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

This research brief describes the outcomes of a focus group to develop guidelines for HCBS quality measures for people with disabilities. This project was primarily published in Easy Read and Plain Language formats, with the intention of being accessible to disabled individuals and HCBS consumers as well as the general public. This brief is intended as a supplement for researchers, and is provided in academic language as an accommodation. While we encourage you to share this research brief widely, in order to get the most comprehensive view of this nuanced topic, you should read through and share the main publication, available here.

Background

Long term services and supports (LTSS) are crucial to the lives of individuals with disabilities, the majority of whom receive these services through Medicaid. While institutionalization of people with disabilities needing these supports was (and still is) common practice, people with disabilities have asserted our right to live in the community through decades of advocacy and research. As a result, more and more individuals are transitioning out of institutions and receiving home and community-based services (HCBS).

As HCBS is an optional Medicaid program with limited funding, and the field of HCBS as a whole is relatively new, the Centers for Medicare & Medicaid Services (CMS) created the HCBS Final Rule in 2014 in order to better define what these services entail and prevent providers within institutions from using money earmarked for HCBS. Part of the process of the rule’s implementation includes creating a set of quality measures for HCBS, as there is currently no mandatory set, and states use varying measures that may not capture necessary data. CMS released a draft of their Recommended Measure Set in 2020.

ASAN, a leading national disability policy organization by and for self-advocates, examined this draft and found certain domains that lacked the detail needed to adequately measure the construct. Specifically, the section of the measure set that addresses “Choice and Control” did not cover the full scope of day-to-day decisions in the lives of disabled individuals. Some measures exist to study choice and control at a “macro level” (for example, “Does this person attend their person-centered planning meeting?”), but few measures really examine the minute-by-minute experience of choice and control in the daily lives of HCBS consumers. In addition, many of the measures are a part of an optional subset of measures and not the proposed mandatory set, despite “Choice and Control” being previously identified as a high priority for disabled people.

The Autistic Self Advocacy Network seeks to advance the principles of the disability rights movement with regard to autism. ASAN believes that the goal of autism advocacy should be a world in which autistic people enjoy equal access, rights, and opportunities. We work to empower autistic people across the world to take control of our own lives and the future of our common community, and seek to organize the autistic community to ensure our voices are heard in the national conversation about us. Nothing About Us, Without Us!

1

For example, the theme of choice and control as a central component of HCBS has long been discussed within the self-advocacy community. Roland Johnson, a founding member of Self Advocates Becoming Empowered (SABE), delivered a speech on this topic in 1993, urging people with disabilities to think about who was in charge of our lives. It is crucial that the "Choice and Control" domain be further fleshed out in order to fully encompass the experiences of HCBS consumers.

In addition to these omissions, we urged CMS to further include people with disabilities in the process of quality measure development for HCBS. Few disabled people were given prominent leadership or advisory positions in the development of the draft measures. Furthermore, the Recommended Measure Set was not provided in Plain Language or Easy Read, making the document inaccessible to people with cognitive disabilities. As disabled individuals are the primary consumers of HCBS, our voices should be prioritized to center our stated wants, needs, and goals. You can read a more detailed response to the CMS HCBS Recommended Measure Set here.

Project/Methods

Based on these factors, ASAN aimed to continue the work of the self-advocacy movement by centering the voices of HCBS consumers in creating a cognitively accessible set of guidelines for developing quality measures for "Choice and Control". In partnership with the Community Living Policy Center at Brandeis University, we convened a focus group of 7 individuals with intellectual and developmental disabilities who receive HCBS. These individuals met for 5, 2-hour Zoom meetings over the course of March and April 2021.

Participants were given prompts in order to prompt questions or discussion that could turn into potential quality measures. Some of these prompts included:

- How can you tell if you're in control of your services?
- What questions would you ask to see if you're in control of your services?
- If you had a friend who got services, what would you look for to see if they were in control?
- Were there times when you felt like you didn't have control over your services? When and why?

Throughout the focus group sessions, a variety of themes emerged relating to choice and control, which will be discussed below. However, a common thread between these themes was the role of staff in the amount of choice and control that an HCBS consumer experiences. Staff coercion was identified as a major struggle that individuals faced when trying to live self-determined lives. This understudied element of choice and control in HCBS is critical to develop quality measures for. As our group narrowed in focus, we created a list of 12 core questions to measure who is in control of their HCBS. We hope that exploring these questions can accurately portray whether HCBS consumers or their staff have control of their day-to-day lives.

Themes

Invading privacy was one way that participants noted staff members attempting to control their lives. They spoke of experiences of staff following them around their house, and needing to "know everything". This also included accessing bank and medical information, as well as going through an individual's room or belongings. Many staff members infringe upon the privacy of HCBS consumers under the guise that it is necessary to keep an individual "safe". Focus group participants challenged that narrative, and wanted to have privacy on their own terms. Out of all the themes which emerged from our focus group, we believe this theme of privacy is the one most well-developed in already existing measures.

Another core theme was the need to be treated like adults. Focus group participants reported staff members treating them as if they were children, and using this mindset as an excuse to control the lives of HCBS consumers. For example, staff might say an individual is not allowed to do adult-oriented activities like going to a bar, or that they can't try and get a job in case they get lost during the commute. Focus group participants expressed their dissatisfaction at having to ask for permission to do basic tasks in their own homes. Needing permission to do everyday things was identified as a subtle and pervasive way people with disabilities were deprived of choice and control, often many times a day. The group characterized this theme as being about respect, and viewed being treated as an adult equal (or even as a boss) as a key part of that respect.

Along with feeling like staff listened to and respected them, focus group participants noted that the ability to give feedback to staff was just as important to feeling in control of their services. Some participants worried that giving critiques about their staff members would lead to retaliation, and noted that anonymous methods of providing feedback or utilizing an ombudsman could circumvent this issue. However, participants felt that more importantly, they should feel safe to tell staff what they need if their staff member is not providing that. If HCBS consumers don't feel safe giving feedback about their services, then they have less control over their services. That safety hinges on staff being receptive to feedback and changing based on this information.

Information access was another important theme participants touched on. To the group, being "in control" meant "knowing what they need to know" about their lives. This included things like medical information, financial documents, explanations of their benefits (SSI, Medicaid, etc.), and educational or vocational information. They expressed that staff often kept this information to themselves, because they believe people with disabilities won't be able to understand the content. This is another way that staff control the lives of HCBS consumers. Participants recommended that staff focus on presenting this information in an accessible way, and that information access also extends to whatever an individual is interested in learning more about. This gives disabled individuals the opportunity to learn new skills, entertain a new hobby, or enter school or the workforce, allowing us to lead more self-determined lives.

Lastly, rules in the home and within the community were additional common themes. Focus group participants stated that rules, both formal and informal, would commonly get made for them by staff, which kept staff in control. Some of these rules included what things someone can do in their house, what time they eat and sleep, where they go and what they do when they go out, how their money got spent, and when and how they get support in the community. Daily schedules were often centered around the needs of staff, who kept a communal schedule rather than allowing for individuals to make their own schedule or forego a schedule entirely. Participants expressed that they should be able to make all the choices in their lives, and having to follow the "rules" of staff members took away control over their lives.

To read a more in-depth discussion of each theme, please see the Easy Read and Plain Language publications that this summary accompanies.

Core Questions

1. Do your staff mind their own business and respect your privacy?
2. Do staff look at your medical or bank information, 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, like go for a walk?
4. Do staff let you speak up for yourself, or do they speak for you when you don't want them to?
5. Do staff say bad things about you, boss you around, or make fun of you?
6. Do you feel safe telling your staff to do things differently, or 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, like saying you can't go out at night, or that you can't go to certain places, like a bar?
11. Will your staff help you understand information you need to know, like information about school, work, or your health?
12. Do staff know what you want help with when they come, and what do they do if they don't? Do they ask, "do their own thing," or do they decide what you're going to do?

Next Steps

These 12 questions are a first step in prioritizing the wants and needs of HCBS consumers when it comes to creating meaningful quality measures around "Choice and Control." However, more research is needed to tailor these into a viable instrument. Refining open-ended questions, deciding how to measure frequency or duration of specific events, and other logistical considerations remain. It is also important to think about instrument adaptations as they apply to people with disabilities, as utilizing cognitively accessible survey tools is of the utmost importance to collecting valid data on HCBS.

Researchers and policy-makers should use these questions as a jumping-off point as they work alongside CMS to develop HCBS quality measures. As they do so, they should prioritize the inclusion of people with disabilities every step of the way, from the refinement process to implementation and evaluation. This commitment shows that people with disabilities should be in control of our own lives at all times, including when it comes to how our services are delivered and evaluated.

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