:23.147

I know a long time ago,

01:41:23.681 --> 01:41:28.681

that it used to cover the air conditioning, but no longer will.

01:41:28.508 --> 01:41:30.508

Now, it's like...

01:41:31.276 --> 01:41:34.276

You need it in the summer, too, not just in the winter. I mean...

01:41:34.808 --> 01:41:36.808

And people...

01:41:36.832 --> 01:41:41.832

that it's, uh, the food prices have gone up, and the SNAP is...

01:41:42.849 --> 01:41:45.849

And they're saying, for people to be able to work,

01:41:47.853 --> 01:41:50.853
And still keep their benefits. That's...

01:41:51.248 --> 01:41:54.248
the main issue to be able to...

01:41:55.160 --> 01:41:58.160
with that, and not to lose or snap.

01:41:58.936 --> 01:42:00.936
And not to lose their other benefits.

01:42:01.636 --> 01:42:04.636
Because SNAP, right now, um...

01:42:04.963 --> 01:42:06.963
Well,

01:42:07.315 --> 01:42:10.315
used to make, uh, you could only work 10 hours

01:42:10.641 --> 01:42:12.641
a week, and still keep...

01:42:12.677 --> 01:42:17.677
your SNAP benefits. Otherwise, if you work more than 10 hours a week,

01:42:18.679 --> 01:42:20.679
You do not qualify for SNAP.

01:42:21.793 --> 01:42:23.793
So, that's...

01:42:24.849 --> 01:42:27.849
that's the deal. When I once had a job.

01:42:28.188 --> 01:42:30.188
I lost my snap.

01:42:31.059 --> 01:42:34.059
And then COVID hit, then you lost that.

01:42:34.059 --> 01:42:36.926
And now, I'm still on Snap, but...

01:42:36.926 --> 01:42:39.105
I'm only getting the minimum. Now, what do you think

01:42:40.015 --> 01:42:42.015
I tell you guys, it's \$20...

01:42:42.015 --> 01:42:44.224
a month, enough for...

01:42:45.437 --> 01:42:50.437

Uh, for food? Obviously not, and that's why a lot of people are...

01:42:52.294 --> 01:42:56.294

I mean, out there needing the daily bread soup kitchen,

01:42:55.996 --> 01:42:57.996

are homeless.

01:42:58.825 --> 01:43:06.825

There's... they don't have enough family members to help them. They need family members, like myself, I would need my help with my mother to help me...

01:43:07.684 --> 01:43:12.684

Depei. It's just, like, you don't... not everybody has all these...

01:43:14.185 --> 01:43:19.185

benefits to help, and then we need the extra help here, too. Bless you.

01:43:20.500 --> 01:43:25.500

to support, and I know people that having mental health issues that...

01:43:25.943 --> 01:43:27.943

I had a friend...

01:43:28.426 --> 01:43:30.426

It once had seizures.

01:43:30.975 --> 01:43:33.975

And when she was... Anne had depression,

01:43:33.973 --> 01:43:37.686

And she was in the psych hospital, and then got moved out.

01:43:37.936 --> 01:43:40.936

And... and was kicked out of Eden.

01:43:40.937 --> 01:43:45.333

Because she was gone so long, and then ended up at Strides.

01:43:45.568 --> 01:43:47.568

They ended up in a hotel.

01:43:47.646 --> 01:43:50.646

And then finally, found a place in Danville.

01:43:50.822 --> 01:43:53.822

It took a long time for her to find...

01:43:54.715 --> 01:43:56.715

affordable place to live.

01:43:57.734 --> 01:44:01.734

This is something that you need, uh... it really...

01:44:01.691 --> 01:44:06.691

It's really important. It is, and your voice has been really important tonight, Jennifer.

01:44:06.974 --> 01:44:11.974

We really appreciate it. I would love... I would love to talk more with you, Jennifer.

01:44:12.963 --> 01:44:14.963

We'll have to exchange numbers. You have mine.

01:44:16.071 --> 01:44:18.071

I'll... I'll get yours if you wouldn't mind.

01:44:21.606 --> 01:44:28.606

All right, well, thank you very, very much. I think, um, we will move on to the next item here.

01:44:29.527 --> 01:44:36.527

I wasn't sure if the staff wanted to share about the results of the CCRPC annual preferences Survey that is available.

01:44:36.621 --> 01:44:39.621

On pages 43 to 87 of the packet.

01:44:40.119 --> 01:44:45.119

Super quick. This is just... this is already in both boards.

01:44:45.801 --> 01:44:51.801

Uh, priorities documents. Some are, like, there's a summary of these data in each of your packets, but

01:44:51.994 --> 01:44:58.994

This is our way of presenting you with the full set of data. They provide this to us every year, it's pretty interesting, I think, so...

01:44:58.995 --> 01:45:01.043

You know, you have it now, and...

01:45:01.198 --> 01:45:03.198

You have the summaries, too.

01:45:09.340 --> 01:45:12.340

Any questions or comments from the board on this?

01:45:15.207 --> 01:45:19.207

boards, I should say. Keep saying board. We're a joint board tonight.

01:45:25.518 --> 01:45:31.518

All right, seeing none, we can move to our second portion of public participation agency input.

01:45:31.901 --> 01:45:36.901

Again, anybody who'd like to speak with us can either approach the podium, fill out a card,

01:45:36.902 --> 01:45:40.990

Um, chat on Zoom or raise your hand on Zoom.

01:45:42.004 --> 01:45:44.004

Um, is there anybody who would like to speak with us now?

01:45:50.256 --> 01:45:56.256

Anyone online? Alright, seeing none, we can next move to board announcements and input. Are there any...

01:45:56.860 --> 01:45:59.860

announcements from board members of either board.

01:46:04.851 --> 01:46:06.851

I did want to share that, um,

01:46:06.850 --> 01:46:19.095

We... the study session I mentioned earlier on October 29th on immigrant and refugee mental health is going to be a joint session with the Developmental Disabilities Board. I just learned, so...

01:46:19.096 --> 01:46:21.235

We are very glad to welcome

01:46:21.355 --> 01:46:26.355

the DDB to that study session and to jointly facilitate that.

01:46:27.383 --> 01:46:29.383

Any other announcements?

01:46:32.768 --> 01:46:38.768

All right, well, with that, we can adjourn. I want to thank everybody for your participation this evening.

01:46:38.965 --> 01:46:40.965

Um, Vicki, any final comments?

01:46:42.181 --> 01:46:50.181

None for me. That's late enough, we should probably just go home, right? It's time to go home, so have a good night, everyone. All right, thank you.