



*Easy Read Edition*

# **“Who’s in Control?”**

## **Control over community services for people with disabilities**

# Focus Group Members

- Chaqueta Stuckey
- Elouise Woods
- Ivanova Smith
- Jason Billehus
- Katie Griffith
- Nicole Leblanc
- Nicole Villemaire

ASAN thanks all our focus group members for their time and effort.

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*The Community Living Policy Center (CLPC) is funded by the National Institute on Disability, Independent Living, and Rehabilitation Research, grant number 90TRCP0004. NIDILRR is a Center within the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS). This resource's contents reflect the views of the authors and not the National Institute on Disability, Independent Living, and Rehabilitation Research*

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# **“Who’s in Control?”**

## **Control over community services for people with disabilities**

### **Part 1: To Start**

## To Start



This toolkit will talk about community services for people with disabilities.



We want to know how we can tell who is in control of their services.



We want to know what questions to ask to see who is in charge.





We talked to a group of self-advocates who get community services.



We asked about how we can tell who is in control of their services.

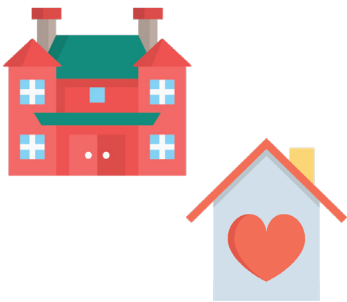


This toolkit will talk about what they came up with.

This toolkit will answer questions like:



- What are long-term services and supports?



- What are institutions? What are home and community-based services?



- What are quality measures?



- How do people come up with quality measures?



- How can we tell who is in control of their community services?



- What questions should people ask to make sure we stay in control?

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# **“Who’s in Control?”**

## **Control over community services for people with disabilities**

**Part 2: What are LTSS?**  
**What are institutions and HCBS?**

# Words to Know in Part 2



## Long-term services and supports (LTSS)

Services that help people with disabilities live our everyday lives. Some kinds of LTSS are job coaches and in-home helpers.



## Institutions

Places where a lot of disabled people live. People living in institutions did not decide to live there. They usually can't leave when they want to.



## Home and community-based services (HCBS)

Getting LTSS in the community. In this toolkit, we usually call HCBS “**community services.**”

# What are LTSS? What are institutions and HCBS?



Some people with disabilities need **long-term services and supports (LTSS)**.



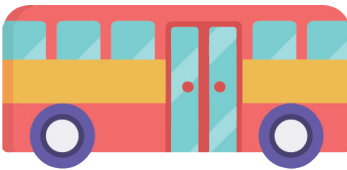
LTSS are services that help people with disabilities live our everyday lives.



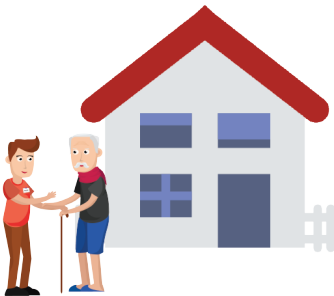
Some kinds of LTSS are:



- Job coaches



- Transportation



- An in-home helper



Some people with disabilities get LTSS in **institutions**.



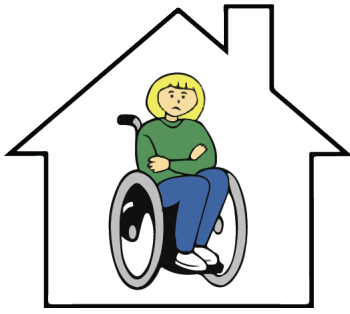
Institutions are places where a lot of disabled people live.



People living in institutions did not decide to live there.



They were usually put there by someone else.



Institutions are not run by the people living there.



Institutions are run by the people who work there.



People living in institutions usually can't leave when they want to.



They usually can't spend their free time how they want to.



Other people with disabilities get LTSS in their community.



They get LTSS in their own homes.



Getting LTSS in the community is also called **home and community-based services**. Some people call them “**HCBS**” for short.



In this toolkit, we usually call HCBS “**community services.**”

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# **“Who’s in Control?”**

## **Control over community services for people with disabilities**

**Part 3: What do community services mean to people with disabilities?**

# What do community services mean to people with disabilities?

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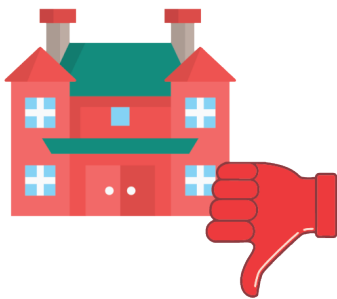
If someone lives in an institution, they *aren't* getting community services.



But people with disabilities have the right to live in the community.



We want to live in the community.



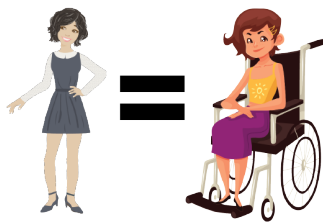
We don't want to live in institutions.



ASAN is a group of autistic people.



We work on disability rights.



We believe people with disabilities have the same rights as everyone else.



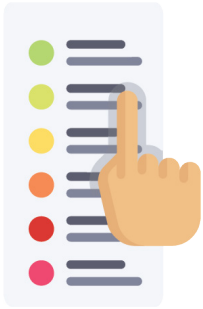
One important right ASAN fights for is the right to get community services.



We want everyone to be able to live in the community.



Living in the community means things like:



- Making your own choices.



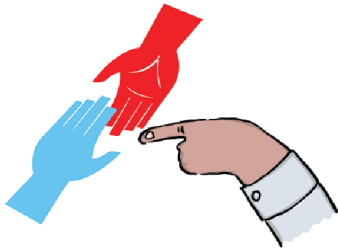
- Going out when you want to, and going where you want to.



- Living in the same places as everyone else.



- Getting the help you need to meet your goals.



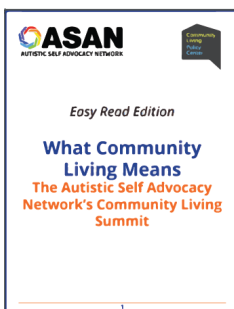
- Getting to choose who helps you, and what help you get.



- Meeting new people, and being with family and friends.



- Getting treated like an adult.



You can learn more by reading [What Does “Living in the Community” Mean?](#)

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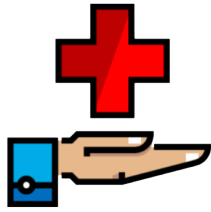
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# **“Who’s in Control?”**

## **Control over community services for people with disabilities**

**Part 4: Who decides if community services do a good job or not? How do they decide?**

# Words to Know in Part 4



## Medicaid

A health care program in the United States. Medicaid helps people get health care if they don't have a lot of money.

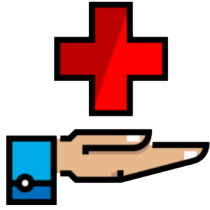


## Quality measures

Questions Medicaid can ask to find out whether health care is good or bad.

# Who decides if community services do a good job or not? How do they decide?

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**Medicaid** is a health care program in the United States.



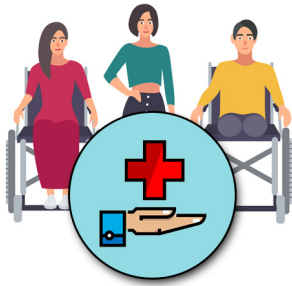
Medicaid is run by the government.



Every state has its own Medicaid program.



Medicaid helps people get health care if they don't have a lot of money.



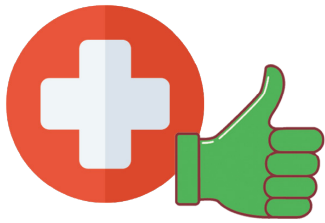
Lots of people with disabilities use Medicaid.



Medicaid pays for most community services.



People get community services from Medicaid using a “waiver”.



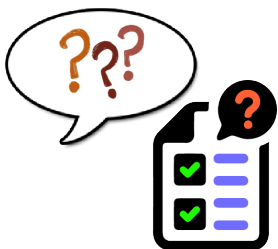
Medicaid wants to make sure people with disabilities get good health care.



Medicaid finds out whether health care is good or bad by asking questions.



These questions are called **quality measures**.



Quality measures are questions people can ask.



They can help figure out if a health care service is good or bad.

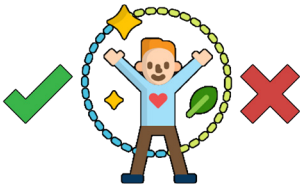




It is hard to figure out good quality measures for community services.

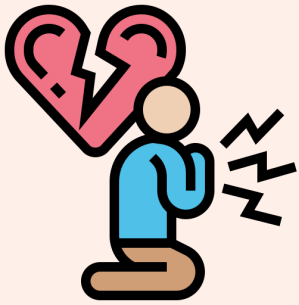


Most Medicaid quality measures got made to see if people are healthy or not.



It is easier to ask questions that help us figure out if someone is healthy.

For example:



Ned had a heart attack.



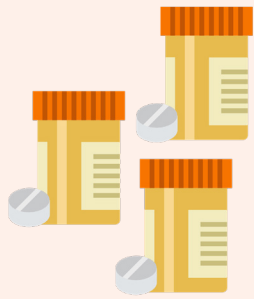
There are lots of questions the state can ask to check how Ned is doing:



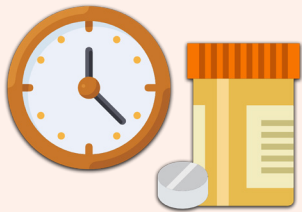
They can ask how long Ned needed to stay in the hospital.



They can ask how long Ned stays alive after the heart attack.



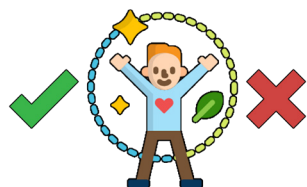
They can ask how much medicine Ned needs to help his heart.



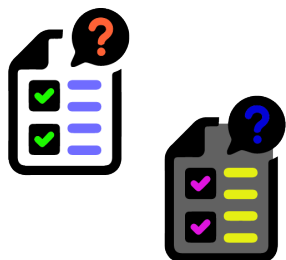
They can ask how long Ned needs medicine to help his heart.



But getting community services isn't just about health.

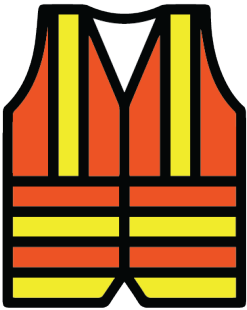


People with disabilities need community services whether we are healthy or not.



And, the things Medicaid should check are different.

Medicaid should ask questions like:



- Are people safe?



- Are people in control of their lives?



- Are people happy?



- Are people *actually* in the community?

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# **“Who’s in Control?”**

## **Control over community services for people with disabilities**

**Part 5: What quality measures are there to tell who’s in control?**

# Words to Know in Part 5



## Centers for Medicare and Medicaid Services (CMS)

The part of the U.S. government that runs Medicaid.



## Self Advocates Becoming Empowered (SABE)

A group for people with intellectual disabilities in the U.S. They do advocacy for disability rights.

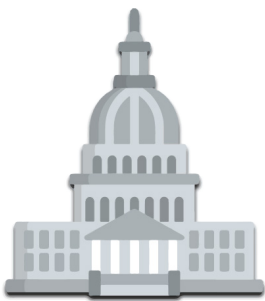


# What quality measures are there to tell who's in control?

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The **Centers for Medicare and Medicaid Services (CMS)** run Medicaid.



CMS is part of the government.



CMS writes quality measures for community services.



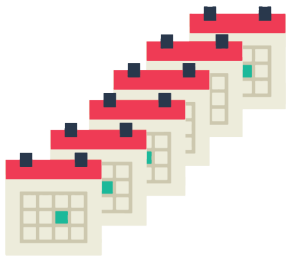
They need to figure out how to tell who is in control of their services.



It's really important to know who is in control of community services!



But there aren't a lot of quality measures to tell who is in control.



This has been a problem for a long time.



Roland Johnson was a Black man with an intellectual disability.



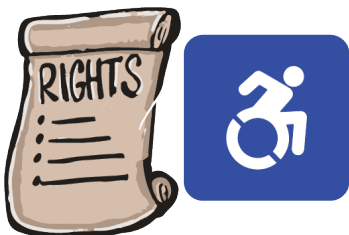
He lived in an institution for many years.



When he got out, he helped start **Self Advocates Becoming Empowered (SABE)**.



SABE is a group for people with intellectual disabilities in the U.S.



They do advocacy for disability rights.



In 1993, Roland gave a famous speech called "Who's in Control?"



He talks about how to tell if staff have control over someone's services.



He says that staff need to listen to people with disabilities.



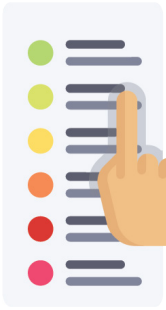
He said people with disabilities need to tell staff, "I am in control!"



That is what will help us take control over our lives.



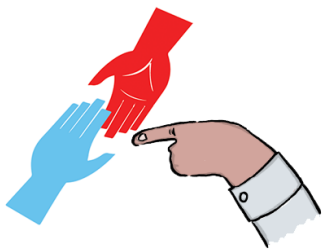
We have the right to live in the community.



We have the right to make our own choices in the community.



That means we should be in control of our community services.



When we are in control, we decide how our staff help us.



We get to figure out what works best for us.

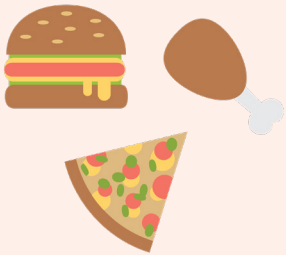


CMS already made a few quality measures about being in control.

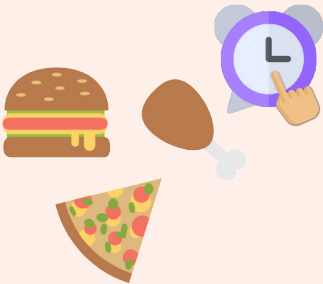


But there aren't enough questions. And the questions don't ask for enough information.

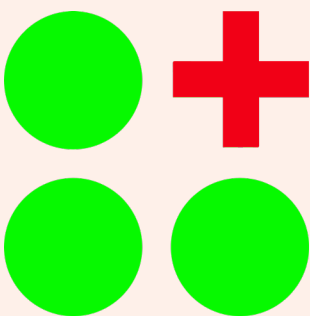
For example:



One question CMS came up with asks about eating.



It asks if someone can eat meals when they want to.



But when to eat meals is only one small part of being in control.



CMS does not ask if someone gets to choose what they eat.



CMS does not ask if they get to make their own food if they want to.



CMS does not ask if staff will help someone make food.



All of these things are big parts of being in control!





We should remember what Roland Johnson said.



We can help make good quality measures.



We can find out who is in control of community services.

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# **“Who’s in Control?”**

## **Control over community services for people with disabilities**

**Part 6: What did ASAN do to try and come up with quality measures?**

# Words to Know in Part 6



## Focus group

When people meet to talk about something

# What did ASAN do to try and come up with quality measures?

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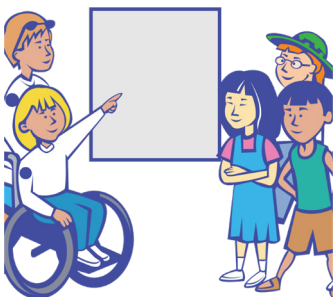
ASAN wants everyone to be able to get good services.



We want to make sure people with disabilities are in control of our services.



We want people with disabilities to help make quality measures.



Nothing about us, without us!



So ASAN had a focus group with people with disabilities.



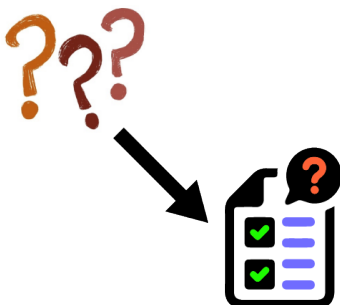
A **focus group** is when people meet to talk about something.



We talked about how to tell who is in control of their community services.



We came up with a list of questions to tell who is in control.



We can use this list to help make quality measures.



We can work with people who study community services.



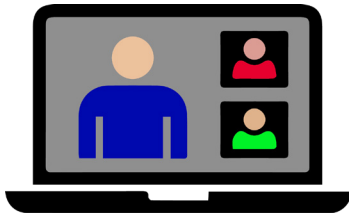
We can also work with CMS.



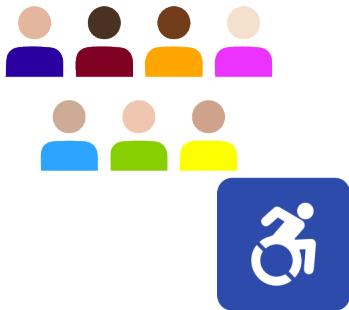
We can all work together to make better quality measures.



ASAN held the focus group over the internet.



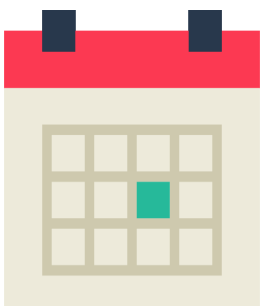
We used a video chat program called Zoom.



7 people with disabilities took part in the focus group.

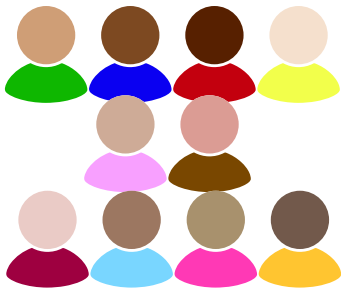


The focus group had 5 meetings. They each took 2 hours.



The meetings were in March and April of 2021.

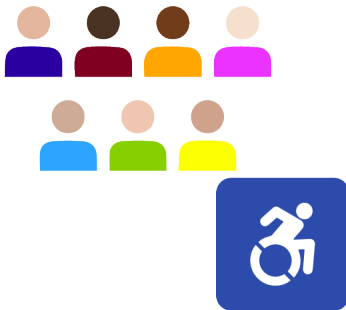




ASAN wanted all different kinds of people in the focus group.



We wanted to hear the experiences of people who got different kinds of services.



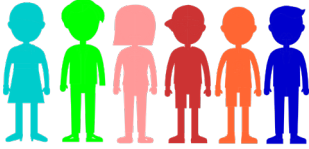
7 people with disabilities took part in the focus group.



They all get community services.



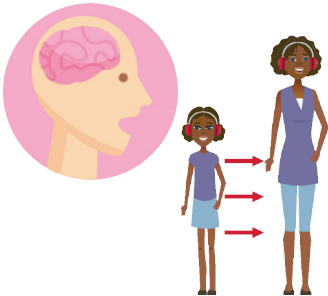
But they need different kinds of help to live in the community.



They are also different from each other in other ways.



They are different races.



They have different kinds of intellectual and developmental disabilities.



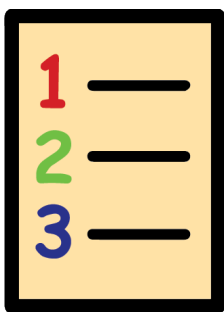
We started the focus group by explaining what quality measures are.



We asked people to think about their community services.



People had a lot of different things to say about being in control!



We split up the ideas everyone had into themes.

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# **“Who’s in Control?”**

**Control over community  
services for people with  
disabilities**

**Part 7: The big question: Are  
staff actually in control of us?**

# The big question: Are staff actually in control of us?

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There was one important point that came up in every theme.



This was about how staff can take control over someone's choices.



Sometimes, staff can be the one in control, even if it seems like they aren't.



They make choices for people with disabilities.



They don't listen to people with disabilities.



Or, they force us to make choices we don't want.



Staff come into our homes to help us.



If staff are in control, they have control over our home.



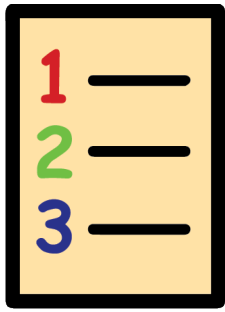
It is like living in an institution.



We want to make sure staff do their jobs.



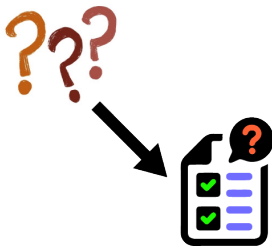
But we need to make sure staff know we are in control!



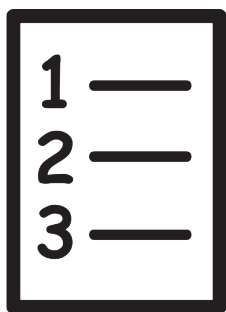
In this toolkit, we will go over each theme that came up in the focus group.



The focus group also came up with 12 big questions.



The group decided these questions should get made into quality measures.



We will list out these questions after we talk about each theme.





We will focus on how to tell if staff control someone's services.



Are people with disabilities in control of their community services?



Or are staff members for community services in control?

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# **“Who’s in Control?”**

## **Control over community services for people with disabilities**

**Part 8: What were the themes?**

# What were the themes?

## Privacy



Privacy is a big part of being in control of community services.



People in the focus group talked about privacy in lots of ways.

They talked about things like:



- Closing and locking the door to their room or house



- Being alone with their friends or partners



- Taking phone calls or making video calls by themselves



One person said staff needed to “mind their own business!”



They didn't like it when staff followed them around the house.



They said staff didn't need to know everything.



Staff can take away someone's privacy in a lot of ways.

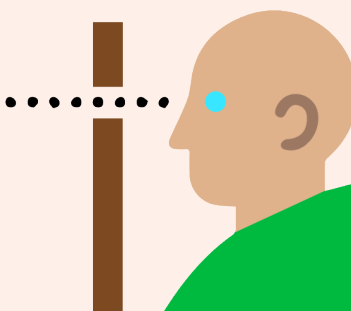
For example:



Amber's staff don't give her privacy.



They say they need to make sure Amber is "safe".



So they go into her room and look through her things.



They don't let her be alone when she wants to be.



They go to the bathroom with her when she doesn't want them to.



Amber's staff try to control her by not letting her be alone.



In this example, the staff are really in control.



Privacy about their community services was also important to the focus group.



They didn't want staff sharing information about them to other people.



They didn't want staff looking at their mail or bank information.



## What did our focus group members say about privacy?

“Internet privacy, like, did they get to have their own social media and have their own, like, privacy with being on social media? Hanging out with their friends? I mean, that’s really a benefit now with this everything being on virtual.”

“They shouldn’t even go out there and be telling our business but none of our information to anybody on anything, as I see, without our permission.”

# Respect



Focus group members said staff should always treat people with respect.



That means listening to and caring about people with disabilities.



Staff should let us speak up for ourselves.



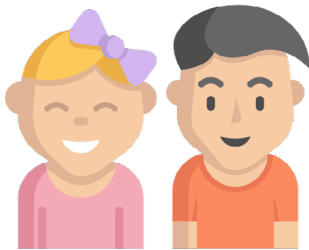
They should take our feelings seriously.



They shouldn't say bad things about us.



Respect also means treating people with disabilities like adults.



Focus group members said that staff treated them "like kids" a lot.



Sometimes, staff make decisions for people with disabilities.



That means we aren't in control of our services.



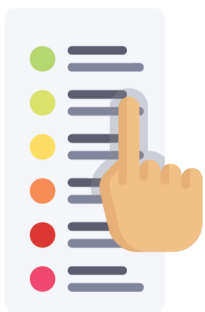
Staff say it's okay to make choices for us because we are "like kids."



They say we can't make our own choices.



Or they say we will make bad choices.



Staff need to know we are adults and can make our own choices!



Getting treated like an adult looks a lot of different ways.



Staff should let us go to places for adults, like bars.



We should get to meet other adults and have hobbies for adults.



Staff need to make sure we get to take risks.



If we want to try something, we should get to try it.



It doesn't matter if it doesn't go well.



Staff should still help us try new things.



Staff need to respect our decisions.



They might not agree with everything we want to do.



But they still need to help us do it.

For example:



Trishelle uses community services.



She has a staff member at her house all the time.



Trishelle decides at midnight that she wants fast food.



Her staff member doesn't want to go to McDonalds.



They don't want to drive so late at night.



But that is the staff member's job. They need to help Trishelle.



So they go to get fast food. Trishelle enjoyed her midnight burger.



Trishelle is in control.





Staff have to help us get what we want.



That is part of being in control for people with disabilities!

## What did our focus group members say about respect?

"You don't want to get treated like a child. You want to get treated respect... I noticed a lot of staff treat your people like they're kids. They tell them, 'Come on, get in line, get your food, eat it...' Or you go to the shopping center, some people might want to go shopping and pick their own outfit out. Nine out of ten, the staff gotta pick them clothes out, they tell the consumer, 'You don't know how to pick your clothes out, you don't know what color to pick your clothes out...' I go out and spend my money the way I want to spend it... And that's a person's rights."

"Sometimes the staff will start talking bad things about you saying like, like... 'Oh, she can't take care of herself. I'm supposed to do all this stuff, I'm doing the cooking for her, I'm not gonna let her touch because she might set the house on fire.' It's like making you look bad... making you feel like you're real low."

## Feedback



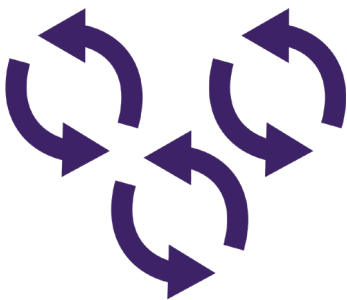
Focus group members wanted their voices heard about community services!



This meant giving staff feedback about how they're doing.



Staff need to listen to feedback.



They need to change what they're doing if we tell them to.



If a staff person doesn't listen to us, we should be able to get a new one.



Focus group members talked about being scared to give feedback.



They were scared to say anything bad about certain staff.



They thought those staff members might treat them badly afterwards.



Focus group members talked about other ways to give feedback.



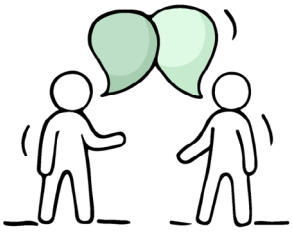
They wanted somewhere private to give feedback about their staff.



One person said they could leave a note card in a “feedback box”.



They could leave their name out, so the feedback stayed private.



Other people said they'd like to have a person they can talk to.



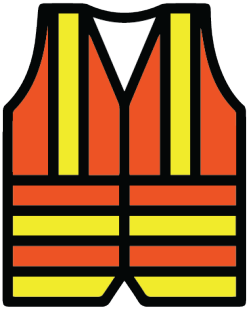
That person can take feedback from people with disabilities.



Then, they can bring that feedback back to their staff.



They can make sure staff don't know who gave what feedback.



These ways help people feel safer giving feedback.



They help us stay in control.

## What did our focus group members say about feedback?

“The thing is, the staff.. they’re all like best friends... So you’re not really gonna get any help, you’re gonna get yourself worse when you talk to [a staff member about] another staff.”

“Can you speak your mind like at a team meeting? When you’re at a team meeting? Are you in an environment where you feel like you know, treated as an equal, you can speak around you know, you’re not gonna like, hold your feeling in because you have a home provider who was hard-nosed, mean, and bossy, let’s say.”



## My house, my rules



Community services happen in the homes of people with disabilities.



Focus group members knew that we should be in control of our homes.

1.=  
2.=

That means making our own house rules.



Staff should not be the ones making the rules.



Rules get made that keep staff in control:

Staff sometimes make rules about:



- When someone has to wake up or go to sleep



- What clothes someone can wear



- Where someone can be in their house, and at what times



- When and what someone can eat



- What time to go to bed



- What hobbies someone can do in the house

1.=

2.=

There are lots of other kinds of rules.



Staff can try and stay in control by punishing people if they break a rule.

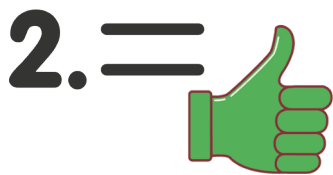


People with disabilities might not have any choice about the rules.



The rules might be unfair, or make us do things we don't want to.

1.=

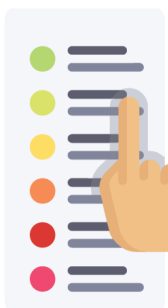


There is nothing wrong with rules!

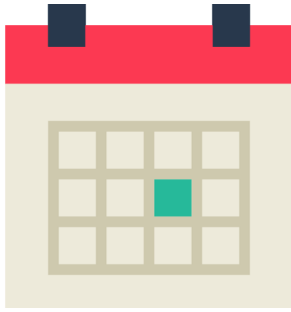
1.=



But people with disabilities should make our own rules.



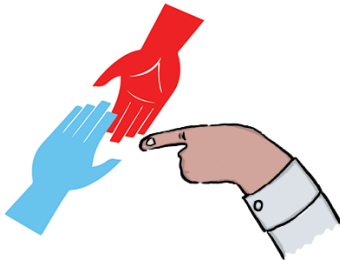
We should get to make all the choices in our lives.



Making the rules also means making our own schedules.



We should get to choose what we do each day.



That also means choosing how staff helps us.



Staff should ask us what we need each day.



They should help us do the things we want to do on our own.



We should get to change our minds about what we do.



Staff should help us no matter what.



That's their job.

For example:



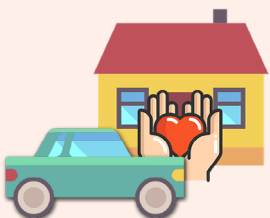
Perry is the staff person for Landon.



They get to Landon's house and ask him what he needs help with.



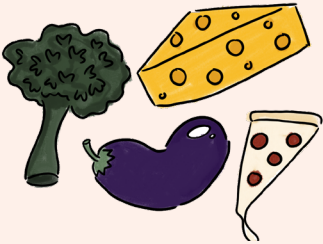
Landon says he needs to go to the grocery store.



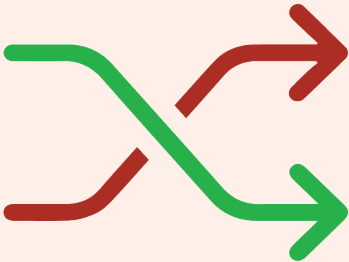
Perry helps drive Landon to the store and buy groceries.



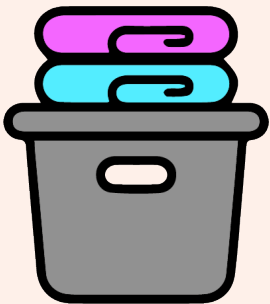
Then, they go back to Landon's house to make lunch.



Landon says he does not need help making and eating lunch.



So Perry does something else until Landon is done.



They help fold some laundry that Landon needed done.





Perry is a good staff person!

## What did our focus group members say about house rules?

“So if you’re making the rules in your house, you have a right to break the rules too, if you want to, because it’s your house, right?”

“I think everybody should... be able to choose about what they want to eat and what time of when they want to eat on, whether they in a group home or not. I know some group homes say that they have... menus, you know... And really you have a lot of them who don’t want what’s on menu but really they [don’t] have that choice.”

“If they have a relationships and stuff, [staff] always make sure that they have to have a door cracked open, or a door partial open and they don’t have much of a privacy with their friends or even with the relationships, and they feel like more like a child, I think, instead of an adult.”

## Choices in the community



Focus group members also wanted to decide about going into the community.



They wanted to feel in control wherever they went.



Staff are a big part of helping someone stay in control when they go out.



Staff shouldn't get to say where and when someone can go out.



They need to help people with disabilities to go out when we want to.



They need to help us get a car, or use public transportation, like a bus.



Staff shouldn't get to make other "rules" about going out.



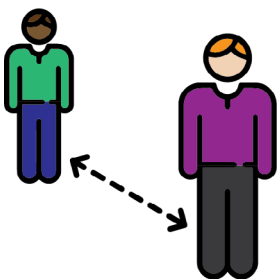
We should get to spend our money how we want to when we're out.



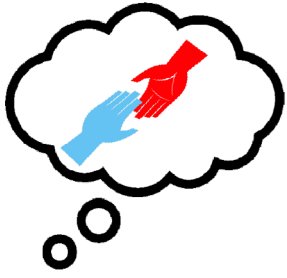
We should get to see whoever we want to see.



We should get help making new friends or partners.



We should get to choose if staff stays nearby us or not.



Being in control also means knowing staff are there when someone needs them.



People with disabilities should get to choose if staff come out with us.



But we should also know that if we need help, we can get help.



Staff need to support people with disabilities in the ways we want support.



That is what helps us stay in the community and stay in control.

## What did our focus group members say about choices in the community?

“Do they let me do an adult restricted thing? Like, can I go to a bar, or get support in those kinds of things?”

“You know when they used to have the fair come out and people go up on those rides and stuff? I remember there are some people that wanted to go out and go to the rides and stuff, but then their staffs didn’t want them to go out and to be apart from each other. So their staffs have them all locked in together. So there are some rides that... they couldn’t go on because [staff] say, ‘Oh, that’s too scary... Nobody’s want to go on that ride. So we all have to go over here to the kiddie ones.’”

“Say, like, you’re going grocery shopping, and you’re trying to get healthier, and you’re trying to, like get stuff that will help you with your grocery shopping... But your staff decided to do their own grocery shopping, while you’re trying, while you need the support to do your grocery shopping.”

## Getting the right information



Focus group participants wanted to know important information about their lives.

These were things like:



- Their health and papers from doctors



- Information about their job, or how to get one





- Information about their school, or how to go to one



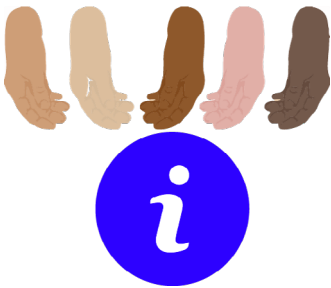
- Information about their money and bank account



- Information about how their benefits works, like SSI and Medicaid



Some focus group members got some of this information.



But they felt like they didn't get enough information.



They didn't "know what they need to know"



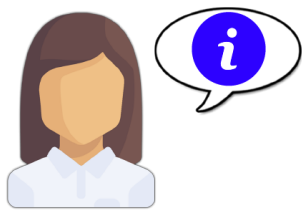
It made them feel less in control.



Staff usually get this information about people with disabilities.



Keeping that information from us keeps us from being in control.



Staff need to share information about our lives with us.



They need to explain the information in ways we can understand.



Focus group members also talked about learning new things.



They wanted staff to help them if they were interested in something new.



Staff should help us find information about things we're interested in.



They should help us find events or programs in the community.



Staff should help us learn new things, too.



They should help us learn to do things we want to do.



They should help us learn in the ways that work best for us.

For example:



Angela wants to learn how to use the computer to send emails.



Her staff member, Luis, knows how to use a computer.



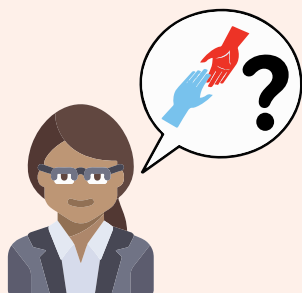
He shows Angela how to type an email.



Angela's disability makes her hands move a little differently.



She can't type exactly the way Luis does.



Angela asks Luis for help.



Luis helps Angela figure out the easiest way for her to type.



He explains how sending an email works in a way Angela understands.



He practices with her until she can do it by herself.



Luis is a good staff person! He makes sure Angela is always in control



## What did our focus group members say about getting the right information?

“Some may want to go back to school. What is the process? You want to go back to school and you want to work on the computer using a staff to help them work on a computer?”

“Maybe like the staff give you the kind of support that you need... to make friends. For example, if you ask for help going to see someone, will they help you with that? Or will they just help you make a phone call?”

Do you have access to benefits counseling... especially if you have [representative] payees and deal with worries on losing SSI, SSDI?”

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*The Community Living Policy Center (CLPC) is funded by the National Institute on Disability, Independent Living, and Rehabilitation Research, grant number 90TRCP0004. NIDILRR is a Center within the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS). This resource's contents reflect the views of the authors and not the National Institute on Disability, Independent Living, and Rehabilitation Research*

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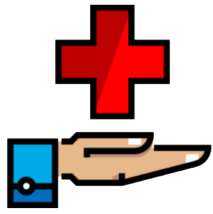
*Easy Read Edition*

# **“Who’s in Control?”**

## **Control over community services for people with disabilities**

**Part 9: 12 Questions to ask to see who is in control**

# Words to Know in Part 4



## Medicaid

A health care program in the United States. Medicaid helps people get health care if they don't have a lot of money.



## Quality measures

Questions Medicaid can ask to find out whether health care is good or bad.

# 12 Questions to ask to see who is in control

---

## 1

### Question 1



Do your staff mind their own business?



Do they respect your privacy?

# 2

## Question 2



Do staff look at your medical or bank information?



Do they look even if you didn't say it was okay?

# 3

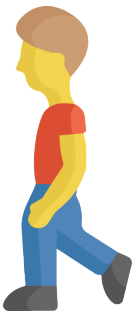
## Question 3



Do your staff treat you like an adult?



Do you have to ask your staff if it's okay to do something?



For example, do you have to ask before you go for a walk?

# 4

## Question 4



Do staff let you speak up for yourself?



Do they speak for you when you don't want them to?



# 5

## Question 5



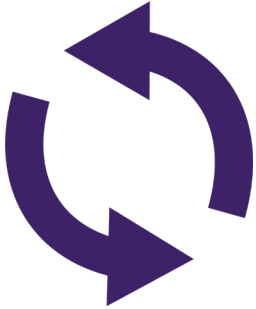
Do staff say bad things about you?



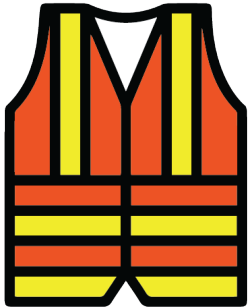
Do they boss you around, or make fun of you?

# 6

## Question 6



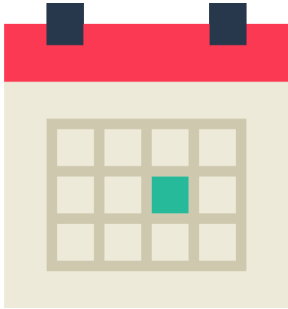
Do you feel safe telling your staff to do things differently?



Do you feel safe telling your staff that you didn't like something they did?

# 7

## Question 7



Can you make your own daily schedule, or do staff do it for you?



Can you choose to not have a schedule?

# 8

## Question 8



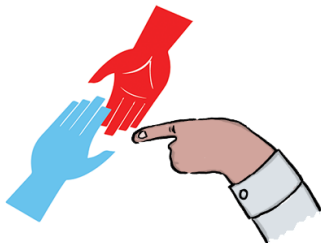
Do staff think you can't do things by yourself, even if you can?



Do staff stop you from doing things because they don't think you can?

# 9

## Question 9



Do you get to pick how your staff helps you?



Do you get to do things by yourself if you want to?



Or, does your staff do everything for you?

# 10

## Question 10

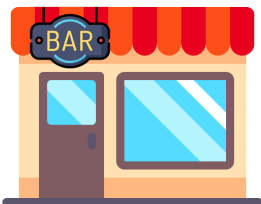
1.=

2.=

Do staff have “rules” about where you can go and when?



For example, do staff say you can't go out at night?



Or that you can't go to certain places, like to see a partner or to a bar?

# 11

## Question 11



Will your staff help you understand information you need to know?



For example, information about school, work, or your health?

# 12

## Question 12



Do staff know what you want help with when they come?



If they don't know, what do they do?



Do they ask? Do they “do their own thing?”  
Or do they decide what you’re going to do?

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# **“Who’s in Control?”**

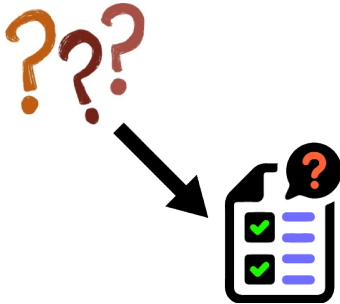
## **Control over community services for people with disabilities**

### **Part 10: What Next?**



## What Next?

These 12 questions are a great start!



But they need to get made into quality measures.



Quality measures need to be more specific.



Quality measures usually show up in surveys.



People take the survey to tell if their services are good or bad.



Surveys can have answers that look different.



It depends on the kind of question.

For example:



Desmond gets community services.



He gets a survey to see if he thinks his services are good.



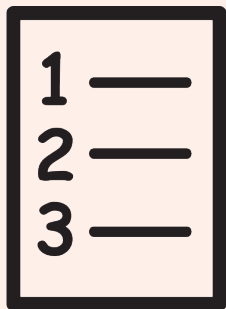
One question asks, "Do your staff say bad things about you?"



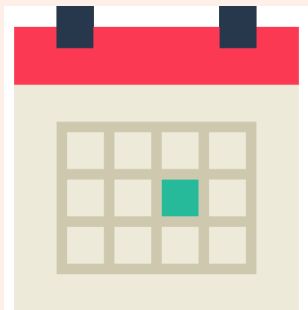
This question could be a "Yes" or "No" question.



But maybe Desmond's staff only said one bad thing.



It may be better to ask the number of times staff said bad things.



Or, the survey could ask how many times a week staff said bad things.



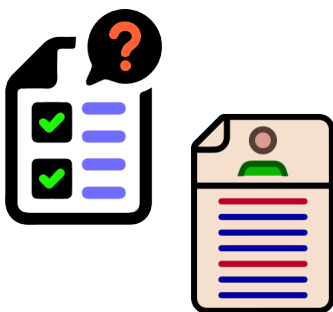
There is no exactly “right” way to write a quality measure!



But people who study community services need to think of the best way.



They need to ask questions that really show who is in control.



That means making sure each quality measure has enough detail.



We hope people who study community services will read this paper.



People who study community services write ideas for quality measures.



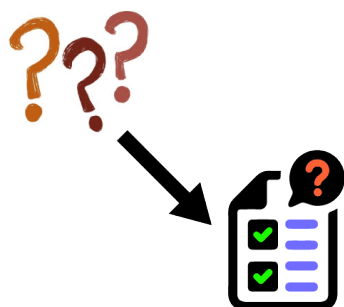
They work with the Centers for Medicare and Medicaid Services (CMS).



Together, they come up with new quality measures.



They can use the questions from our focus group.



They can turn our questions into quality measures.



Remember, quality measures get used to check Medicaid programs.



People with disabilities get surveys about their community services.



They can tell Medicaid if their services are good or bad.





Medicaid can look at the surveys to make choices about their programs.



They can give more money to community programs doing a good job.



They can give less money to community programs doing a bad job.



Medicaid can use quality measures to help us.



They can make sure people with disabilities are in control of our services!



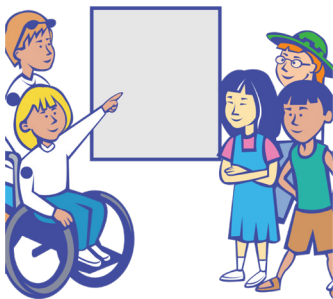
People who study Medicaid should also talk to more people with disabilities.



They should do more studies to see how community services work for us.



They should keep talking with us as they make quality measures.



Nothing about us, without us!

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# **“Who’s in Control?”**

## **Control over community services for people with disabilities**

### **Words to Know**



## Centers for Medicare and Medicaid Services (CMS)

The part of the U.S. government that runs Medicaid.



## Focus group

When people meet to talk about something.



## Home and community-based services (HCBS)

Getting LTSS in the community. We also call these “**community services.**”



## Institutions

Places where a lot of disabled people live. People living in institutions did not decide to live there. They usually can't leave when they want to.



## Long-term services and supports (LTSS)

Services that help people with disabilities live our everyday lives. Some kinds of LTSS are job coaches and in-home helpers.



## Medicaid

A health care program in the United States. Medicaid helps people with disabilities get health care.



## Self Advocates Becoming Empowered (SABE)

A group for people with intellectual disabilities in the U.S. They do advocacy for disability rights.



## Quality measures

Questions people can ask. They can help figure out if a health care service is good or bad. Medicaid uses quality measures.

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# **“Who’s in Control?”**

## **Control over community services for people with disabilities**

**To Learn More**



1

## **To Learn More**

[Who's In Control?](#) - A speech by Roland Johnson.

2

[ASAN Comments On CMS HCBS  
Recommended Measure Set](#)

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