

How do we measure “who’s in control”?

ASAN’s focus group on quality measures for community services



What are quality measures?

Quality measures are questions people can ask to figure out if a health care service is good or bad.



Example: quality measures for health care after a heart attack

- How long does the person need to stay in the hospital?
- How long does the person stay alive after the heart attack?
- How much medicine does the person need to take for their heart?
- How long does the person need to take medicine?

The answers to these questions help researchers figure out if the person got good health care.

What are community services?

A lot of people with disabilities need services, like:

- Job coaches
- Transportation
- An in-home helper

Community services are services that people with disabilities get in the community, not in institutions.



Who's in control?

Whether community services are good depends on whether people with disabilities are truly in control of our own services.

Roland Johnson, an institution survivor, activist, and one of the founders of SABE, asked “Who’s in control?” in a famous speech in 1993.

He said 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.



Are there quality measures to find out who's in control of community services?

Kind of!

Medicaid funds a lot of community services and makes quality measures for community services.

They have some quality measures that ask about control, but we think we need better measures about this.

For example, Medicaid has a quality measure that asks if someone can eat meals when they want to. But there are other important ways to be in control of our own food that Medicaid does not ask about.

ASAN's quality measures project

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.

ASAN's quality measures project

ASAN held the focus group over the internet, on Zoom.

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.

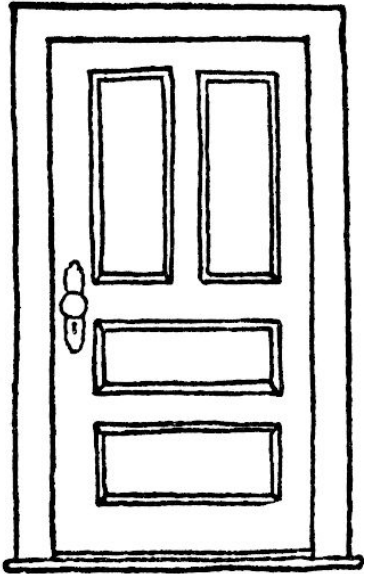
The big question: are staff controlling people who get services?

Staff can “take over” control of someone’s services, even if *on paper*, the person controls their own services.

Our focus group was clear that having a person-centered plan or a self-directed waiver is not enough to keep staff from taking control. Both are good things! But sometimes support staff try to take control of someone’s life anyway.

The focus group talked about this and came up with 6 themes (important parts of being in control) and 12 questions. Researchers can use these themes and questions to make quality measures.

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.

People in our focus group didn’t want staff sharing information about them to other people. They didn’t want staff looking at their mail or bank information.

Privacy: example

Amber's staff don't give her privacy.

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

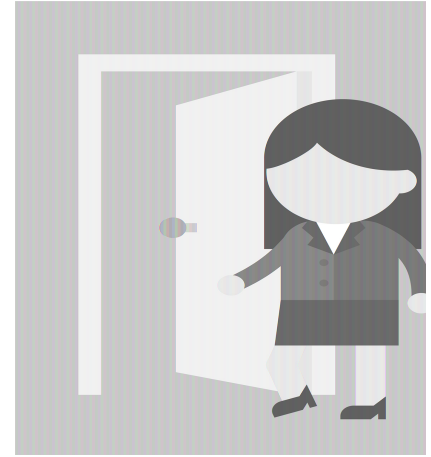
So they go into her room and look through her things.

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.



Respect

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

- Take our thoughts and feelings seriously
- Treat us as adults, not like kids
- People with disabilities should not need “permission” from staff to do what we want to do.
- We have the right to make our own decisions and to take risks. Staff should respect our decisions, whether or not they agree with them.

Respect: 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 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.



Feedback

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.

Feeling safe giving feedback helps people with disabilities stay in control.

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.

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

Staff shouldn't be in control of these things. People with disabilities should control these things for ourselves.

My house, my rules

Staff sometimes try to stay in control by “punishing” people if they break a rule.

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

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

If there are going to be rules in our homes, people with disabilities should make our own rules.

Making the rules also means making our own schedules -- or choosing not to have a schedule!

We should be able to decide what to do with our day, and get support to do what we choose. We should be able to change our minds about what to do.

My house, my rules: example

Perry is the staff person for Landon.

Perry goes to Landon's house and asks Landon 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.

Landon is in control of what Perry helps with. Perry is a good staff person!



Choice 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 drive places, 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.

Choice in the community

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.

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.

Staff need to share information about our lives with us. They need to explain the information in ways we can understand.

Getting the right information

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.

Getting the right information: example

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

Angelica's disability makes her hands move a little differently. She can't type exactly the way Luis does.

Angelica asks Luis for help.

Luis helps Angelica figure out the easiest way for her to type. He explains how sending an email works in a way Angelica understands. He practices with her until she can do it by herself.

Luis is a good staff person!

He makes sure Angelica is always in control, and gets the information that she needs



Any questions before we move on?



Discussion: what are some questions that we can ask to figure out whether people with disabilities, or their staff, are controlling their services?

- Think about “clues” that show whether or not someone is in control
- Think about our themes:
 - Privacy
 - Respect
 - Feedback
 - My house, my rules
 - Choice in the community
 - Getting the right information

We can make quality measures by asking questions.

Example question: “Do you have to ask your staff for permission to leave the house?”

Who's in Control? 12 Questions

- 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?

Who's in Control? 12 Questions

- 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?

Who's in Control? 12 Questions

- 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 to your house?
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's next?

Releasing our resource on community service quality measures in Easy Read, plain language, and researchers' versions.

We hope that researchers will learn from people with disabilities when they are developing quality measures.

Researchers can make our questions and themes into quality measures by adding specifics and different ways of answering.

Then, Medicaid can use these quality measures to decide which services are good and which ones are bad, and encourage service providers to make their services better.

Questions? Comments?

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

What else should we measure to make services better?

