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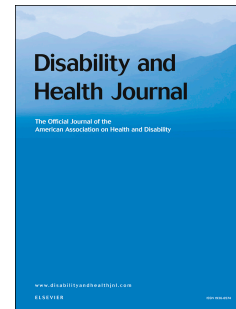
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## **Facilitators and Barriers to Person-Centered Planning from the Perspectives of Individuals Receiving Medicaid Home and Community-Based Services and Care Managers**

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# Facilitators and Barriers to Person-Centered Planning from the Perspectives of Individuals Receiving Medicaid Home and Community-Based Services and Care Managers

## Abstract

Background: While person-centered planning is required within Medicaid Home and Community-Based Services (HCBS) programs, we know little about the extent to which it is being implemented and best approaches to measuring quality.

Objective: Our study explored the experiences of individuals receiving Medicaid HCBS and care managers facilitating person-centered planning in three states to learn from their perspectives of facilitators and barriers.

Methods: We partnered with a national health plan and affiliated health plans in three states for recruitment. We used a semi-structured interview guide to conduct remote interviews with 13 individuals receiving HCBS and 31 care managers. To triangulate our findings, we reviewed assessment instruments from the three states and the person-centered care plans of HCBS recipients.

Results: From the perspectives of individuals receiving HCBS, facilitators to person-centered planning included: choice and control, personal goals and strengths, and relational communication. Care managers similarly identified the importance of relational communication, but also identified the development of measurable goals. Barriers from the perspectives of individuals receiving HCBS included: medical orientation of care plan, administrative and systemic barriers, and competencies of care managers. Care managers similarly identified administrative and systemic barriers.

Conclusions: This exploratory study provides important perspectives on implementation of person-centered planning. Findings can help inform improvements in policy and practice, as well as guide future directions in quality measure development and assessment.

**Keywords:** Medicaid, HCBS, person-centered planning

## Introduction

Person-centered planning is an approach to planning and coordinating services and supports based on an individual's goals, needs, preferences, and values.<sup>1,2</sup> While the planning process is facilitated, the person is at the center and directs the development of the plan. The goal of person-centered planning is to create a plan that optimizes the person's self-defined quality of life, choice and control, and self-determination through meaningful exploration and discovery.<sup>1</sup> The process typically involves assessment and planning that is based on the preferences of the individual and includes family, friends, and others that the individuals chooses to be involved.<sup>1</sup>

Origins of person-centered planning date back many decades, particularly within the intellectual and developmental disabilities (IDD) service system.<sup>3</sup> Although similar philosophical underpinnings have emerged in service systems for other populations receiving HCBS, including older adults and individuals with dementia.<sup>4</sup> Many different definitions of person-centered planning exist, consensus has been challenging, and there are ongoing debates about best approaches, terminology, and key aspects of the process.<sup>5</sup>

Over the last decade, the Administration for Community Living (ACL) and the Centers for Medicaid and Medicare Services (CMS) have worked to promote greater clarity and consistency to advance person-centered planning broadly within Home and Community-Based Services (HCBS) programs. In 2014, CMS issued regulations requiring aspects of the person-centered planning process and components of the service plan for individuals receiving Medicaid HCBS.<sup>6</sup> The US Department of Health and Human Services (HHS) has further extended these requirements to other federally funded programs beyond Medicaid.<sup>7</sup> Given the lack of a national quality measure for person-centered planning, and the lack of evidence-based strategies to inform such a measure, ACL and CMS also supported a multi-stakeholder National Quality

Forum (NQF) Committee on Person-Centered Planning and Practice that sought to develop a common definition, identified core competencies of individuals facilitating person-centered planning, and developed an initial framework for measuring person-centered planning.<sup>1</sup> Building on this work, ACL and CMS has supported the National Center on Advancing Person-Centered Practices and Systems (NCAPPS) to provide technical assistance to assist states and systems in implementing person-centered planning.

Studies on the extent to which person-centered planning is being implemented and evidence of the impact on community living and health outcomes are limited. Few studies on outcomes exist and most are focused on individuals with IDD. Syntheses of the research literature<sup>8,9</sup> found that the overall quality of evidence was low, but suggestive of positive outcomes, including increased choice and control, community participation, and improved relationships and social networks. Research has identified the importance of contextual factors on access to and efficacy of person-centered planning.<sup>10</sup> Lack of agreement on a definition and conceptual measurement framework, best approaches to measurement, and availability of standardized measures have posed challenges to research.<sup>2</sup> The NQF Committee on Person-Centered Planning and Practices suggested an initial measurement framework consisting of three domains: Person-Centered Plan (i.e. plan creation, content, person-reported measures), Facilitator (i.e. facilitator competencies, communication, plan content development), and System Level (i.e. structures, process, and outcomes related to training, resources, quality).<sup>1</sup> However, additional work is needed to provide more specifics on potential measurement approaches within these domains.

We conducted an exploratory study to identify key aspects of the person-centered planning process from the perspectives of (1) Medicaid HCBS beneficiaries receiving person-

centered planning and (2) individuals facilitating the person-centered planning process in three states (referred to as care managers within the context of this study). With the overarching purpose to inform potential approaches to measurement, our two primary research questions were:

1. What are facilitators of person-centered planning from the perspectives of individuals receiving HCBS and care managers?
2. What are barriers to person-centered planning from the perspectives of individuals receiving HCBS and care managers?

## **Methods**

### **Recruitment and Data Collection**

We partnered with a national health plan providing managed long-term services and supports (MLTSS) and affiliated health plans in three states - two Southern states and one Midwestern state. The health plans were in states with MLTSS programs primarily serving older adults and adults with physical disabilities. In each state, we recruited individuals served by the plan who were receiving HCBS and care managers who facilitate person-centered planning. We developed interview guides in collaboration with the health plans to ensure understandability (i.e. terminology used within each state and plan) and appropriate reading level. Input from the health plans was primarily to assist with clarity and context. For examples, some states use different terminology for “care managers.” Study materials, including the recruitment flyer and the interview guide, were prepared in English and Spanish. The entire study protocol and materials were approved by the authors’ IRB as well as the three state Medicaid agencies.

#### *Interviews with individuals receiving HCBS*

Due to the COVID-19 pandemic and changes in the normal processes for person-centered planning, individuals receiving HCBS were recruited who had been enrolled in the plan for at least 12 months to ensure they had previously had an in-person meeting to develop their service plan. State plans randomly generated lists of members; care managers then contacted these individuals to provide information about the study. Some care managers also recruited individuals during regularly occurring person-centered planning meetings. Twenty nine people allowed care managers to share their information with study staff; 13 of these people (45%) completed interviews. While we originally planned to conduct in-person interviews, due to the COVID-19 pandemic all interviews were conducted remotely over the phone and through Zoom (March – August 2021). Participants received a \$50 gift card for businesses approved in their state.

#### *Interviews with care managers*

Care managers were randomly selected from all care managers within each state health plan for potential participation in the study. To avoid potential biases, these care managers were not the same care managers who assisted with recruiting individuals receiving HCBS for the study. These interviews took place via Zoom from March through July of 2021.

#### **Sample**

We interviewed 13 individuals receiving HCBS and 31 care managers. Demographic information of participants is in Tables 1 and 2.

**Table 1: Participant Demographics, Individuals Receiving HCBS**

	N (%)
<b>Race</b>	
<i>White</i>	11 (84.6%)
<i>Black</i>	2 (15.4%)
<i>Hispanic / Latino</i>	0 (0%)
<i>Asian / Pacific Islander</i>	0 (0%)

<b>Gender</b>	
<i>Male</i>	3 (23.1%)
<i>Female</i>	10 (76.9%)
<i>Transgender / Non-Binary</i>	0 (0%)
<b>State</b>	
<i>State A</i>	1 (7.7%)
<i>State B</i>	8 (61.5%)
<i>State C</i>	4 (30.8%)
<b>Age</b>	
<i>18-65</i>	5(38%)
<i>65+</i>	6 (46%)
<i>Unknown</i>	2 (15%)

**Table 2: Participant Demographics, Care Managers**

	N (%)
<b>State</b>	
<i>State A</i>	11 (35.5%)
<i>State B</i>	11(35.5%)
<i>State C</i>	9 (29.0%)
<b>Race</b>	
<i>White</i>	15 (48.4%)
<i>Black</i>	1 (3.2%)
<i>Hispanic / Latino</i>	11 (35.5%)
<i>Asian / Pacific Islander</i>	1 (3.2%)
<i>Missing</i>	3 (9.7%)
<b>Gender</b>	
<i>Male</i>	2 (6.5%)
<i>Female</i>	26 (83.9%)
<i>Transgender / Non-Binary</i>	0 (0%)
<i>Missing</i>	3 (9.7%)
<b>Years at health plan</b>	Range (Mean)
<i>Employed (full or part time)</i>	11 mo – 6 yrs (4.90)

### **Data Analysis**

Interviews were professionally transcribed. Notes were also taken during interviews and used in data analysis. We used qualitative software, ATLAS.ti, to assist with coding data.<sup>11</sup> We used thematic analysis to identify patterns in the data.<sup>12</sup> Coding was conducted by two research staff who also conducted interviews with participants (individuals and care managers). One staff member is a person with a disability who receives Medicaid HCBS; the other is a family member



of a person with a disability. Initial coding was conducted separately on a subset of interviews. Following this initial coding, the research team convened to discuss discrepancies, further refine the coding scheme, and initially identify themes. The research team continued to meet regularly and discuss emerging themes and subthemes, and to refine names for themes. In addition, we collected assessment instruments used within the three states and copies of the person-centered care plans of individuals receiving HCBS in order to provide additional understanding of the person-centered planning process in each state and to triangulate our findings.<sup>13</sup>

## Results

Figure 1 depicts each theme that emerged, including both facilitators and barriers to person-centered planning, from the perspectives of individuals receiving HCBS and care managers. This figure shows how each facilitator and barrier aligns with the three components of the National Quality Forum's Person-Centered Planning Measurement Framework: (1) Person-Centered Plan; (2) Facilitator; (3) System Level<sup>1</sup>. Each facilitator and barrier, from the respective perspectives, are described below.

### *What are facilitators of person-centered planning from perspectives of individuals receiving HCBS?*

Individuals receiving HCBS overwhelmingly viewed person-centered planning as a team effort between them, their care managers, and other providers. Three key themes emerged as facilitators: *choice and control*; *personal goals and strengths*; and *relational communication*.

#### Choice and Control

Individuals highlighted the importance of choice and control. Most individuals felt that they had some level of choice over what is included in their care plan and the ability to include or exclude things based on their desires and importance. For example, one individual discussed

how she was able to select Meals on Wheels providers to meet her dietary needs and preferences.

Another individual had choice in hiring and firing direct support workers based on preferences.

Care managers were often key in facilitating opportunities for choice and control.

### Personal Goals and Strengths

The development of personal goals was viewed as a key aspect of person-centered planning. Individuals frequently mentioned these goals. While older adults often cited goals related to staying home and maintaining a baseline level of autonomy (i.e., “getting back to normal” after a fall or a stroke), younger adults often emphasized wanting to pursue interests, such as art, employment, and political involvement. It is important to note, however, that often these goals seemed constrained by what the care manager suggested or asked, as many members stated they didn’t know what services were available.

When individuals were asked how we might go about measuring the extent to which personal goals and desires are reflected in care plans, they offered some strategies. Individuals emphasized the importance of “asking” them directly what is important and then seeing if that matches the care plan. As one person said,

*So, the best thing that you can do is make sure that the paper matches what consumers are really telling you. And the only thing that I can say is mine doesn’t match.*

Another individual suggested the following approaches:

*I guess just if the plan is meeting their needs, I guess, or if there are other services that they would like or that would be helpful or beneficial to them, and I guess, if they feel like their care manager listens to them and is cooperative and understanding.*

Individuals also stressed the importance of recognizing their strengths and “responsibilities” in the planning process. As one individual stated:

*And I'm very much a believer that I have responsibilities in my care and I think that's important for any patient to know. It's caregiving, not care taking... So, I view my care, whether it's with my care manager or my waiver services coordinator or my aides or my nurse or any of my doctors, that it's a team effort. It helps if they feel that way too. Not all doctors do, unfortunately.*

### Relational Communication

Individuals stressed the importance of relational communication with care managers for successful person-centered planning. Stories from individuals about positive relationships with their care managers highlighted trust, respect, and listening. Individuals appreciated accountability to ensure that services were implemented according to plan. For example, one individual noted that she utilized transportation services to get to church, and because these services could be unreliable, the care manager had the transportation company confirm each ride. The importance of trust and accountability in general is conveyed by another individual:

*Even if she doesn't know the answer right then, she will find out whatever I want to know and get back to me with it. Now, during this time of COVID, it sometimes takes a little bit of time. But she's good about returning phone calls, and she's good about following up.*

Most individuals felt that their care managers knew them well. They were familiar with family structures and dynamics. One individual shared that her care manager knows her so well that she has picked up on when she is not feeling well just by a change in her voice. In another instance an individual felt comfortable confiding in her care manager about experiences of abuse and trauma.

The vast majority of individuals were satisfied with their current care managers, although some also had negative experiences with previous care managers. The importance of trust and respect is conveyed in the following story:

*And so, you know, but like the old case manager had inputted it into the computer as if I made that goal for myself... But like I didn't approve, you know. I didn't approve, you know, that goal.*

***What are facilitators of person-centered planning from the perspectives of care managers?***

Care managers described facilitators of person-centered planning somewhat differently than individuals receiving services. Major themes that emerged from perspective of care managers included: *development of measurable goals and relational communication.*

***Development of Measurable Goals***

Care managers placed more emphasis on developing measurable and attainable goals. As one care manager shared:

*If the individual wants to say they want to walk. Tell me what do you mean by that? Do you want to walk ten feet without a walker? You know, define that, you know what I'm saying? Or do you want to not fall? What are you going to do for fall prevention?... Attainable, measurable.*

Some care managers reported that if individuals weren't sure of their goals, part of their role was to help guide individuals in choosing goals by looking at their clinical needs. Many care managers actually referred to personal goals as "health goals," and stated examples such as losing weight, staying at home and out of the nursing home, improving walking, and medication management.

When asked how to potentially assess the person-centeredness of the planning process, care managers offered several strategies. Some care manager suggested improving the assessment tools used during the person-centered planning process (often prior to the meeting) and using them to inform the development of personal goals.

In regard to the care plan, care managers suggested looking closely at the language because they felt it would be easy to identify "copy and paste" goals that were not individualized. As one care manager described,

*Because there are just standardized things that are carried through, and they have to be on there because that's what national health plan and [my state*

*Medicaid agency] require... If you get a care plan from somebody else, you can tell what was there standardized or you can tell what that member wanted for their care plan or for their goal. You definitely can tell, yes.*

### Relational Communication

Similar to individuals receiving services, care managers underscored the importance of relational communication. Care managers enjoyed asking individuals about their lives, having informal conversations, and weaving conversations into development of goals. As one care manager described her process:

*Asking open-ended questions for starters. Building some rapport to establish some trust relationship between you and the member or patient and kind of having a conversation about what's important to them and really making sure you're answering open-ended questions. Because especially with the elderly population, I find that if you don't do that, you're just going to get a lot of yeah, uh huh. They're just agreeable with everything.*

Another care manager described personalizing the relationship as a facilitator to person-centered planning. As she explained:

*I'll ask them, what are you looking for from a case manager?... How often do you want your case manager to interact with you?... Do you want a phone call or do you want in-person? Do you want us to send you literature? Do you mind us emailing you stuff? So that way, they feel like, oh, wow, okay because it's not me throwing all this information down your throat. I'm asking you what you need and what would you like.*

### ***What are barriers to person-centered planning from the perspective of individuals receiving***

### ***HCBS?***

From the perspective of individuals receiving HCBS, three themes emerged as barriers to person-centered planning: *medical orientation of care plan, administrative and systemic barriers, and competencies of care managers.*

### Medical Orientation of Care Plan

While individuals expressed the importance of choice and control and personal goals, there was often a disconnect with the care plan. As one individual described,

*And the system in [my state] is so medicalized, they don't let anybody have any choice about what they do. Care plans are written without people's knowledge. I spend very little time looking at my personal care plan.*

Most individuals had not looked at their plans in a long time, and/or did not remember what was on it. Many individuals viewed their care plans as a medical document, and not as a person-centered planning tool to help achieve a good life. One member expressed,

*The medical – the whatever – those people that make all those medical laws, and you have to fill them out and ask the questions, that's why. It has nothing to do with what [my care manager] would want to do. But she has to answer them – ask me the questions. And then she fills out the form.*

In order to triangulate this finding, we obtained copies of individuals care plans and project staff reviewed them. Each state uses different forms. In one state, the care plan consists of multiple documents. Care plans we reviewed primarily consisted of medical diagnoses, types of services provided, and amount of services. In two of the three states, we were unable to clearly identify personal goals. In the state we were able to identify personal goals, most of the goals were medically oriented (i.e, goals related to diabetes management or weight loss).

#### Administrative and Systemic Barriers

Individuals also cited administrative and systemic barriers. Some individuals felt that care managers were constrained by the bureaucracy in which they worked. The assessments and care planning meetings themselves take a long time, and some individuals experienced this process as burdensome and overwhelming.

*But in my opinion, the managed care system [in my state] has done nothing but make my life considerably more difficult and created more bureaucratic hoops for me to jump through.*

Some individuals expressed confusion due to having multiple plans and providers that were not always well coordinated. Individuals also discussed systemic barriers in obtaining referrals and services and supports in their care plan.

The COVID pandemic also changed the delivery of person-centered planning from in-person to virtual. Some individuals noted this impacted their relationships with care managers.

As one individual shared:

*Since they're over the phone visits, I think that they're about as good as can be expected... Well, you know, you can't judge people by their expressions. You can't, I don't know, I tend to talk more than I should, and I don't like to take up too much of her time because I know care managers are busy.*

#### Competencies of Care Managers

Other barriers to person-centered planning, from the perspective of individuals receiving HCBS, related to competencies of care managers. Some individuals perceived that their care managers had limited knowledge in some areas, such as Medicaid policies within the state. Individuals explained that care managers would proceed according to the routes that they knew to be available, but this wasn't necessarily reflective of all options. Regarding competencies in the planning process, one individual shared that her care manager viewed her as overweight, and created a goal to eliminate protein shakes from her diet, despite the member, doctor and nutritionist disagreeing with this goal and plan.

#### ***What are barriers to person-centered planning from the perspective of care managers?***

Care managers largely focused on *administrative and systemic barriers*.

#### Administrative and Systemic Barriers

Care managers highlighted bureaucratic and administrative barriers, such as completing multiple assessments and forms. They tried to find ways to work around these barriers to make the process more person-centered and relational. As one care manager stated:

*But I for the most part don't even take my laptop in because it limits so much eye contact and I don't like that. I remember when we first started with those computers and we had the little handheld ones, a member actually said you need to stop playing that game while you're here. So, I just personally don't like taking a laptop in the home.*

Caseloads and time to establish relationships were also seen as barriers:

*I personally try to schedule at least the two hours if I need to talk to the member more. When I'm out in the field, sometimes I've been in people's houses for three hours, not just completing the assessment but really getting to know them. But a lot of our case managers don't have three hours to really get to know our individuals because of the time restraint.*

Similar to individuals receiving HCBS, care managers also expressed frustration with systemic barriers in obtaining services, including durable medical equipment and the availability of direct support workers, particularly since the COVID-19 pandemic. One care manager also pointed out that in her state, care plans are currently only available in English, which limits the ability of some individuals to understand their care plans.

## **Discussion**

Through interviews with individuals with disabilities receiving HCBS and care managers in three states, we identified key aspects of the person-centered planning process. From the perspectives of individuals receiving HCBS, themes that emerged as facilitators to person-centered planning included: *choice and control, personal goals and strengths, and relational communication*. From the perspective of care managers, *development of measurable goals* was seen as a key to their role in person centered planning; and similar to individuals receiving HCBS, the importance of *relational communication* was stressed. The following themes emerged as barriers to person-centered planning from the perspectives of individuals receiving HCBS: *medical orientation of care plan, administrative and systemic barriers, and competencies of care managers*. Care managers similarly identified *administrative and systemic barriers*. These



themes largely align with the three components of the National Quality Forum’s Person-Centered Planning Measurement Framework: person-centered plan, facilitator, and system level.<sup>1</sup>

Our findings support the importance of person-reported outcomes in assessing person-centered planning. As one participant recommended, “So, the best thing that you can do is make sure that the paper matches what consumers are really telling you.” Several existing survey instruments have recently developed measures that could be built upon. Most notably, the National Core Indicators –Aging and Disabilities (NCI-AD) developed a 10-item person-centered planning supplement and the National Core Indicators –Intellectual and Developmental Disabilities (NCI-ID) embedded person-centered planning questions within the core in-person adult survey.<sup>14</sup> In addition, the HCBS Consumer Assessment of Healthcare Providers and Systems (CAHPS) also contains some questions related to person-centered planning.<sup>15</sup> To varying degrees, these surveys measure aspects such as whether individuals receiving HCBS feel they have choice and control over the planning process, whether their preferences and desires are heard, and whether their plan includes personal goals and things important to them. Based on our findings, and specifically the importance of relational communication from the perspectives of both care managers and members, additional measurement concepts that could be expanded upon include perspectives of individuals receiving HCBS on the relationship, communication and competencies of individuals facilitating person-centered planning and coordinating services.<sup>1,16</sup>

Some approaches to measuring person-centered planning have examined individuals’ service plans. For example, NCI-ID examines service plans to see if they include goals that match what individuals say is important (e.g. community employment). However, few individuals within the current study viewed their plan as a person-centered planning tool (i.e., “And the system in [my state] is so medicalized, they don't let anybody have any choice about

what they do”), plans varied considerably from state to state, and we found it difficult to clearly identify personal goals when we examined plans. Based on recommendations from care managers in our study, another approach might be to review a randomly selected sample of plans and assess the extent to which the same goals are seen (i.e, the extent to which they are “copied and pasted”), which might indicate they are not individualized.

Administrative and systemic issues were also identified as barriers to person-centered planning, such as high case loads, difficulty obtaining Durable Medical Equipment, and bureaucratic constraints. These findings support the need to examine person-centered planning and practices at multiple levels, including the systems level.<sup>1</sup> For example, some care managers suggested examining assessment data as a strategy. However, similar to care plans, there was a wide variation across states in the instruments they used, one state used multiple tools, and they were mostly medically oriented assessments that did not ask about personal goals. In the states we examined, these tools were required by the state within their managed care contracts. More standardization of assessments and integration of key elements of person-centered planning within assessments could improve practices and potentially open new measurement approaches. These measurement approaches could eventually yield information about state and regional differences that some of our participants alluded to. For example, members and care managers in each state differed in the extent to which they highlighted language barriers, transportation issues, and availability of direct care workers. Finally, our study examined person-centered planning with MLTSS Health plans, coordinating acute medical care and long-term services and supports. Person-centered planning primarily originated within fee for service models providing only LTSS. Advocates have raised concerns about historical predominance of the medical model

within managed care.<sup>17</sup> More research is needed on promising practices in person-centered planning aspects that integrate medical and social aspects.

This study has several limitations that are important to note. First, we faced many challenges in recruitment due to the COVID-19 pandemic, and these challenges ultimately resulted in a small sample of HCBS users. Many participants rescheduled or cancelled their interviews due to demands and challenges associated with navigating the pandemic. Since care managers were working remotely, it was difficult in some states to obtain a required physical signature for the HIPAA form, which was necessary to release member names for recruitment. While we translated materials into Spanish, offered options to conduct interviews in Spanish, and asked care managers to assist with recruiting a diverse sample based on race/ethnicity and other demographics, our sample of individuals receiving HCBS was predominately White and English speaking. Additional research is needed to explore the perspectives and experiences of racial/ethnic minorities with person-centered planning. This research should also address the impact of the diversity and cultural competency of the care manager workforce. The current study also did not explore how users' experienced varied as a function of disability type; this is an important area for future research.

In addition to recruitment challenges, the context of the COVID-19 posed other challenges that may impact findings. Care managers' interactions with individuals were abruptly changed from in-person to remote. Thus, we were asking questions about the planning process that had been changed. Lastly, our sample consisted of care managers and individuals receiving HCBS within MLTSS programs. Within MLTSS, care managers are responsible for coordinating acute care used within this as well as HCBS, which likely influenced the context of person-centered planning process and may contribute to more inclusion of medically oriented aspects.

Our sample is also limited to one health plan and the three states that primarily served older adults and individuals with physical disabilities.

### **Conclusion**

Despite limitations, this exploratory study provides important perspectives from individuals receiving HCBS and care managers facilitating person-centered planning. Findings can help inform policy and practice to remove barriers and improve implementation. In addition, findings build on recent work to assess person-centered planning through recommending approaches to quality measurement and future measure development.

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**Figure 1 Facilitators and Barriers to Person-Centered Planning (caption)**

The facilitators and barriers, from the perspectives of individuals receiving HCBS and care managers, as they align with the three components of the National Quality Forum's Person-Centered Planning Measurement Framework.<sup>1</sup>

