



*Plain Language Edition*

**“Who’s in Control?”**  
**Control over community**  
**services for people with**  
**disabilities**

# To Start

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This toolkit is about community services for people with disabilities. We want to know how we can tell who is in charge of these services and what questions people can ask to see who is in charge.

We talked to a group of self-advocates who get community services and asked them how we can tell who is in control of their services. This toolkit will talk about their answers.

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?

# What are LTSS? What are institutions and HCBS?

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Some people with disabilities need **long-term services and supports (LTSS)**. LTSS are services that help people with disabilities live our everyday lives. Some examples of LTSS are job coaches, transportation, or an in-home helper.

Some people with disabilities get LTSS in **institutions**. Institutions are places where a lot of disabled people live. Most people living in institutions did not choose to live there; they were usually put there by someone else.

Institutions are run by the staff members who work at them, not the people with disabilities who live in them. People living in institutions usually can't leave whenever they want to, or spend their free time how they want to.

Other people with disabilities get LTSS in their own homes and in their communities. Getting LTSS in the community is also called **home and community-based services**, or **HCBS**. In this toolkit, we usually call HCBS "**community services**."

# What do community services mean to people with disabilities?

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People who live in institutions, by definition, do not get community services. All people with disabilities have the right to live in the community. We want to live in our communities, not in institutions.

ASAN is a group of autistic people who work on disability rights. We believe that people with disabilities have the same rights as everyone else, including 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?](#)

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

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**Medicaid** is a government-run health care program in the United States. Every state has its own Medicaid program. Medicaid helps primarily people with disabilities and people who don't have a lot of money get health care. People can get most community services through Medicaid by using a "waiver."

Medicaid wants to make sure people with disabilities get good quality health care. Medicaid finds out whether health care is good or bad by asking questions called **quality measures**.

It is hard to figure out good quality measures for community services. Most Medicaid quality measures ask whether people are healthy or not, because that is easier to ask about than whether someone gets good quality community services.

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 community services are about more than just health. People with disabilities need community services whether we are healthy or not. Medicaid needs to ask different things to see if our community services are good or not.

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

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The **Centers for Medicare and Medicaid Services (CMS)** is the government agency that runs Medicaid. CMS writes quality measures for community services, so 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.

Roland Johnson was a Black man with an intellectual disability who 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 which does advocacy for disability rights.

In 1993, Roland gave a famous speech called "Who's in Control?" In the speech, 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!" and that is what will help us take control over our lives.

We have the right to live and make our own choices in the community. We should be in control of our community services. When we are in control, we decide how our staff help us and 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, if they get to make their own food if they want to, or 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 to find out who is in control of community services.



# 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. Together, we came up with a list of questions to tell who is in control, which we can use to help make quality measures. We can work with people who study community services, like CMS, to make better quality measures.

ASAN held the focus group over the internet, using Zoom. 7 people with disabilities took part in the focus group. The focus group met 5 times in March and April of 2021. Each meeting was about 2 hours long.

ASAN wanted all different kinds of people in the focus group because we wanted to hear the experiences of people who got different kinds of services. All 7 people in the focus group get community services, but they need different kinds of help to live in the community. The focus group members were also different from each other in other ways, including being of different races and having different kinds of intellectual and developmental disabilities.

We started the focus group by explaining what quality measures are. Then we asked people to think about their community services. People had a lot of different ideas about being in control, so we split up the ideas everyone had into themes.

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

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One important point came up in every theme: 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, don't listen to people with disabilities, or 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, which 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 and 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. Who is in control of the community services: people with disabilities or staff members?

# What were the themes?

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## *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 being able to close and lock the door of their room or house, being alone with their friends or partners, and being able to make phone calls or video calls by themselves.

One person said that staff needed to “mind their own business!” They said that they didn’t want their staff to follow them around the house and that their 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, don’t let her be alone when she wants to be, and 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 looking through their mail or bank information or sharing information about them to other people.

## **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. Respect means listening to and caring about people with disabilities. Staff should let us speak up for ourselves, and take our feelings seriously. They shouldn't say mean or hurtful 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, which means that we aren't in control of services. Staff say it's okay to make choices for us because we are "like kids" and can't make our own choices, or that we will make bad choices. Staff need to know we are adults and can make our own choices, even if those choices might be bad!

The focus group members said getting treated like an adult means a lot of different things. Staff should let us go to places for adults, like bars, if we want to. We should also 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, even if it might not go well. Staff should still help us try new things. Staff need to respect our decisions, even if they don't agree with everything we want to do. They still need to help us do what we want.

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 but her staff member doesn't want to go to McDonalds. They don't want to drive so late at night. But the staff member's job is 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 and 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 or 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, like leaving a notecard in a feedback box. They wanted somewhere private to give feedback about their staff. 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 who can take feedback from people with disabilities and give it to their staff. That person could make sure staff don't know who gave what feedback. These ways help people feel safer giving feedback, which helps 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. That means making our own house rules, not having staff make rules for us.

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

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, even if the rules are unfair or make us do things we don't want to.

There is nothing wrong with rules! However, people with disabilities should make our own rules, just like 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, including choosing how staff helps us. Staff should ask us what we need each day, and then help us do the things we want to do on our own. We should get to change our minds about what we do if we want to. Staff should help us no matter what because it's their job to help us.



For example:

Perry is Landon's staff person. They get to Landon's house and ask him what he needs help with. Landon says he needs to go to the grocery store, so 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 folds some laundry until Landon is 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, including if we need to drive somewhere or take 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 and 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, even if staff aren't right there with us. Staff need to support people with disabilities in the ways we want support so we can 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 medical records
- Information about their job, or how to apply one
- Information about their school, or how to go to one
- Information about their money and bank account
- Information about how their benefits work, like SSI and Medicaid

Some focus group members got some of this information but felt like they didn't get enough information. They didn't "know what they needed to know" and that 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 and explain the information in ways we can understand.

Focus group members also talked about learning new things and wanting staff to help them if they were interested in something new. Staff should help us find information about things we're interested in and 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 and help us learn in the ways that work best for us.

For example:

Angelica wants to learn how to use the computer to send emails. Her staff member, Luis, knows how to use a computer, so he shows Angelica how to type an email.

Angelica's disability makes her hands move a little differently, which means 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 and then practices with her until she can do it by herself.

Luis is a good staff person because 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?"

## 12 Questions to ask to see who is in control:

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1. Do your staff mind their own business? Do they respect your privacy?
2. Do staff look at your medical or bank information? Do they look even if you didn't say it was okay?
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. Do staff let you speak up for yourself? Do they speak for you when you don't want them to?
5. Do staff say bad things about you? Do they boss you around, or make fun of you?
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. Can you make your own daily schedule, or do staff do it for you? Can you choose to not have a schedule?
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. 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. 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. Will your staff help you understand information you need to know? For example, information about school, work, or your health?
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?

## What Next?

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These 12 questions are a great start, but they need to get made into quality measures, so they need to be more specific. Quality measures usually show up in surveys that people can take to say if their services are good or bad. Surveys can have answers that look different depending 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, so it’s hard for him to answer that question “yes” or “no.” It may be better to ask the number of times staff said bad things or 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, which 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), and together, they come up with new quality measures. They can use the questions from our focus group and turn our questions into quality measures.

Remember, quality measures get used to check Medicaid programs. People with disabilities get surveys about their community services where they can tell Medicaid if their services are good or bad.

Then Medicaid can look at the surveys to make choices about their programs. They can give more money to community programs doing a good job and give less money to community programs doing a bad job. Medicaid can use quality measures to help us to make sure people with disabilities are in control of our services!

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



## Words to Know

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**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.

## To Learn More

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

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

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