

13:00:09 ROSA PLASENCIA:

13:00:12 Welcome, all.

13:00:15 I am happy to welcome you to our webinar

13:00:18 titled

13:00:19 'Empowering Choice - Exploring
Self-Direction Experiences Among National

13:00:22 Core Indicators Respondents"'.
13:00:23 This is a joint effort of several speakers

13:00:27 and associations.
My name is Rosa Plasencia

13:00:30 .

13:00:31 This webinar was spearheaded by HSRI

13:00:34 (indiscernible)

13:00:35 in memory of our colleague Sarah Taub

13:00:38 .

13:00:41 We have an incredible group of speakers and
I will ask them to introduce themselves.

13:00:48 VALERIE BRADLEY:

13:00:50 Hi, I am Val Bradley.
The president

13:00:52 of

13:00:53 the Human Services Research Institute

13:00:55 .

13:01:04 My (indiscernible) goes back to the 1990s
when we worked on the (unknown name)

13:01:09 demonstration and it has been a passion of
mine ever since, so, welcome.

13:01:14 LINDSAY DUBOIS: Hello, my name is Lindsay
DuBois.

13:01:18 My pronouns are she, her.
I am a middle-aged white woman in my office

13:01:23 and behind me are pictures my children have
drawn.

13:01:27 I am wearing a white shirt and have blonde
hair and glasses. Thank you for joining us.

13:01:34 MOLLY MORRIS: Hello, I am Molly Morris, the vice presidentst

13:01:40 at Applied Self-Direction.

I use she, her pronouns. I am a middle-aged

13:01:44 woman with white, blonde hair

13:01:46 .

13:01:51 I have a black turtleneck on with a floral background. Looking for to talking with

13:01:56 everyone today.

ALICIA BOEHME:

13:01:57 Hi, I am Alicia Boehme

13:01:59 .

13:02:06 I am a white woman with brown hair and brown eyes and I'm sitting in my living room

13:02:13 with a couch and art and piano in the background. Good to see everyone.

13:02:18 CHRISTIAN MORAN:

13:02:28 Good afternoon.

My name is Christian Moran, I am also from

13:02:32 the Wisconsin Department of Health Services

I am a white, middle-aged man with a shaved

13:02:37 head and a beard.

I am wearing a blue sport coat and a white

13:02:42 shirt.

I am in my small, home office. Happy to be

13:02:46 here.

ROSA PLASENCIA: Thank you so much, everyone.

13:02:49 I apologize, I missed my visual description.

I am a middle-aged woman with light,

13:02:54 although skin, wavy hair and a blue

turtleneck. I have a cold today so I am

13:02:59 sorry about that.

Participants will be muted during this

13:03:03 webinar.

Please use the q and a feature in the chat.

13:03:07 Toward the end of the webinar panelists

will be

13:03:10 participants will be able to

13:03:15 ask and have their questions answered.

13:03:17 ,

13:03:17 ..

13:03:18 .

13:03:25 Live Spanish interpretation can be accessed
by clicking the interpretation button at the
13:03:30 bottom of your zoom screen which is the
world icon. (indiscernible) silenced the
13:03:35 original audience (audio issues)

13:03:37 audio.

13:03:38 (Speaks Spanish)

13:03:39 .

13:03:48 Due to a recent Zoom

13:03:50 update,

13:03:53 full accessibility may not work if you are
joining with a mobile devices and slides

13:03:59 can no longer be viewed

13:04:03 simultaneously via tablet or phone.

Please swipe to find the ASL Interpreter on

13:04:07 your mobile device.

This webinar includes polls's

13:04:10 and we appreciate your interaction
throughout

13:04:12 .

13:04:19 Slides will be available on our website at
a later date. Val, I will turn it over to

13:04:26 you.

Thank you. VAL BRADLEY: Hi, this is Val

13:04:29 again.

I neglected to say I am a middle aged woman,

13:04:33 well, no, that is not true (Laughs) I am a
much older woman with red hair, wearing a

13:04:39 black sweater with white stripes.

I am sitting in my somewhat cluttered office

13:04:44 with plants and bookcases behind me.

I use she, her pronouns.

13:04:51 This webinar is named after a colleague of
ours, a dear colleague of ours named Sarah

13:04:56 Taub.

Before she passed away, Sarah was the

13:04:59 National Core Indicators Director

13:05:01 until 2013

13:05:03 when a very aggressive cancer took her life

13:05:06 , much to all of our sorrow.

13:05:09 Her mission and purpose was really

13:05:11 the central part

13:05:16 of the growth of NCI and has made it what
is today

13:05:20 .

She was a very fierce advocate for people

13:05:24 with disabilities and advocated for the
representation at all levels

13:05:27 of the work that we do.

13:05:30 She never really that as forget who

13:05:32 were the people behind the numbers.

13:05:36 That is why we have called these webinars
the Sarah Taub

13:05:40 Webinars.

13:05:41 This is what we call

13:05:47 hope you will get out of this webinar
today. First, to increase your knowledge in

13:05:53 general about self-direction and people's
experiences with self-direction.

13:05:57 We want to share some best practices, some
exemplary practices

13:06:00 that will hopefully

13:06:03 give you some ideas about how to expand the
opportunity for self-direction

13:06:08 in your states.

We want to show how NCI data

13:06:11 highlight the characteristics and outcomes

13:06:13 of people who are using self-direction.

13:06:16 And then we want to speculate on some of
the additional areas

13:06:21 that we really should be exploring in the
future.

13:06:29 So, now we want to take a minute just to
find out who is in our audience

13:06:38 and for you to give us a bit of a
self-assessment about how familiar you are

13:06:44 with self-direction.

We are going to Luntz launch a poll.

13:06:52 Can you describe yourselves?

13:06:57 Just check

13:06:59 whichever best characterizes you

13:07:03 .

13:07:12 OK, now we need to go to the next poll, is that right, Laura?

13:07:27 So, please rate your knowledge of self-direction supports.

13:07:30 Zero

13:07:32 being next to nothing.

Five

13:07:34 being a lot

13:07:35 .

13:07:49 Great, and Laura,

13:07:51 are we ready to see the results?

13:07:59 OK, in terms of knowledge,

13:08:01 some people with a lot of knowledge

13:08:04 ,

13:08:05 and a bit of knowledge

13:08:07 .

13:08:08 It looks like a fairly knowledgeable group

13:08:13 with some people still here to learn more.

That is great, thank you

13:08:18 .

And have about who is here, Laura?

13:08:27 We have a few people with lived experience.

13:08:30 A few more family members and advocates

13:08:32 .

13:08:34 We've got some public managers working at the state level

13:08:38 ,

13:08:38 case managers who are absolutely crucial to this whole process

13:08:42 ,

13:08:43 some policymakers, service providers and some researchers

13:08:45 .

13:08:47 A real, interesting, diverse group.

Thank you so much

13:08:50 .

13:08:54 Let us do a brief overview of the history of self-direction

13:08:58 .

13:08:59 In the traditional model,

13:09:02 which I assume you are all pretty familiar with,

13:09:05 the public money goes directly to the provider.

13:09:09 And the services are basically driven by the case manager

13:09:12 and the service provider.

13:09:14 We call that sort of a wholesale model

13:09:17 .

13:09:17 The self-direction model is really more of a

13:09:20 (indiscernible).

13:09:23 The public funds go to an individual's support budget

13:09:26 and it is up to the individual

13:09:28 to determine which services

13:09:30 they want to purchase

13:09:32 ,

13:09:34 which goods and services they want to take advantage of

13:09:38 .

13:09:38 The responsibility of forming the service packages on the individual
13:09:42 .

13:09:51 In my judgment self-direction is part of a larger human right that we all have to
13:09:57 self-direction.
Which asserts that we all should have agency
13:10:01 in our lives and that we have control over the decisions that really determine the
13:10:06 course of our lowers lives.

13:10:08 Self-direction really reflects the promise of self-direction
13:10:10 by putting power in the hands of people

13:10:13 who need supports

13:10:21 (audio issues)

13:10:22 .

13:10:23 Here is a brief timeline

13:10:25 .

13:10:26 These are sort of some of the major milestones
13:10:30 over time.

13:10:33 Important to know that self-direction goes back even to 1953 in California
13:10:37 , where people who were covering

13:10:41 recovering from polio were given the ability to purchase their own
13:10:45 personal care attendants.
That program is now part
13:10:48 of a huge service provided in California.

13:10:56 In the 1980s, Massachusetts and a few other states had pressure from the independent
13:11:01 living movement gave people with physical disabilities the ability to purchase their
13:11:05 own personal care attendants.

13:11:06 1995 Cash and Counseling came along which made it possible to cash out certain public
13:11:12 benefits, for older adults, people with physical

13:11:15 disabilities, to use the money to use as
they wish for the services they needed
13:11:21 .

13:11:21 The amount of institutionalization among
the group went down as a consequence
13:11:26 .

In 1997, the (unknown name)
13:11:28 funded (indiscernible)

13:11:29 .

13:11:30 ..

13:11:31 2003

13:11:36 self-direction became a service option for
multiple groups

13:11:39 through the use of HCBS waivers.

13:11:42 And in 2023,

13:11:46 a year before last, there were 260
self-direction programs

13:11:50 throughout the country

13:11:53 serving a total of 1,520,267 individuals

13:11:55 .

13:11:56 How do we know that?

Because of our friends

13:11:59 at Applied Self-Direction,

13:12:01 who you will hear from next.

Molly?

13:12:07 MOLLY MORRIS:

13:12:12 Val, I think you have one more slide to
cover. You want me to jump in? VAL BRADLEY:

13:12:22 Very quickly.

Sorry. Because self-direction is not a

13:12:25 national program with national standards and
expectations, states vary significantly and

13:12:29 how to implement self-direction.

Some states

13:12:31 use their own state case managers to be
support

13:12:35 (indiscernible), other states contract,
some states allow people to have their own

13:12:40 personal facilitator or personal agent

13:12:41 as part of their budget.

13:12:44 The supports that people are likely to purchase

13:12:47 very widely from state

13:12:49 to state,

13:12:50 including staffing and goods and services

13:12:53 .

13:12:56 Populations in each state may vary the magnitude of those populations

13:13:00 .

13:13:00 And finally, there are a multitude of funding authorities

13:13:04 that states

13:13:05 (indiscernible)

13:13:07 support self-direction

13:13:09 including (unknown name)

13:13:15 Older Americans Act, state general fund and even a veterans administration

13:13:19 program for self-directed Veteran Directed Care. Now I will posit

13:13:23 pass it on to our good friend, Molly.

13:13:26 MOLLY MORRIS:

13:13:28 Thanks so much, Val, happy to be here.

I am with

13:13:32 an organization called Applied Self-Direction.

13:13:34 Some background about us

13:13:40 is that we are a mission driven organization and our focus is on advancing

13:13:45 some direction, understanding all things self direction. We try to serve as a

13:13:50 national hub that really provides technical assistance, training, community, building to

13:13:54 be that resource around this model.

We serve many different stakeholders

13:13:58 from state agencies

13:14:00 to financial management services, service providers, managed care organizations to
13:14:04 participants advocacy groups, support brokers.

13:14:07 Basically all of you and the different categories you indicated on the

13:14:12 survey, we are here to be a resource.

13:14:15 I am going to be

13:14:20 giving some background and context that I think is going to be giving you

13:14:25 a bit of the lay of the land

13:14:29 when we get more into what Lindsay is going to talk about with the findings on

13:14:35 self-direction from the National Core Indicators study. I will give you a sense of

13:14:40 the broad landscape nationally of the growth of self-direction, pulling from our recent,

13:14:44 Self-Direction National Inventory from 2023.

The project was really all about measuring

13:14:49 the breadth and scope of self-direction offerings across the country.

13:14:53 This is a study we have conducted every three years since 2011.

13:14:57 We have that historical data that continues to give us a better picture of trends

13:15:02 year-over-year.

13:15:03 The data that we collected in 2023 is notable for a couple of reasons

13:15:08 .

One,

13:15:09 it was the first time we did an inventory post pandemic

13:15:17 and so, we wanted to know what was the impact of the pandemic specifically on

13:15:23 self-direction?

I will talk about that in a bit. We

13:15:26 coincided with a huge wave of new interest in self-direction, both at the participant

13:15:31 and program level.

And while we have seen consistent, steady

13:15:35 growth every three years that we have measured, we sought a sharper rate of

13:15:40 enrollment in 2023.

More states implementing new programs and

13:15:43 program expansions that at any point in the previous decade.

13:15:50 It's exciting and I will talk more about that in a moment.

13:15:57 A bit more context about our methods.

Sorry, it looks like the text is a bit small

13:16:03 on the slide.

I do not know how that happened but the

13:16:07 program data I will refer to today was collected from October I do not know how

13:16:13 that happened but the program data I will refer to today was collected from October

13:16:17 2022 through February 2023 so I generally refer to it as 2023 data. We collected the

13:16:22 data through initially very in-depth review of publicly available documentation about

13:16:26 publicly funded self-direction programs.

Then we conducted interviews, we were able

13:16:29 to have 65 interviews with state staff from 43 states,

13:16:32 and we did have at least some form of correspondence, including email with

13:16:36 administrators in every state.

In a few cases, and Roman Tama

13:16:39 -- data is not available for self-direction from administrators.

13:16:44 We were able to contact financial services providers to provide that data

13:16:47 or we used enrollment estimates that are often included

13:16:50 in Medicaid documentation.

13:16:54 Finally, as a quality check, we work with a community of

13:16:57 state administrators and financial

13:16:58 management services providers that

13:17:02 applied self-direction, we shared our initial data with that group

13:17:08 as a quality check to make sure that the numbers we collected kind of looked right to

13:17:13 people in the industry who no particular programs.

13:17:18 I talked about the spike in enrollment

13:17:21 .

13:17:25 From 2019 to 2023, we actually saw 23% increase enrollment

13:17:28 .

By comparison, from

13:17:30 2016 to 2019

13:17:31 it was a 17% increase

13:17:33 .

13:17:34 That is a bigger spike

13:17:35 that we were excited to see

13:17:38 .

13:17:41 As Val mentioned, we had found 1.5 million
people self directing

13:17:45 nationwide.

13:17:45 For perspective on this, I have a chart

13:17:50 on the slide and you can see that in 2011,
there was about

13:17:55 700,000

13:17:55 + people self directing.

13:17:57 Year over year 2013 that was

13:18:00 up to 800,000+

13:18:01 .

13:18:06 2019 we got to 1.2 million and then up to
1.5

13:18:10 .

13:18:10 You can see this is a program that just
continues to grow

13:18:15 .

13:18:17 Of course

13:18:19 , I was just talking about national numbers

13:18:22 ,

13:18:24 but self-direction enrollment increases do
vary state to state

13:18:27 .

13:18:30 When we collected this data in 2023, most states reported an increase in self-direction enrollment.

13:18:36 That was 44 states.

13:18:37 But if you did report a decrease.

13:18:41 As Val mentioned, California was an early adopter of self-direction

13:18:45 and it is a large state.

13:18:50 In our national accounting of enrollment, it has always tended to be well over 50% of

13:18:56 people self directing live in California.

That percentage has continued to decrease.

13:19:04 In 2023, for the first time less than 50% of people self directing live in California.

13:19:11 That shows that nationally we are showing greater growth but not saying California is

13:19:16 getting smaller.

We also had six states that more than

13:19:20 doubled self enrollment.

Alabama, Connecticut, DC, Florida, Maryland,

13:19:23 South Dakota had huge leaps.

13:19:27 I will spend a few minutes talking about some major trends that we have seen

13:19:32 from this data and from our interviews with states.

13:19:37 One is that there are a variety of different funding sources for

13:19:42 self-direction, publicly available funding sources. By far the Medicaid 1915(c)

13:19:47 waiver is the most frequently used source but other authority uses are growing.

13:19:51 I will talk about that in a bit.

13:19:56 We talk a lot about Medicaid self-direction but the veterans health administration

13:20:00 also has their own

13:20:01 self-direction program called Veteran Directed Care.

13:20:05 Really exciting.

From 2019 to 2023

13:20:07 we saw 157%

13:20:10 increase in enrollment

13:20:11 ,

13:20:14 which is the difference between an average of 33 veterans per site

13:20:19 288 veterans per site.

Huge, huge growth.

13:20:22 On the next slide we will talk briefly about why that is

13:20:27 .

For one, the veterans health administration

13:20:29 is really committed

13:20:32 to making Veteran Directed Care available to every Veterans Affairs Medical Center by

13:20:37 2026.

Just this month the Elizabeth Cole HCBS act

13:20:41 was signed into law which also has some really ambitious goals for Veteran Directed

13:20:46 Care.

Exciting to see that growth.

13:20:50 Availability of self-direction varies by population.

13:20:52 Most all states provide at least one

13:20:55 Medicaid funded self-direction offering

13:20:57 for adults over age 65

13:20:58 ,

13:20:59 for adults with physical abilities

13:21:05 disabilities and adults with intellectual and develop mental disabilities

13:21:08 .

13:21:13 It is less available as an option for other populations, for instance, people with

13:21:18 serious mental illness, children who are medically fragile. It is not like these

13:21:22 programs are available in every state all of the time but we are hearing from states they

13:21:28 are signaling more interest in expanding these options. That is a trend to watch.

13:21:33 As I mentioned, the COVID pandemic really did make a significant impact.

13:21:38 People were looking to receive care at home and have more control over their care. Also

13:21:45 as I think many of you know, the majority of states created temporary emergency

13:21:50 options via their appendix K allowing for legally responsive individuals to provide

13:21:55 care which is an important feature of self-direction.

13:21:58 States also talked about self-direction as filling a critical void when a lot of other

13:22:03 services were shutting down and there was significant federal funding during this time

13:22:08 period that helped galvanize the model.

13:22:10 It is important to note

13:22:12 that in self-direction there is both the option

13:22:15 of having employer authority, were you choose your own workers

13:22:19 , and, or, budget authority,

13:22:22 where you have decision-making power over your budget

13:22:25 , can set the rate of wages for your workers

13:22:29 and can even

13:22:32 in some cases purchase goods and services that support your independence

13:22:36 .

In 2023 we found states that demonstrated

13:22:39 the most growth in Medicaid funded enrollment

13:22:41 also tended to offer budget authority.

13:22:44 It starts to tell us a story that perhaps the more flexibility we give

13:22:49 , the more people are opting into self-directed.

13:22:52 More than ever,

13:22:54 we are seeing states have more sophisticated funding structures

13:22:57 ,

13:22:58 specifically pairing their 1915 C waivers

13:23:02 with other funding authorities including state plans

13:23:04 ,

13:23:05 which in some ways it really signals

13:23:07 embedding self-direction more permanently

13:23:09 in the structure of the state

13:23:11 .

13:23:12 In some cases making it

13:23:14 something that everyone is eligible for

13:23:17 that meets the criteria.

13:23:22 We also looked closely at the workforce

13:23:25 .

13:23:30 Obviously there is a self-direction, and overall workforce crisis impacting the home

13:23:34 and community-based services sector.

13:23:35 Several states reported that self-direction mitigated

13:23:42 workforce shortages, particularly being able to hire paid family makes a difference

13:23:46 but at the same time

13:23:49 we also heard from states that self-direction is in no way exempt from

13:23:54 these concerning patterns in the direct care workforce crisis. We need to keep an eye on

13:23:59 this.

Lots of areas for future workforce to

13:24:02 understand including what could be the positive impact of increased wages and

13:24:07 benefits?

What is the impact of paid family caregiving

13:24:10 unavailability of workforce?

And what is the impact of budget authority?

13:24:14 We see that plays an important role as well.

There is a lot of potential in the future to

13:24:21 do deeper research, particularly working with financial management

13:24:23 service providers, using the data they already collect often times through their

13:24:28 state contracts.

13:24:33 Future research that we are looking towards coming out of this most recent inventory as

13:24:39 we are preparing for the next one is again, continuing conversations about workforce.

13:24:44 How self-direction can scale to support historically marginalized and underserved

13:24:47 communities.
is going to be really critical. Not everyone
13:24:50 has equal access to self-direction.
Understanding the difference in unmet needs
13:24:54 and people who self directing people using
traditional services.
13:24:58 And also understanding some of those states
that had a decrease enrollment. What is that
13:25:03 due to?
Obligated enrollment processes?
13:25:05 EVV

13:25:07 implementation not going well?

13:25:15 With that said I think it covers trends
normal pass things over to Lindsay. Thanks,
13:25:20 everybody for stopping the Mac thanks, Molly.

13:25:31 This slide shows a timeline of the surveys
that comprise the National Core Indicators
13:25:36 for NCI.
NCI tools collect data
13:25:40 on performance and quality of life directly
from people who use disability and, or aging
13:25:45 service systems, their families and those
who deliver services. Since the first NCI
13:25:50 intellectual and develop mental disability
survey, or NCI-IDD in 1997,
13:25:53 we have had 48 states participate.

13:25:56 Since launching the NCI aging

13:26:00 (unknown name) or NCI-AD in 2013, we have
had 26 states participate

13:26:05 .

We also hear from 30 states...

13:26:09 Five on the NCI state of the workforce

13:26:11 .

13:26:13 On the next slide we have the goals of our
NCI tools

13:26:17 .

Really, there are three angles.

13:26:21 To establish a nationally recognized set of
performance and outcome into quarters

13:26:28 indicators for aging and disability service
systems.

13:26:34 To use valid and reliable data collection
methods and statistical techniques to

13:26:38 capture information directly for people who use services. And report those individual
13:26:43 state results

13:26:44 (audio issues) national benchmarks of the surveys

13:26:46 .

If you have questions you can check out

13:26:50 our website.

The link should be in the chat

13:26:53 .

13:26:55 I wanted to touch briefly on the overall methods for collecting NCI data

13:27:00 .

States work closely with (unknown name)

13:27:04 to design samples to be representative of their surface population

13:27:07 .

13:27:09 On the AD survey, this is anyone who receives one active service

13:27:13 at least twice a week from their state

13:27:16 aging and disability service system, that is the eligible population

13:27:19 .

On the idea decide you need to be receiving

13:27:23 at least one service in addition to case management.

13:27:26 All of the surveyors that collect the data

13:27:34 ..

13:27:35 .

13:27:38 Confidentiality is important.

13:27:44 Since COVID many states have offered both in person, or remote interviews to complete

13:27:49 the surveys.

We have the surveys in multiple languages

13:27:52 and we allow for these proxies for selected questions.

13:27:56 On the next slide we have a map showing the 18 states who dissipated

13:28:01 in the 2022/2023 NCI AD

13:28:03 .

13:28:06 Altogether we heard from more than 15,000 individuals of which about one third were
13:28:11 male, average age was 67.

13:28:14 We see a fairly diverse sample in terms of race, ethnicity and diagnosis
13:28:18 .

13:28:20 On the next slide we have a map showing the 33 states that participated in the 2022
13:28:27 - 2023 NCI- IDD.

13:28:37 Altogether we heard from more than 25,000 individuals of which more than half are
13:28:42 male, average age was younger, around 40 years old and again really diverse sample
13:28:47 when we look at demographics like race and ethnicity and diagnosis. Before jumping to
13:28:52 the data, on the next slide I just wanted to share a small caveat around using NCI data
13:28:59 for advocacy.

A good analogy is to think about NCI data is
13:29:03 an exit ramp.

The data can reveal patterns and trends and
13:29:07 may point to a few areas where you want to look deeper at how your system is working.

13:29:13 NCI data does not necessarily tell you all of the root causes or the right solutions.

13:29:19 It is not going to give you directions from start to finish but it will tell you some

13:29:25 possible exit ramps to take on your journey to quality improvement. Let us take a closer

13:29:31 look first at who uses self-directed supports. You will see here to doughnut
13:29:36 charts.

They represent the percent of respondents

13:29:38 with the NCI-AD survey on the left of the screen and the NCI-IDD survey on the right.

13:29:44 This is the percent were using self-directed supports. It is important to note that

13:29:49 because not every waiver population might be sampled to the same extent,

13:29:53 at a state in a given year, this is not necessarily a perfect proxy for the extent

13:30:00 of self-direction in a state.

But at the national level it does give us a

13:30:05 glimpse of who uses self-direction within state-funded LTS as populationsS

13:30:09 populations.

13:30:16 The use of self-directed supports is about two times higher in the NCI-AD population at 13:30:22 around 34% than the NCI-IDD, which is 17% nationally.

13:30:25 On the next slide we have a packed circles graph.

13:30:28 This is intended to show the use of self-directed supports broken down by age

13:30:34 group.

Within the NCI-AD and NCI IDD surveys

13:30:36 ,

13:30:38 you see the use of self-direction is lower among older respondents

13:30:42 .

13:30:43 We also see that for each age group, the use of self-direction is higher

13:30:48 among NCI-AD respondents.

13:30:54 We have sent demographics of people who use self-directed supports by race and ethnicity

13:30:59 .

13:30:59 There are a lot of numbers on this table so I will just point out a few of the

13:31:06 similarities and the differences for our two surveys that were for Deaf we are focused on

13:31:12 today.

For both groups

13:31:13 ...

13:31:15 Lower for Black respondents.

13:31:22 We see differences between the surveys however in terms of the use of

13:31:27 self-direction among white respondents and Hispanic respondents. This is a good example

13:31:31 of why we think we need to think about NCI data as an exit ramp

13:31:37 because these numbers show interesting patterns but ultimately we need further

13:31:41 research to really understand the factors that contribute to different rates of

13:31:45 self-direction for different groups.

The last slide

13:31:48 that I have on demographics shows us the difference in the use of self-directed

13:31:52 supports for those whose preferred means of communication is spoken,

13:31:56 and those who use sign language, gestures or communication devices to communicate.

13:32:03 I thought this was really interesting to see that in both the NCI-AD and the NCI-IDD

13:32:11 there are significantly higher rates of self-direction among those who prefer

13:32:15 non-spoken forms of communication.

We will come back to this in a bit when we

13:32:21 look at some of the experiences.

On the next slide we will turn to

13:32:26 some slides that showcase outcomes related to the experience of self-direction.

13:32:32 Here are two tree maps of the responses to the question who makes the decisions

13:32:38 about the services that are self-directed?

13:32:41 Ultimately we see that not all people who use self-directed supports are making

13:32:45 decisions about their services,

13:32:47 and from these two tree maps side-by-side, we see that that is much more common among

13:32:53 NCI-IDD respondents.

On the NCI-AD

13:32:57 survey we see 60% of people said they mostly make the decisions about the services

13:33:03 that are self-directed.

That is the teal box at the top.

13:33:07 On the NCI-IDD just 14%

13:33:09 40% say they mostly make the decisions, another

13:33:15 40% say they have family friends help make the decision and 46% say

13:33:27 that

13:33:28 someone else decides

13:33:29 .

.

13:33:30 ..

13:33:34 Differences in how people are expensing self-direction in our survey populations

13:33:38 .

13:33:41 On the next slide we have a table showing the national data on measures of the

13:33:47 experience of self-direction.

13:33:48 The good news is that we see relatively high rates in both surveys of people saying
13:33:53 they have enough help deciding how to direct their services, that they can make changes
13:33:59 to their services and that they have the amount of control they want over the
13:34:04 services that are self-directed.
However, we also see that three quarters of
13:34:08 NCI-AD respondent say the services and supports
13:34:11 they want to self direct are always available in about two thirds of NCI-IDD
13:34:16 respondent say this.

13:34:19 We also see about one third of our NCI-AD respondent say they need help with at least
13:34:25 one part of self-direction like getting their staff paid, funding staff, managing
13:34:30 benefits and this is higher on NCI-IDD with about one into respondents.
13:34:34 In this slide we will look at some of these outcomes related to the experience of
13:34:40 self-direction and how those are tied to demographics.
13:34:43 We've noticed some rather stark differences on both the NCI-IDD and NCI
13:34:47 AD surveys with people who prefer non-spoken forms of communication.
13:34:51 We see a pattern that they are a lot less likely to have make or
13:34:56 have input on self-direction decisions.

13:34:59 Of all people use on the garage, gestures or communication devices, may use family,
13:35:04 friends and staff to help interpret their communication, they should absolutely have
13:35:09 the same opportunities as their peers to make decisions about services. It may be
13:35:14 there -- additional supports needed to facilitate decision-making such as enhanced
13:35:18 training for staff

13:35:19 or updated requirements for individuals who helped to develop
13:35:22 person centered centered plan -- patient plants.
13:35:28 This slide shows who makes the decisions
13:35:30 ...

13:35:32 Just wanted to spotlight one of the surveys

13:35:35 .

13:35:41 This is a stacked bar graph that shows the percent who say they mostly make the
13:35:46 decisions, that they have input, or that someone else makes decisions. One of the
13:35:51 bars shows that breakdown for those who prefer spoken communication. That is the one
13:35:56 at the top.

The bottom shows the break down for those
13:36:00 who prefer non-spoken forms of communication. The dark green here shows the
13:36:05 percent that say they mostly make the decisions. 60% for those who use spoken
13:36:10 communication while just 12% of those who prefer non-spoken communication say that
13:36:14 they mostly make the decisions. At the other end of the bar, the yellow,
13:36:19 you see the present who say someone else makes the decisions for them is just 13% for
13:36:25 those who prefer spoken communication, while 56% for those who prefer non-spoken forms.

13:36:30 It is almost an exact flip. I will just finish with a quick look at the
13:36:36 experience of self-direction by age group on the next slide. I was so
13:36:43 somewhat surprised by these results, really that they looked so similar across NCI-AD
13:36:47 and NCI-IDD.

The green column are those using
13:36:50 self-directed supports who are 18 through 44.

13:36:53 The teal is 45 through 64.

13:36:55 The gray is 65+ group.

13:37:01 You see both for NCI-AD and NCI-IDD, the younger group have lower rates
13:37:06 of saying the services and supports they want to self direct are always available.
13:37:12 They have higher rates of saying that they need help on at least one part of
13:37:18 self-direction compared to their older peers. We know that there
13:37:25 are long-standing workforce shortages that contribute to these numbers but additional
13:37:29 research is needed to understand the factors that contribute to the younger adults having

13:37:34 a different experience of self-direction so we can better plan for the future.

13:37:38 I wanted to plug that we are in the process of developing some of these analyses into a

13:37:45 full issue brief with more information.

So, stay tuned for that. Thank you.

13:37:50 ALICIA BOEHME: Thank you, hello everyone my name is Alicia Boehme.

13:37:54 Christian Moran and I are here to talk about the long-term care self-direction

13:37:58 programs in Wisconsin.

13:38:00 We both work in the division of Medicaid Services and oversee different aspects of

13:38:05 the adult Medicaid long-term care and also acute and primary care programs, including

13:38:09 the programs we are going to be talking about today.

13:38:13 Today we will cover

13:38:19 a few topics including the Wisconsin long-term care waiver program, landscape in

13:38:23 Wisconsin.

The Iver self direction program overview.

13:38:27 How Medicaid collaborates with participants, families, advocates, providers

13:38:30 and partners.

13:38:31 And opportunities to improve growth and access to quality

13:38:34 .

We will also talk about what we wish we knew

13:38:39 when we started the program.

13:38:41 In Wisconsin

13:38:44 we have a number of adult long-term care waiver programs

13:38:48 .

13:38:48 All of them cover adults with disabilities and older adults.

13:38:55 We know that every state looks different but we are here to let you know more about

13:39:00 the models in Wisconsin.

Family care, there are about 53,000

13:39:04 individuals in this program.

This is our adult long-term care managed

13:39:08 program.

13:39:10 The second program which is really what we
will be focusing on a lot today is our IRIS
13:39:17 program.
It stands for include, respect, I self
13:39:20 direct.

13:39:23 This is our self-direction program in
Wisconsin, we have almost 20,000, 27,000
13:39:28 individuals in this program.
The third program we have
13:39:31 programmed in Wisconsin is the partnership
program.
13:39:33 It has about 3000 individuals.

13:39:41 This is a much smaller program, not
statewide and covers acute and primary and
13:39:46 long-term support services in Wisconsin.
On the right-hand side you can see the NCI-AD
13:39:53 data and you can see that in family care we
do have a self-direction option.
13:39:59 32% of those in family care choose this
option.
13:40:02 It allows individuals to self direct

13:40:04 some things in their managed care program

13:40:07 including you can choose some services,
staff
13:40:10 ,

13:40:10 create their own schedule and set standards

13:40:13 for individuals who are working for them.

13:40:16 This is a small subset and people can choose

13:40:20 if they want

13:40:21 to self direct certain aspects

13:40:23 .

Secondly,

13:40:26 is the self-direction program which is IRIS

13:40:28 .

13:40:30 This is 99% but hundred percent of these

13:40:34 the individuals

13:40:36 in this program to self direct

13:40:38 .

13:40:49 The history of

13:40:50 the IRIS program

13:40:51 .

13:40:55 It is a fully self-directed program which means the participants

13:40:58 have the freedom to decide how they want to live their lives.

13:41:03 It was created in 2008

13:41:05 for individuals over the age of 18 years old

13:41:08 .

Currently, the budget for this program

13:41:11 is about \$1 billion

13:41:12 .

13:41:13 This is a very large program

13:41:15 .

13:41:16 IRIS participants

13:41:20 are supported by IRIS consultant agencies, we call them ICA

13:41:24 s, and fiscal employment agents or

13:41:26 FDAs

13:41:27 .

13:41:30 Workers and participants are paid through the FDA

13:41:33 .

13:41:44 The buyers benefit package includes vocational, transportation, supportive

13:41:47 homecare, personal care

13:41:48 , medical equipment and supplies, counseling and therapeutic services.

13:41:51 IRIS participants must have a nursing

13:41:55 home level of care in order to qualify for the program

13:41:59 ,

13:41:59 and they receive a budget for long-term care services and supports

13:42:03 .

They manage their monthly budget,

13:42:06 caregiver hiring and their individualized program

13:42:08 .

13:42:10 plan

13:42:11 .

13:42:16 This shows the growth of the program which has been astronomical. You can see that in

13:42:22 2008 we started off the program and it has consistently increased year-by-year

13:42:26 by significant amounts.

Now we are

13:42:29 around 27,000 participants in the program

13:42:31 .

13:42:36 This map here on the right hand side

13:42:39 shows

13:42:40 both the F

13:42:41 ea

13:42:41 ea

13:42:43 E

13:42:43 A

13:42:48 and ICA footprints within Wisconsin.

Individual

13:42:50 have a choice for

13:42:52 FEA

13:42:52 s

13:42:57 and about five ICA's located in different parts of the states and regions

13:43:02 .

The individual's choice depends on the

13:43:05 region that they are in.

IRIS

13:43:15 physical employer agencies help

participants choose and manage the work is

13:43:19 that Harpo stop and the IRIS consultant

agencies help participants manage their own

13:43:23 care and handle the day-to-day program

operations. We also have

13:43:27 an IRIS self-directed personal care agency

that we contract with that allows

13:43:31 participants to hire, train and oversee

their personal care workers.

13:43:40 We have what we call the IRIS advisory

committee and they are responsible for

13:43:45 providing feedback on the program.

This is very important to the program.

13:43:49 They provide feedback to us on proposed

changes to program policies, to the

13:43:54 contracts we have with the various ICASa and

FEA

13:43:57 s

13:43:57 and also provide input

13:44:00 -- input on federal waivers.

13:44:07 They also provide feedback on reports such
as NCI

13:44:11 and state led participant satisfaction
surveys

13:44:13 and implementation of program operations
and infrastructure

13:44:16 .

13:44:19 The committee members include participants,
family members, providers, advocacy groups

13:44:25 and whispered that across all three target
groups

13:44:28 served by the program.

13:44:32 So again, individuals with intellectual
develop until disabilities, those with

13:44:36 physical disabilities and older adults.

To highlight within the context of these

13:44:40 meetings, we have a public

13:44:44 comment period so anyone is welcome to come
on and provide feedback to the committee

13:44:49 and to the Department of health services on the program.

13:44:54 I will pass it along to Christian Moran who will talk more about the IRIS waiver.

13:45:00 CHRISTIAN MORAN:

13:45:05 Thank you, Alicia.

My name is Christian Moran, I am with the

13:45:10 Wisconsin division of Medicaid Services.

Just want to take a few minutes to talk

13:45:15 about the process we are in and renewing a waiver for the self-direction that smacks of

13:45:20 directed program.

We operate IRIS under in 1915(C)

13:45:23 waiver and we are very excited with the opportunity to make updates to the waiver

13:45:29 as this opportunity only comes around every five years.

13:45:35 Our current waiver runs to the end of this year, December 31 and the new waiver will be

13:45:41 effective, sorry, January 1 of next year.

13:45:44 We want to take this opportunity to improve the policies and services to make our

13:45:49 program better and keep it sustainable for the 27,000 people who are served by the

13:45:55 program.

In the next slide I want to talk briefly

13:45:58 about our outreach efforts we have done in the last year. We began working on our

13:46:04 waiver in earnest last spring.

As part of the process we did an extensive

13:46:09 outreach campaign.

At the onset we wanted as much as input from

13:46:13 program participants, families and our partners, essentially all of the people

13:46:17 served by support or have an interest in our program. We conducted an online survey. We

13:46:23 got input our IRIS advisory committee that Alicia mentioned as well as our tribal

13:46:28 health directors.

We held two virtual public input sessions,

13:46:31 one in the day and one in the evening.

Through all of the outreach efforts we

13:46:37 received over 2100 comments.

13:46:41 In the next slide I want to go over the themes we heard as a result of these

13:46:47 this outreach.

There were six major themes.

13:46:49 The largest proportion of the comments we received were about services

13:46:54 , about 40%.

There was an equal share about

13:46:59 -- with comments about transportation, cultural competency and integrity at about

13:47:03 15% each.

13:47:04 Likewise about housing and self-direction at roughly 8%.

13:47:09 While transportation and housing

13:47:10 are

13:47:14 services, we decided to break this out separately given how many comments we had

13:47:19 received about the services.

13:47:21 I will note that many of the comments we

13:47:25 seed were about complex issues that could not be addressed solely through the waiver

13:47:30 itself.

We have collected all of that input and are

13:47:34 looking at other ways to address those

issues outside of the scope of the waiver,

13:47:40 either through policy changes, changes in our contracts with their vendors

13:47:44 or other means.

13:47:45 In the slide

13:47:52 the next few slides I will go over some of the themes we receive. Again, we received

13:47:58 many comments about services.

Just to give you an example of some of the

13:48:03 contents we received, comments about employment

13:48:05 and vocational services, need for that employment, training, job training

13:48:11 support with those with disabilities looking to enter or stay in the workforce.

13:48:19 I do not have time to read all of the comments in the slides but we did want to

13:48:25 highlight some of the direct feedback we received. On each of the slides you will see

13:48:31 in blue are direct comments that we received. I want to highlight a theme of

13:48:37 transportation.

We received a significant amount of comments

13:48:39 around alternative transportation solutions.

Using for example, Huber and Whiffed LIFT

13:48:44 Lift as a transportation option.

13:48:45 We had our camera care

13:48:49 family care

13:48:53 On the next slide I want to briefly

13:48:56 draw upon some NCI data.

13:48:59 As a point of comparison we have survey
results

13:49:02 for Wisconsin's 22 1

13:49:04 20

13:49:04 22

13:49:05 -2

13:49:05 0

13:49:06 23

13:49:10 NCI-AD and NCI

13:49:13 IDD for transportation

13:49:14 .

13:49:21 86%

13:49:23 of IRIS participants

13:49:26 compared to 80% for family care

13:49:28 .

13:49:28 By comparison

13:49:30 the table on the right

13:49:36 shows slightly absent for IDD population,
76%

13:49:41 for IDD population who do not self direct
say they have access to transportation

13:49:46 compared to 71% to self direct.

13:49:49 As Lindsay mentioned earlier, we consider these results and exit ramp

13:49:53 .

The results are helpful as we are looking to

13:49:56 understand differences in how participants are experiencing our programs

13:50:00 as we look to explore solutions to close these gaps.

13:50:04 In the interest of time,

13:50:07 if we could just briefly go through each of these quickly.

13:50:11 You will receive the slides.

13:50:13 The next was touching on cultural competency.

13:50:16 The following slide touched upon integrity

13:50:18 .

13:50:21 In the following slide touched upon housing

13:50:23 .

13:50:24 If you have an opportunity

13:50:29 to look the slides you will see some of the comments we received from people who

13:50:35 responded to our outreach efforts.

With that I will turn it to Alicia for our

13:50:41 closing slide.

ALICIA BOEHME:

13:50:42 Thank you, Christian.

13:50:45 In hindsight, as you saw in the previous slide that I shared

13:50:50 , the program has grown very quickly and so that

13:50:54 has proposed some challenges for us over the years

13:50:57 when we created the program we created it for a very small number of people

13:51:02 .

In hindsight we would have built policies

13:51:05 and program infrastructure differently had we known

13:51:08 it was going to be about \$1 billion program

13:51:11 with 27,000 individuals as a part of it.

13:51:17 In response to that we have increased our internal resources in the IRIS program

13:51:22 over the past couple

13:51:26 number of years will stop we now have a larger cross Bureau structure that helps us

13:51:31 manage the policy, fiscal and oversight needed for this large program.

13:51:35 I will pass this along to the next person.

13:51:43 LAURA VEGAS:

13:51:46 Good afternoon, I am Laura Vegas

13:51:48 with the (unknown name) team.

13:51:50 What does it mean for us

13:51:52 and what are some of the takeaways from today

13:51:56 in some future directions?

13:51:59 One of the things we learn today is the use of self directed supports continues to expand

13:52:05 across all populations that we support in the country.

13:52:08 And it is important to ensure that all populations have the same opportunity

13:52:13 to find information about and

13:52:15 access self-direction.

13:52:20 As self-direction expands we need to measure and monitor the quality of

13:52:25 self-direction.

And continued research will be needed to

13:52:27 explore more deeply

13:52:29 the associations between the use of self-direction

13:52:31 and community living outcomes

13:52:33 .

13:52:34 People have been really busy

13:52:36 answering the questions in the chat

13:52:38 .

13:52:39 So, thank you everybody

13:52:42 .

13:52:44 I think that is all we have

13:52:47 .

Thanks everyone for coming

13:52:48 .

13:52:57 I'm just reading the question.

A bit about HSRI. They are all about

13:53:01 improving systems and changing lives.

They are a nonprofit organization founded in

13:53:06 1976,

13:53:08 looking to craft community-based, person
driven solutions across service systems

13:53:11 and they gather research using a
collaborative, inclusive

13:53:14 and participatory model.

13:53:15 They are a great partner, by the way

13:53:18 .

13:53:18 So, thanks to everyone

13:53:20 .

13:53:22 Are the questions in the chat that we can
answer?

13:53:26 before...

13:53:29 Or are people taking care of all those?

LINDSAY DUBOIS: Yes

13:53:32 .

I saw a question about

13:53:35 kind of self-direction

13:53:36 for people with IDD

13:53:37 ,

13:53:43 data on states that are supporting people
to self-correct even when they have high

13:53:48 support needs like 24/7 support.

With the NCI data we can look at that.

13:53:53 We do have questions on the extent of
supports

13:53:56 required and we can look at self-direction
for folks

13:53:59 .

13:54:00 And then in terms of comparisons to spending

13:54:03 ...

13:54:03 Laura or Molly

13:54:08 (indiscernible) if there is any data you
are familiar with

13:54:11 that could make that connection to state
budgets

13:54:14 related to self-direction?

13:54:18 MOLLY MORRIS: This is Molly.

13:54:20 I do not have access to that budget
information

13:54:23 but I would love to have access to it
(Laughs)

13:54:27 I want to know that story as well.

13:54:30 I also just wanted to jump in on the other
question

13:54:34 where the person was asking about what is

13:54:37 Deaf what is up direction look

13:54:39 like for people with

13:54:41 IDD when their parents H out from being in
a caregiver role?

13:54:46 I want to acknowledge what an important

13:55:02 ..

13:55:03 .

13:55:05 Interesting solutions to that problem

13:55:07 but it will also require innovation.

13:55:14 LAURA VEGAS:

13:55:18 Any other questions that are not being
answered in the chat?

13:55:22 Molly, there is one more question for you.

13:55:25 It says we hope you can help us learn about
aging in place,

13:55:29 about 24/7 supports

13:55:31 and Applied Self-Direction

13:55:32 can truly be helpful

13:55:34 .

13:55:34 MOLLY MORRIS:

13:55:36 Thank you, Maggie

13:55:37 .

13:55:39 I know who you are and I appreciate that
comment and I will just say

13:55:45 , as a sibling of someone with IDD,

13:55:48 this particular issues close to my heart.

13:55:50 LAURA VEGAS: Someone asked if the

13:55:58 (indiscernible) is the independent facility
or like a sport broker? Also where is it

13:56:03 required in statute to the previous
question? Anyone want to take that one?

13:56:08 Is an independent facility or like a
support broker?

13:56:12 VAL BRADLEY:

13:56:19 What the function of independent -- the
function of an independent facilitator is

13:56:23 our CMS's

13:56:26 definition of self direction.

If the state is doing self direction they

13:56:30 have to provide independent facilitation.

States vary in terms of how they

13:56:35 operationalize independent facilitation.

13:56:38 That could be through contract and support
brokers, it could be through the state or a

13:56:44 case manager.

It could also in some states be through a

13:56:48 contracted staff person or personal agent

who can serve that function. Our friends from

13:56:53 Wisconsin and Molly may have other answers

to that question.

13:56:58 MOLLY MORRIS:

13:57:02 I was a bit distracted looking at all of these inputs (Laughs)

13:57:06 people asking question.

13:57:10 I will just reiterate, forgive me if I am repeating anything Val said, nationally,

13:57:18 every state structures their programs differently. Information and assistance is a

13:57:22 broad category of support that is different from a case manager that is their job,

13:57:27 coaching you to be an employer.

That looks and is called and is structured

13:57:32 in different ways state to state.

13:57:34 LAURA VEGAS: Thank you, Molly.

There were some comments and questions about

13:57:39 oversight.

The FSA

13:57:45 and states, I am wondering if Wisconsin, since we have a few minutes, would mind

13:57:51 speaking to how they provide oversight of their self-directed work and ensure the

13:57:55 services are quality?

ALICIA BOEHME: This is Alicia again. Yes, we

13:57:59 have a whole team that ensures that our contracted entities, the FEA

13:58:04 s ,, the ICAs

13:58:08 and (unknown name) are meeting the expectations of the contract

13:58:11 .

13:58:13 If they are not we work with them and we also have a team to help solve problems

13:58:20 where participants might be having disagreements with

13:58:22 the program or concerns about the program.

13:58:25 We also step in to make sure that those are resolved

13:58:29 , and work with our contracted entities to do that.

13:58:33 If the contracted entity is not meeting the expectations of the contract

13:58:38 or there are major concerns, then we can hold them accountable

13:58:42 through corrective action plan and that is one tool that we use

13:58:50 .

13:58:50 There is sanctions if we

13:58:56 choose to implement them.

But we like to have a collaborative working

13:59:00 relationship with all of our contractors and

work with them to make sure that

13:59:05 improvements are made.

LAURA VEGAS: Thank you. Thanks to everyone

13:59:08 and to our state panel.

I always learn a lot

13:59:12 on these panels.

13:59:14 You will see on your screen a post webinar

13:59:20 evaluation.

Please let us know how we did. We are always

13:59:24 a need for feedback to constantly

13:59:26 improve the work that we do and resources
we provide. Have a great afternoon.

13:59:31 We appreciate your purchase a patient and
active conversation in the question and

13:59:36 answers.

Thanks.

13:59:48 (

13:59:48 End

13:59:48 of w

13:59:49 ebinar

13:59:50)