# **Create Your Own Community: Understanding Your Role in Decision Making Transcript with Time Stamps**

0:01

this meeting is being recorded welcome everybody hello thank you so

0:08

much for joining us today um happy Friday to everybody

0:13

um you are here because you are very interested in talking about creating your own Community understanding your

0:20

role in decision making which is what we're here to talk about today this self-advocacy training will focus

0:26

on a new home and community-based services for HCBS settings rule that

0:33

empowers Advocates to make their own decisions in their community my name is Donna Meltzer and I'm the CEO

0:40

of the National Association of councils on developmental disabilities or nacdd

0:47

[Music] nacdd is the National Association for the 56 council's on developmental

0:54

disabilities or sometimes who are called DD councils for short and we are across the United States and

1:01

the territories I'm so pleased today to join with our longtime partner Autism Society of

1:08

America Kim mushino and Chris Banks I want to thank you both for welcoming us

1:14

as your partner in this training session so today we are going to bring you new

1:19

information hopefully Empower more self-advocates and family members to

1:25

understand this new rule and make a plan to exercise your rights under the new

1:30

HCBS settings rule self-advocates fought for years to get

1:35

the government to make this rule the HCBS settings rule reaffirms that people with disabilities and older adults

1:43

receiving Medicaid home and community-based services um receiving Medicaid services have the

1:50

right to community life including access to the broader community control over your daily lives and opportunities for

1:58

employment we're holding this webinar now because the rule is finally going to be taking effect in just a few months

2:04

and we want to make sure that you are prepared so in the next 90 minutes or so we will

2:11

explain this new HCBS settings rule in plain language so you can use it as a

2:17

tool to have discussions with your provider or case manager your support team your family about the community you

2:25

want to live in we will also hear from self-advocates about the importance of person-centered

2:31

planning and how to express and get what you want from providers and your family so you can live the best life that you

2:40

want finally we'll break into some smaller groups so that you can work on an action

2:45

plan to develop your own plan for creating the community you want to live in again I want to thank you for joining

2:53

with us today I hope you will learn a lot and will fully participate now it is my pleasure to introduce Kate

3:01

Brady from the Human Services Research Institute or hsri Kate will speak with

3:08

us about the rights guaranteed to all people receiving Services Medicaid

3:13

Support Services Under the HCBS settings rule Kate thank you so much for being

3:19

with us today I turn it over to you thank you Donna and thank you to

3:25

everyone who's here to learn about the home and community-based settings role uh which

3:32

really is tremendously important in our everyday lives so before we talk about

3:38

the very key rights that the home and community-based settings rule affords us

3:45

I want to be sure we are thinking of the same thing when

3:50

we think about home and community-based services these are services that provide support or help for

3:57

employment Transportation um Home Health like housekeeping or

4:03

in-home therapies like physical therapy or occupational therapy or help with

4:09

activities of daily living like getting dressed every day uh getting in the shower going to the bathroom cooking

4:17

and then other things like assistive technology and modification of your home

4:24

and there are four point in 2018 so there's more now in 2018 there were more

4:31

than 4.7 million people so we have 36 people on today and all of you probably

4:38

have thoughts and things to say about the supports that you receive

4:44

and HCBS services are Medicaid funding meaning they're federally and

4:49

state-funded supports and every state provides the supports differently which

4:56

is why it it's so important to be clear about what rights

5:02

the settings rule gives you so I'm going to go through some key

5:08

rights the first is privacy

5:15

meaning you should wherever you live be allowed

5:20

to be in your own bedroom by yourself if you want or go somewhere else in the house to get

5:27

away from other people uh you also should be allowed to have visitors in that space and have privacy

5:34

with your visitors in that space the rule also affords us the right to

5:40

dignity and really simply dignity just means that you should uh in your everyday life

5:48

and with the services that you're getting and the hope that you're getting from the people around you you should uh

5:54

be allowed to feel good about yourself and be treated like you're worth something

6:00

another really important right afforded by the HCBS settings rule is the freedom

6:07

from coercion meaning that the people supporting you and other people in your

6:12

life should not be making you do things that you don't want to do

6:19

the next one is freedom from restraint and freedom from restraint is probably

6:26

the most complicated of the rights that this rule gives you because

6:32

unfortunately people with disabilities experience being restrained

6:38

in lots of different ways it can be really simple like somebody

6:45

holding them somebody holding you to keep you from doing something

6:50

um it can be uh having somebody put something on your wrist like restraints

6:56

um or tying your arms down um or making you stay in bed and using

7:01

restraints that keep you in bed or something to cover your hands uh it can

7:07

also be being locked in a room uh not being allowed to get out or not being allowed to get food

7:15

um and being punished right so restraint is usually about being punished and

7:21

people in HCBS services are everyday citizens nothing about your

7:27

support should involve being in trouble or being punished another example of

7:32

restraint is using alarms to make you stay in bed or stay in your house

7:40

and the last way that we know that sometimes people experience restraint is

7:46

that they're given medicine to control their actions so maybe too much medicine to make you sleepy

7:53

um or not care about stuff and that isn't allowed either

7:58

um respect much like dignity is a right that you have within your

8:03

services uh and that just means treating other people with kindness and consideration

8:10

um and that means that you should expect to be treated with kindness and consideration and that you should expect

8:16

to treat others in that way as well and it also means being allowed to speak up

8:22

and that's what we're going to talk about today being able to speak up about what you need and want

8:29

um so you'll notice that the home and community-based service settings will uh

8:35

says settings meaning we are interested in where do the supports that you get

8:42

happen and do you have full access to the Greater Community

8:48

um so that means that you should have choice about where you live where you work um where your job is if you go to a day

8:55

program um if instead you want to do things with

9:00

people without disabilities and be able to go to the coffee shop or the movies

9:06

um and the other right is choosing from non-disability specific options right so

9:13

that means um spending your time with people with and without disabilities

9:19

um the rule also requires that you have a personal centered plan and that what

9:25

they call your individual initiative is optimized and that just means that

9:32

you're supported to live your life the way that you want um so what you do having control over

9:39

your schedule having control over your money um

9:45

and choosing who provides your help as well as what hope you get

9:51

and those are the main rights afforded to you uh by the HCBS settings role they are

9:58

easier to describe than they are to make happen so I'm going to turn it over to

10:04

Emmanuel so that we can talk more about this thanks

10:12

um thank you for for the very quick overview and welcome everyone to our

10:19

example advocacy LED they know about the new Roman community-based Services

10:25

ruling uh as Kate mentioned uh the rule

10:30

has uh more than uh more main points but today

10:36

we are here to talk about those but primarily talking about and showing that you as an

10:44

individual are uh involved in those decisions and making sure that you have

10:50

need power to enjoy that you receive the services that you want that you are not

10:57

coerced into doing things that you don't want to do that you are able to have

11:02

visitors uh and months months more so I have a manual objective I am the

11:08

community relations officer for the Delaware developmental disabilities Council and I've had the pleasure of

11:15

being there the moderator today what's an amazing panel member uh so I'm Kate

11:23

has already been in an introduced But Cake does a really big job

11:29

um that she does really well working for I want to make sure I say this

11:36

properly Human Services Resource Institute

11:42

um again welcome game uh and we've got Liz weintra

11:48

I need a leader in these stuff I advocacy movement I am the host of

11:55

Tuesdays would live um lives and it's also an important time

12:00

staff member for aucd which is the answer Association of

12:08

the universities are the center for disabilities

12:14

and then we have in one second

12:19

I'm using the screen reader so I do apologize for giving me one sec we have

12:24

Derek's fun Derek um they're great on Derek was diagnosed

12:31

with autism uh in 2014 they're graduated from

12:38

Old Dominion University in December of 2020 with a double major

12:47

in Spanish and English

12:53

um with sorry I'm Butcher and Derek's Derek I

13:00

apologize give me one second my screen reader has frozen

13:06

speaking of assistive technology we have one on that one

13:23

you want me to help out your manual oh hold on one second I'm sorry now

13:34

where they're gone he had an emphasis on

13:41

um English and creative writing uh they

13:47

joined the board of Autism Society uh where he can continue

13:53

his work and advocating for those with autism so again welcome

14:00

to all of the panel members uh and we will jump right into our questions

14:07

my first question is for list one drop

14:12

uh Liz can you tell us a little bit about your community living

14:19

um your community living situation and Edison

14:25

important uh for you to be able to make decisions

14:31

thanks thanks and Mel um Manuel and I'm really excited to be

14:40

here today um so thank you DD as well

14:48

um the autistic Autism Society of America for inviting

14:55

me community means to me freedom and that I

15:03

can walk around in around the community just like anyone else

15:10

I know what community means I know what community means and what it's not

15:19

um because um when I used to live

15:25

um in um I used to live in an institution and because there's a community they called

15:33

the big community and that's how they got my parents to

15:40

okay say that I should go and um it's not the kind of community

15:48

television today oh where I can where I can shop and eat and be part of

15:56

the community um so that's a little bit about

16:04

what community means thank you Lynn so much uh my next

16:10

question is for Derek uh Derek what service what services do you receive

16:18

hi thank you um I I'm currently receiving case management with um the

16:24

city of shares of peak and and I have a housing guide because I'm working on

16:29

moving into um my first apartment and um I also

16:35

um for I'm temporarily getting a recreational and occupational therapy

16:42

thank you Derek and congratulations for working on moving into your own uh

16:50

apartment or a house so congratulations on that thank you mind that question is

16:57

for King uh k Why Why is the HCBS are setting rules so important

17:07

thanks Emmanuel uh it's so important because it affects

17:15

all of our everyday lives uh it affects all the people with disabilities uh and older Americans we

17:22

know get services and all the people in their lives and their neighbors and their co-workers because

17:29

it says finally that Services must uphold those rights that

17:37

we talked about and that they must make our lives better and they must be the ones that we choose they must be the

17:43

services that we choose um so that's why it's so important it's

17:53

taken so long for it to happen it's been eight more than eight

17:59

years we've been in what we call the transition process because it's a huge

18:05

complicated system and like we said states have choice in how they

18:10

administer services and there is money could be made and

18:16

serving people in segregated settings and not providing choice

18:23

so it has taken us time to move the system and finally uh we are we are

18:31

coming up on the deadline um so we'll see that

18:36

there will be a requirement that states are in compliance in March 17th of 2023

18:45

thank you so much uh for for that and uh to live as Kate just

18:53

mentioned uh this woman has took uh quite some time uh but you've been

18:59

you've been fighting uh to see this will really come to reality why do you think

19:07

um why do you think a rule left had to be put in place for this to uh to really

19:14

come to fruition for people with disabilities there and that question is for Liz

19:20

um and thank you thank you Emmanuel for asking that question because yes it has

19:29

been a long time and I don't know if I did

19:34

um to to not only be here but to see that this is going to be a reality

19:44

um in in March going to really be here

19:51

um because um because unfortunately some some people

19:58

should just provide their families um don't often see us as as people who

20:06

can decide for decide what we want in our life people see us as children

20:13

people see us as they were not able and

20:19

able to make a decision if I make the wrong decision

20:26

who who is anyone to tell me that I'm making the wrong decision

20:34

I'm an adult um I'm over 50 years old

20:39

I think that's an adult and why am I treated with the kids

20:50

thank you so much Liz you're welcome uh my next question is for Derek Derek

20:57

are you excited about the uh new settings rule

21:03

I am because I think it's important to have um rules that um help people with

21:09

disabilities to to get the the rights they deserve set in stone

21:16

um and I I would say that um like I I used to receive in-home services

21:23

um and um it I I um I often had to deal with workers

21:31

um who were rude or showed up late and left early and

21:36

um because I needed help with getting with them getting me to appointments um and if I didn't get there on time

21:43

then I wouldn't be able to have the appointments that was um that was more than inconvenient

21:54

thank you so much Dirk hey you are absolutely come back in with this new ruling uh you

22:00

know you'll have more control with people's uh believing early and and

22:06

things of that nature so thank you for that my very last question

22:12

um before we close on this panel it's brickade okay all students have to follow this

22:19

rule um starting in March 17 2023 why why is this date so important

22:27

for self-advocates to remember and what can we do to ensure that we are

22:34

ready when March 17th comes around thank you Emmanuel you can tell that I

22:41

was so excited about that date that I jumped the gun and I already said it and and then Kim put it in the chat so the

22:48

date for all states to have either an approved Statewide transition plan

22:54

saying how they're going to come into implant compliance or a corrective

23:00

action plan saying what they're going to do about the places they don't that can be in compliance uh is March 17

23:09

2023 and so what that means is that all of those basic rights should be honored

23:16

everywhere that you're getting Services uh and the only exceptions that some

23:22

states may ask for is they may ask for more time to offer everybody employment

23:29

supports and they may ask for more time to be sure that people can choose their roommates but every other thing privacy

23:37

dignity respect freedom from coercion all of those rights should be in place

23:43

so what that means is that we need to be ready to say if it isn't and that could be telling a friend or a family member

23:50

it could be talking to a case manager it could be changing your services it could

23:57

be talking to your elected official your Senator your representative your city

24:02

council person um always speaking up if you feel like you're rights are being violated

24:10

that's the biggest biggest most important thing and then if you want to you can also

24:16

contact nacdd or the Autism Society and they will help get you in touch with the

24:22

right person and remember that that person-centered plan is the pathway that

24:29

you have for planning out how you want your life to go for the year and you're entitled to that plan being completely

24:37

up to you how it goes Who's involved how you make those decisions

24:43

I think those are the important things to remember thanks Emmanuel absolutely thank you so much so March

24:50

17th is the most important day that I can think of support so if we all have

24:55

which I hope that we all have a calendar and then we don't got a 23 calendar yet

25:01

we need to get one and make sure that we put that date on our calendar and continue to educate and Advocate

25:09

individuals uh before that day comes around I want to take all of my panel members

25:15

uh through such a great discussion and very willing to open up and talk about

25:22

your settings and why this is so important and and how we can work together to

25:28

ensure that every person with a disability that receives Home and community-based Services is ready for

25:36

March 17th when it comes around I will now turn to go over

25:41

to Aaron frankly policy director for

25:46

nacdd thank you Emmanuel and all of our

25:52

panelists uh we do we are running a little ahead of time so if anybody has a

25:58

question they should feel free um to raise their hand in the chat the

26:03

participant room or just type it in the chat box um I have a question for

26:11

um for Kate um Kate could you could you remind us

26:17

what a person-centered plan is and how do we know whether we have a

26:25

person-centered plan and who do we talk to

26:30

thanks Aaron that's a great and important question um I'll also put the website for the

26:36

national Center and advancing person-centered uh practices and systems in the chat uh

26:43

but a person-centered plan in this context is the plan that you make with the people

26:50

that you trust in your life might be family friends neighbors co-workers for

26:56

the kinds of supports that you're going to get in the year and it and it should

27:02

be a conversation about what you want your life to look like and

27:09

what your goals are of your choosing and so how to know the difference between a

27:16

service plan and a person-centered plan is that somebody will have talked to you about

27:22

who you are and what you want and what your interests are and what your strengths are and What needs you have

27:29

and as we mentioned you will have had choices about disability specific and

27:35

non-disability specific environments and that planning process probably

27:42

happens every year for most people but it's a live thing right our lives change

27:49

and it's something that you should be able to change um throughout the year when you

27:55

want to and the person helping you write that plan should be

28:01

really good at it they should have lots of tools and ideas for how to help people think about there their lives

28:09

I hope that answers that question Aaron yes thanks Kate and we have a couple of

28:14

other comments uh Liz did you want to go ahead and go next yeah and then after Liz we'll go with

28:20

Nathaniel thanks um I I wanted to share a story about my

28:27

services and my husband's services and by the way I was given permission to

28:34

talk about on that with my my husband so I I want

28:42

to make it real clear that I asked him about on the story as well first

28:51

um and this happened yes with the last few months

28:57

um since May um we we haven't had the DSP

29:05

um because of the ideas people shortage which is

29:12

not my providers fault it's just a

29:17

um another issue that is on the uh

29:22

chopping pot um and um we need to work on that as well

29:31

um but so um

29:36

my DSP quit and they um

29:43

our providers um um I I needed

29:49

someone to go shopping with me not for food for clothes and

29:56

um and that was all fine and then I needed

30:02

someone to help me go to mail something

30:08

um and um and that's when I ran into this issue

30:17

the issue was that we um my husband and I wanted the DSP to

30:25

come at a certain time um because we have a routine

30:31

we have a life to deal with of our own

30:37

lives we we do things the way we want to deal with

30:44

um have and it's not up to Pro

30:49

um the provider to tell um me or my husband when we want

30:57

um our DSP to help we're not there to

31:03

um to fit into their schedule they need to fit into our schedule and

31:11

um this is about us this isn't about families there's ours the state it's

31:20

about us meaning people with disabilities

31:25

we give Services is like going to pick

31:30

out um um the apple or the orange at the

31:37

grocery store well nobody says pick the pear

31:43

you you picked Where You Are so

31:48

um that's my story thank you Liz and then Nathaniel um put

31:56

in the chat I am on private insurance and was told that in order to keep my case manager I was coerced into Medicaid

32:03

why are people on private insurance excluded from getting the same Services as people in Medicaid Nathaniel did you

32:11

want to add anything to that yes my name's Nathaniel Guyer and I am a

32:18

research of poor technologist at Hershey Medical Center I make over the threshold

32:24

of Medicaid threshold and many of you are on so I was excluded because of

32:32

income and I and I was coerced even though I have private

32:39

insurance I was coerced into applying for Medicaid I ultimately was rejected fortunately but I guess I was coerced

32:49

and I was so embarrassed that I was coerced and I actually was dropped by

32:54

the county because I wasn't on Medicaid and that is something that gives me a

33:01

big stick in the mud being coarse in the applying for something that I honestly

33:06

don't need because I drive I am a voter I pay taxes but yet I was coerced into

33:14

Providence Public Insurance private insurance does not have all the rights as people in public

33:21

insurance and I'm glad that I'm not on Medicaid I have a different perspective

33:28

about this rule I think it's a good start but it needs to include people in public and private insurance as well

33:37

did you want to did you want to try to uh address that issue of why don't private

33:44

insurance companies have to follow this rule yes that is a

33:52

yeah that's a good question so before I try

33:57

to answer that question although I don't know all the answer I want to point out that

34:03

this Rule and advocacy around the rights that people with disabilities have is

34:10

something you can absolutely be involved in while not being a person who gets

34:16

Services right like we all need allies and so you can still care about it and

34:22

speak up about how you think things should be even though you're not a person getting Services the reason that

34:31

um someone might have said Medicaid is important is that Medicaid allows for what's called a

34:38

Medicaid waiver and the waiver I'm familiar with that yeah so it's it's that

34:46

it's that option to waive the limitations that exist in private

34:51

insurance and get the community-based services that a waiver allows

34:57

um that is so unique to to federally and state-funded Home and

35:03

community-based Services this thing is like help with um getting dressed every day and

35:09

maintaining your house and cooking meals and going to the grocery store like Liz said those are things that regular

35:16

health insurance private regular health insurance and regular Medicaid doesn't

35:22

pay for you can only get these things yeah so that's probably why

35:27

yes yes but I don't have a concern about that my concern is more or less the fact

35:33

that the poverty threshold has not been a rose in several years and I make more

35:39

money than the property threshold allows and that's and it's very concerning to me that

35:46

people have advocated for service things but haven't actually Rose in the poverty

35:51

threshold no kidding could not agree with you more and that

35:57

is a such an important advocacy area because some states because this is up

36:02

to States some states have created higher income thresholds some states

36:08

have created Medicaid buy-in so that even if you earn a lot of money you can purchase Medicaid so there are solutions

36:16

but they are not available everywhere so um completely thank you

36:22

thank you Nathan and Kate and there is federal legislation to increase those

36:27

income thresholds it's going to take a lot more advocacy as well um the next person is read Eaton read

36:36

would you like to ask a question or give a comment

36:44

I'll do it towards the end but um I'll wait but uh

36:51

I'm going to continue listening on what's going on thank you

36:59

foreign thank you Reed and I don't see any other

37:04

questions did any of our panelists want to give any final remarks or share stories that you weren't able to share

37:10

in your comments before we go to the workshop yeah I do this list and I just

37:18

would like to say because I was part of the

37:23

um a small group uh people who were talking

37:30

about this um in the 2000s early 2000s I think it

37:37

was like 2000 and five or six or seven I'm not quite sure

37:46

wins um I I keep on forgetting

37:51

um but it was in the early 2000s and I

37:57

we want it to be a rule so not

38:04

um that um that this is our life

38:10

um I know we get services from our provider and our families

38:16

and um even the state might have a safe in their services

38:22

but but whose services are they

38:28

it's my services or my um my husband's services so yes yes my my

38:39

family might have something to say about about

38:46

our services and what they how have how about work or what we want

38:54

to use or our DSP for but at the back at

39:00

the end of the day is our decision it's our decision and I

39:08

want to make that real clear to the audience that it's our decision if no

39:15

one else's decision than us so

39:22

thank you Liz and you always remind us nothing about us without us right that's what is the most important thing and um

39:30

again I don't see any other questions um any of the other panelists have

39:35

closing remarks or something they forgot to say

39:42

um I I just wanted to add that um I I am with um the moving that I'm doing um and

39:49

the the housing guide that I have um sometimes it can be tough to um to make

39:57

decisions um because and this this isn't

40:02

necessarily because of um the the a lack of um protection in in the in the way

40:09

it's done but um uh so with um with the housing guide that I have um I I I've

40:17

had trouble communicating with them and they're further away um so um I met with my case manager this

40:24

morning and I um it just since it's a newer thing a newer um

40:32

um area in this in this um just um well I'm sorry but um it's a new it's

40:39

a newer area and so um I've um they're just aside from um the

40:48

the the housing guide I currently have there's only one other company I can switch to

40:55

and I don't really know much about them so anyway what I'm just trying to say is um sometimes it's just there's just a

41:02

lack of options in general and that can be tough um um especially when you only know so much

41:08

about them so it's just um it it just like a little bit of um

41:14

playing around I guess you'd say can this is this Liz and can I also make

41:24

one of the point by telling a story that I probably forgot to tell

41:32

um this happened probably I'm guessing probably

41:39

um seven or eight years ago and it was on a hot day

41:45

and our warm day I should say and

41:51

um to the um my project my DSP came into our apartment it was my

42:00

husband and my apartment it was not his apartment and he he said oh I'm hot

42:10

and he turned up the air conditioning and without even asking my husband and I

42:19

and um that wasn't very like it like if we

42:25

went into to someone else's house and say

42:31

oh oh I'm hot um you were yelling me you would say

42:38

that I'm rude well I can't say that about that about him because he he give

42:47

me services and sometimes I'm afraid to be rude to him because

42:54

I worry that that my services will will disappear well that's not right

43:02

you have a right to say to Jim and they're using Jim as a name

43:10

um because I don't want to use his real name you can take to Jim look this is my

43:17

house and I'm uh I don't want it to be cold I want it and if you don't like it

43:25

leave Liz I think your stories are so

43:31

important um and it just I we we do have to go to the next section in just a minute but um

43:38

Kate I did want to ask you following up on what Liz said so um so yeah how do you you know how is

43:46

this rule going to help people who you know are afraid of retaliation you know a lot of the supports that are provided

43:53

could be you know help very very important help they can't you know that

43:58

they need in order to live their lives and that maybe they're a little afraid to to speak up how how is this rule

44:06

supposed to help them yeah yeah and it is totally scary Liz and

44:13

I've been in that exact situation and it's infuriating but also scary

44:20

um so there are some ideas and some processes that states are supposed to

44:27

put in place and the big one is that every state will have a plan for how any

44:34

person getting Services can make a complaint and get a response and help solving that

44:43

issue and they are obligated to make sure

44:48

that when you make that complaint you can do so safely and nothing bad can

44:53

happen um and your services and needs are safe now the truth is states are still in the

45:02

process of deciding how they're going to do that so in the meantime

45:08

everybody getting Services also has some kind of case manager or a support

45:14

coordinator and that job is always supposed to be that person should always be on your

45:21

side and they should be a safe person to tattoo um but we know that

45:28

sometimes you don't know that person really well I think I've had like 10 case managers in two years

45:36

um so that's why it's so important that the state is going to come up with a plan um

45:42

and it's also why it's so important that we have self-direction and that we have lots of choices of providers like you

45:50

were saying Derek right because if there's only one choice and Liz if you fire that guy that turns

45:56

the AC on and there's nobody coming later then you're stuck so that's

46:01

another reason we have to work on provider development oh and yes

46:07

ndrn of course Liz so everybody in their state has

46:12

what's called a protection and advocacy organization we'll put the link in the chat and that organization

46:21

um is federally funded to help with violations of your rights

46:27

is that anything you want to add Liz no you said

46:38

well again this is Aaron I want to thank all the panelists and participants for those great questions

46:44

um we're going to move on to our Workshop where everyone's going to have a chance to break into small groups but

46:50

first so let me introduce myself my name is Aaron prangly I am the vice president for the National Association of councils

46:56

on developmental disabilities and it's time to get to work on making our own plans to exercise our right to live the

47:03

kind of lives we want to live using the tools of this new settings Rule and

47:10

building off of the stories that we've heard today so we're going to watch a very short video it's about five minutes

47:15

long during the video You're Going to Hear questions that you might want to think about

47:21

so if you have a pen or pencil or someone with you who could help you you know jot down your answers to those

47:28

questions or thoughts about those questions that could be helpful when we break out into small groups so after the

47:34

video we will break into small groups and discuss ways that we can make changes to our services or other ways

47:40

that we can support the lives of people with disabilities in our community thanks everyone see you in a couple

47:45

minutes thank you

47:54

your services should be all about you if you receive services from a provider

48:00

organization or staff your services should be person centered this means your services should be based

48:07

on your hopes goals and dreams that is what's important to you need to be happy with the services that

48:13

you are getting you should be the driving force behind your services if you're not you need to speak up this

48:19

video talks about what your services should do for you and some of the ways you can figure out what types of services you want

48:26

all people have rights some rights you have because you're human some rights you have because you live in this

48:32

country some rights you have because you have a disability and some rights you have because you receive services

48:39

basically you have the right to a lot of different rights when it comes to your rights for your

48:44

services you have the right to be safe and healthy you have the right to privacy you have the right to dignity

48:49

and respect you have the right to choice and many other rights if trying to figure out which of your

48:55

rights are respected it may be helpful to think about these questions as examples do people listen when you speak up for

49:02

yourself are you able to have personal space and alone time

49:10

are you able to come and go in your home as you please are you able to have visitors where you

49:17

live if you answered no to any of these questions it may be helpful to think

49:22

about what changes should be made to your services so that your rights are respected

49:27

to fully exercise your rights you need choices Choice means that you can select the

49:33

services and supports that you need and want examples of choices include who provides

49:40

your services where to live where to work what to do for fun what friends to

49:45

hang out with what you want your future to look like and many more your services should provide you with choices

49:52

trying to figure out if you have choices it may be helpful to think about these questions did you choose the services you receive

49:59

and where they're provided did you choose who provides your services

50:07

choose where you live did you choose who you live with

50:13

if you answer no to any of these questions it may be helpful to think about what changes you would like to

50:19

make to your services so that they allow you to make these and other choices

50:24

Independence means that you are in charge of making decisions about your life for example you should be able to

50:31

choose what you do during the day you should be able to choose where you go and you should be able to choose who you

50:37

interact with trying to figure out if you have Independence it may be helpful to think

50:42

about these questions do you have a chance to make decisions about your life and what you want to do

50:50

you choose what you do for fun are you able to choose your own schedule

50:57

you choose how to spend your money if you answered no to any of these

51:03

questions it may be helpful to think about what changes should be made so the services you receive promote your

51:09

Independence you have the right to community integration access to the community

51:15

means you are an included member of your neighborhood and community for example you should be able to

51:21

participate in local activities and events receive services in your community

51:26

run errands and go shopping have a job in the community and many more

51:31

if trying to figure out if you're integrated into your community it may be helpful to think about these questions

51:36

do you spend time in places where other people living in your community go

51:43

do your service providers support you to do what you want to do in your community

51:49

[Music] do you get to do as much as you want in your community

51:54

foreign

52:00

if you answered no to any of these questions it may be helpful to think about what changes should be made so the

52:06

services you receive provide the opportunities you want to access and be part of your community

52:12

like I said before your services should be all about you your rights your choices your Independence and your

52:19

community integration if your rights are not about you and you're not happy with your services you

52:25

need to speak up it's your right your organization should know what's important to you and your services and

52:31

supports should help you achieve your goals if you're nervous about speaking up you should talk to someone you trust about

52:37

what you want and need another way to advocate for the services you want is by sharing your opinions

52:44

with your case manager or support coordinator your ideas will help them make changes so your services are about

52:50

what you want if you feel that your rights aren't being respected you should talk to the

52:55

human rights committee at your provider organization in each state there's also a disability

53:00

rights protection and advocacy system which can help people with disabilities with legal or advocacy support

53:07

your services should be all about you you have the right to make decisions about your services and speak up for

53:12

yourself as self-advocates say nothing about us without us

53:19

this video was made by the idd mltss work group you can find more resources like this on

53:25

our website c q dashl.org mltss for more information about what we

53:33

shared in this video see HCBS guide your right to a community life developed by

53:38

the bogg center on developmental disabilities at Rutgers University

53:44

thank you so again you know this service these services are all about you

53:50

um we're this time we're going to break up into small groups and we'll have about oh probably about actually more

53:56

time now than we had before 15 minutes I'd say Delancey can we do 15 minutes

54:01

um so each room will have uh so you'll see a button pop up on your screen assigning you to a room go ahead and

54:08

click that button and you'll get into a room a small group where there will be a leader to lead the discussion for you

54:15

this is your time to share how you want to make a plan

54:20

um and so others can listen from you too so go ahead and click that button uh

54:26

we'll let you know when time is up and then we'll return to the main room for remarks thanks everyone see you soon

54:34

thank you everyone um for rejoining us this is the um this

54:40

this has been a really wonderful Workshop um thank you for participating in your breakout rooms I hope you found the

54:46

conversation valuable as I know I did we probably could have talked for another 15 minutes

54:52

um but as we begin to gather in the main room there are just a couple of poll questions that we would like to ask you

55:00

um so Delancey if you wouldn't mind publishing the first poll question and

55:07

it should come up there and the question is uh well it's a statement this

55:13

Workshop helped me understand my right to receive Support Services better so you can only pick one you can say

55:19

strongly agree agree or neutral so go ahead and pick one and then question two says I am better

55:27

prepared to work with my support team to create the life I want because of this

55:32

workshop and then once again you can answer agree strongly agree neutral or disagree

55:38

and these this poll will help us um to talk to our funders and government

55:44

to tell us you know what value we see in continuing uh programs like this but

55:51

also if you have other feedback that you would like to give about the program again please include the technical

55:57

feedback because that was a big problem today and I apologize again for that but if you have other things you'd like us

56:03

to do in the future please send me an email directly and I will put my email in the chat box

56:11

and at this point I'm going to turn it over to Kim muchino for closing remarks

56:17

Kim well thanks Aaron um and I I just want to apologize up

56:22

front for anybody who was in a breakout room and got and was speaking and got cut off

56:29

um that wasn't your moderator's um fault it's just the time ran out

56:35

um and uh on that point you know we can keep this discussion going

56:40

um if you you know want to email any of us feel free also while we were in the

56:45

discussion groups um we did learn that um you know some of the some folks in in

56:51

my room at least um could use some some uh support some advocacy

56:57

if you need some help in your in your self-advocacy for getting the services

57:02

that you need please feel free to reach out as we said to

57:08

um your DD Council in your state uh your um local Autism Society affiliate uh

57:15

your uh disability rights Network um or other um other advocacy organizations that

57:23

might be able to help you you shouldn't have to feel like you have to do everything alone

57:29

so thank you everybody for joining this Workshop I I hope that you found it

57:34

valuable and I want to thank um Donna Meltzer um Kate Brady Liz Weintraub uh Derek

57:42

spawn Emmanuel Jenkins Aaron pringley the Autism Society and the National

57:48

Association for councils on developmental disabilities for helping to put this workshop together today we

57:55

really appreciated everybody's participation we we have recorded the session and we'll be sure to send out

58:01

the recording so that others can read listen to parts that they want to or if

58:07

they missed it they can watch it so please uh be sure to join us for this

58:14

Workshop which we're planning to do annually with different themes and topics

58:20

um and uh again um please feel free to reach out um thank you and have a great rest of your

58:26

day

English (auto-generated)

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