



Easy Read Edition

“Who’s in Control?”

Control over community services for people with disabilities

Part 8: What were the themes?

What were the themes?

Privacy

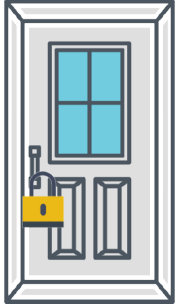


Privacy is a big part of being in control of community services.



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.

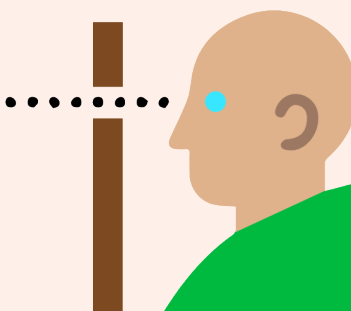
For example:



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.



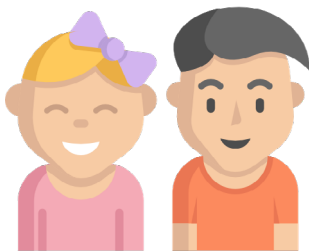
They should take our feelings seriously.



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.



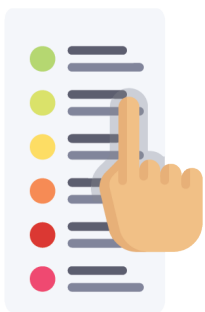
Staff say it's okay to make choices for us because we are "like kids."



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



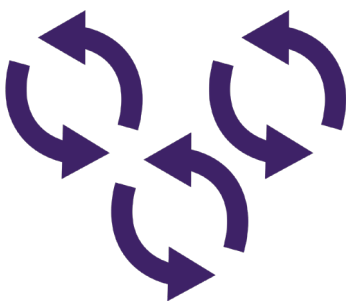
Focus group members wanted their voices heard about community services!



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.



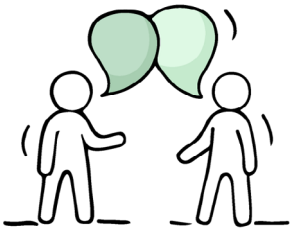
They wanted somewhere private to give feedback about their staff.



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.



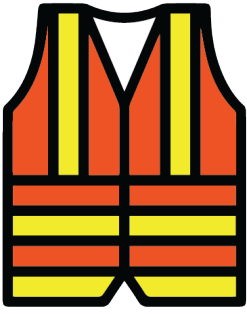
That person can take feedback from people with disabilities.



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.

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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:



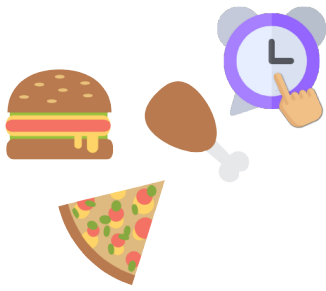
- When someone has to wake up or go to sleep



- 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

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There are lots of other kinds of rules.



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

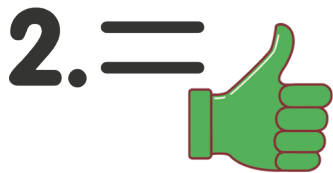


People with disabilities might not have any choice about the rules.



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

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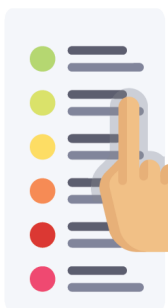


There is nothing wrong with rules!

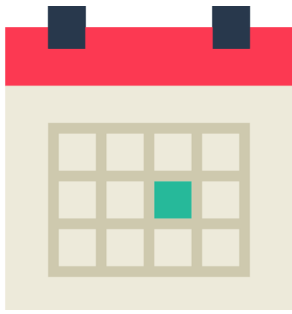
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But people with disabilities should make our own rules.



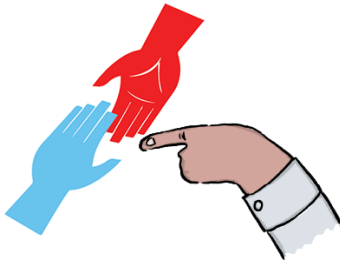
We should get to make all the choices in our lives.



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:



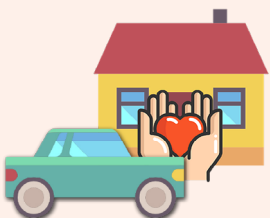
Perry is the staff person for Landon.



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



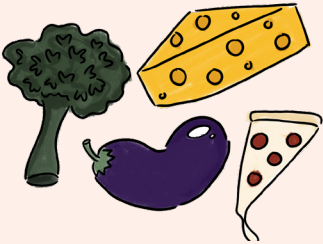
Landon says he needs to go to the grocery store.



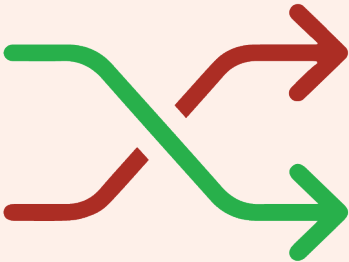
Perry helps drive Landon to the store and buy groceries.



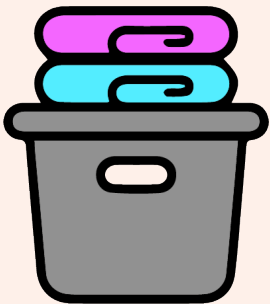
Then, they go back to Landon's house to make lunch.



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.



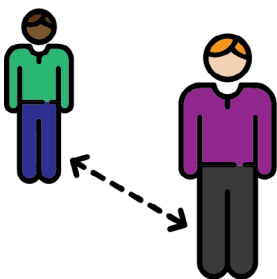
We should get to spend our money how we want to when we're out.



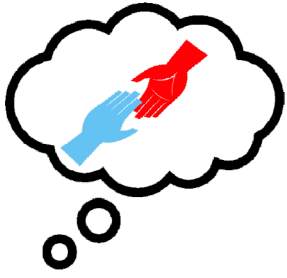
We should get to see whoever we want to see.



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



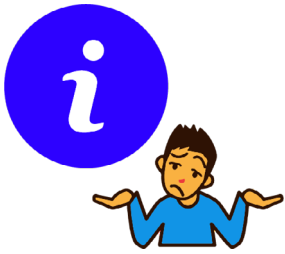
- Information about their school, or how to go to one



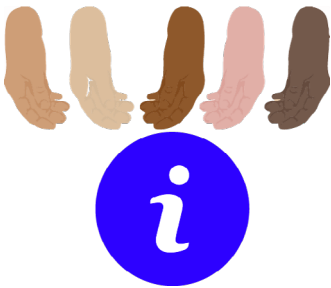
- Information about their money and bank account



- 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.



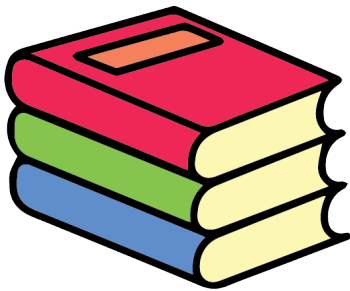
They need to explain the information in ways we can understand.



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.



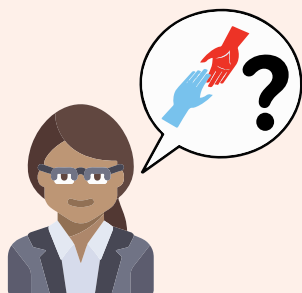
He shows Angela how to type an email.



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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