

Easy Read Edition

"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?



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



CMS is part of the government.





CMS writes quality measures for community services.



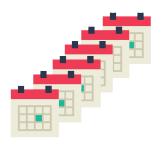
They need to figure out how to tell who is in control of their services.



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.



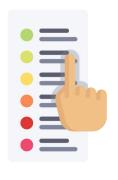
He said people with disabilities need to tell staff, "I am in control!"



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.

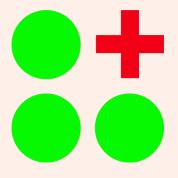
For example:



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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