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Original Study

Rural-Urban Disparities in Access to Home- and Community-Based Services and Supports: Stakeholder Perspectives From 14 States



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A B S T R A C T

Keywords:

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Objectives: Trends over time in the United States show success in rebalancing long-term services and supports (LTSS) toward increased home- and community-based services (HCBS) relative to institutionalized care. However, the diffusion and utilization of HCBS may be inequitable across rural and urban residents. We sought to identify potential disparities in rural HCBS access and utilization, and to elucidate factors associated with these disparities.

Design: We used qualitative interviews with key informants to explore and identify potential disparities and their associated supply-side factors.

Setting and participants: We interviewed 3 groups of health care stakeholders (Medicaid administrators, service agency managers and staff, and patient advocates) from 14 states (n = 40).

Measures: Interviews were conducted using a semistructured interview guide, and data were thematically coded using a standardized codebook.

Results: Stakeholders identified supply-side factors inhibiting rural HCBS access, including limited availability of LTSS providers, inadequate transportation services, telecommunications barriers, threats to business viability, and challenges to caregiving workforce recruitment and retention. Stakeholders perceived that rural persons have a greater reliance on informal caregiving supports, either as a cultural preference or as compensation for the dearth of HCBS.

Conclusions/implications: LTSS rebalancing efforts that limit the institutional LTSS safety net may have unintended consequences in rural contexts if they do not account for supply-side barriers to HCBS. We identified supply-side factors that (1) inhibit beneficiaries' access to HCBS, (2) affect the adequacy and continuity of HCBS, and (3) potentially impact long-term business viability for HCBS providers. Spatial isolation of beneficiaries may contribute to a perceived lack of demand and reduce chances of funding for new services. Addressing these problems requires stakeholder collaboration and comprehensive policy approaches with attention to rural infrastructure.

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Over the past several decades, state and federal initiatives have aimed to reduce use of institutional long-term services and supports (LTSS), such as nursing homes, through the increased use of home- and community-based services (HCBS).^{1–6} The recent Balancing Incentive Program (BIP) sought to facilitate increased use of HCBS among states spending less than 50% of Medicaid LTSS funds on HCBS. Such “rebalancing” efforts reflect consumer preferences for HCBS over institutional care^{3,7–10} and may facilitate community integration of beneficiaries in compliance with the Americans with Disabilities Act

and the *Olmstead* decision.¹¹ Because HCBS is generally less costly than institutional forms of LTSS, rebalancing may also offer potential cost-savings for state Medicaid agencies¹² as well as beneficiaries and their families.¹³

However, given well-recognized differences between urban and rural areas in access to medical care,^{14,15} LTSS rebalancing efforts may face similar challenges ensuring access and result in inequitable impacts across rural and urban environments. There is a dearth of literature examining potential HCBS disparities in the context of rebalancing policy efforts such as BIP. Rebalancing may have unintended consequences if implemented amid baseline inequities in health and in noninstitutional LTSS availability, access, and quality for rural populations. For example, as non-Hispanic white older adults decreased use of nursing homes and shifted toward increased use of HCBS between 1998 and 2008, the proportion of racial- and ethnic-minority older adults in nursing homes grew.³ Additionally, recent analyses found that in rural areas, nursing home closures occurred despite the limited availability of HCBS services in their stead.¹⁶

Medical care access disparities have been attributed to structural factors, such as limited transportation infrastructure, distances separating providers and patients, and provider shortages.^{15,17–19} In tandem with these medical care barriers, rural populations tend to be older, poorer, and fare worse on numerous health indicators compared to urban residents.^{20,21} Poorer health and greater physical and functional limitations^{1,20,22–24} place rural persons at increased risk for unmet HCBS needs when compared to their urban counterparts.

Research on potential rural disparities in HCBS is pressing, given the attention to rebalancing LTSS and the growth of the older adult population in rural regions.² Because rebalancing efforts seek to shift the supply and availability of health care (in this case, HCBS in place of institutional LTSS), our analysis was informed by a multilevel framework focused on health care access and the structural factors that might exacerbate disparities, rather than a focus on the individual-level factors that predominate in health care disparities literature generally.^{25–27} Specifically, we applied a supply-side framework developed by Levesque et al.²⁸ This framework synthesizes several decades of research regarding dimensions of health care access, and distills these perspectives into 5 distinct but interrelated domains. In this framework, *approachability* reflects concepts such as informational access, *acceptability* reflects the cultural and social acceptability of the services, *availability* and *accommodation* reflects the presence of services and also the pragmatics of accessing these services, *affordability* reflects the financial accessibility of services, and *appropriateness* reflects the concordance between services and needs, as well as adequacy and continuity of these services.²⁸

Methods

We examined the potential for rural-urban disparities in HCBS access, drawing from qualitative interviews in a larger mixed-method study of BIP implementation and impacts on HCBS access and utilization. A key component of these interviews was a formative assessment of stakeholders' perceptions of the LTSS and HCBS landscape in their states, inclusive of states that did and did not participate in BIP. These data were used for the present analyses.

Sample

We conducted 40 interviews with key informants from 14 states that were eligible to apply for BIP (8 BIP-participating states and 6 BIP nonparticipating states). Interviews were stratified into 3 key informant types: state Medicaid administrators ($n = 13$), service agency staff (including managers and direct service providers; $n = 14$), and patient advocates ($n = 13$). Recruitment was initiated with a letter to state Medicaid Directors requesting permission to contact staff for an

interview. Service agencies and patient advocates were identified through online professional organization directories, newspaper or other media references to their organizations, summaries from LTSS program meetings hosted by the state, or direct referral from prior interviewees. Interviewees were invited to participate in an interview via e-mail and phone call and received an e-mail confirmation and calendar invitation following agreement to participate.

Interview Procedures

Telephone interviews were conducted by an interviewer using a semistructured discussion guide with a note-taker present. As part of a larger effort to inform subsequent quantitative analyses, the interview guide covered a wide range of topics aimed at each of the key stakeholder groups: (1) current state and perceptions of LTSS programs in the state; (2) perceptions of the relative access or availability of HCBS for different geographic and demographic groups; (3) the decision to and process of applying for BIP; (4) barriers and facilitators to BIP implementation; and (5) impacts of BIP and related programs on important outcomes such as patient health and well-being, access/use, or cost. Interview questions that specifically elicited information regarding potential rural disparities are included as an [Appendix](#), though the findings we present here reflect a thorough analysis of all interview data relevant to disparities. Interviews were audio-recorded following respondent consent, and eligible respondents received a \$100 honorarium for their participation. The study was approved by the institution's Human Subjects Protection Committee.

Data Coding and Analysis

All recordings were transcribed verbatim, deidentified, and coded using a standardized codebook. The codebook was developed in 2 stages: first, we developed a hierarchical coding scheme drawn from the discussion guides and organized by topic area. Next, 2 coders independently applied this coding scheme to an initial set of 5 transcripts. These coders subsequently conferred to identify emergent themes and refine the codebook. The codebook was finalized following coder consensus and team review. Each transcript was coded by one researcher. Coders met weekly to discuss progress and questions about code application; areas of disagreement were resolved via consensus. Codes were applied using Dedoose.²⁹ Text excerpts could receive multiple codes, and coders were instructed to include relevant surrounding text when needed for context.

After coding, text excerpts were extracted into a sortable database that permitted filtering by respondent characteristics or hierarchical code. In weekly meetings and 3 structured debriefings, team members reviewed the extracts to identify key themes, areas of disagreement, thematic trends, and anomalies. Analytic findings and interpretations were developed into a manuscript and reviewed by all members of the qualitative team.

Results

Within the domains of supply-side disparities,²⁸ stakeholders identified factors related to *approachability*, *acceptability*, *availability* and *accommodation*, and *affordability*. We did not find notable differences or patterns by stakeholder category in the disparities they perceived, with 1 exception. Service agency managers and patient advocates raised multiple points regarding limited business viability and worker shortages in rural areas relative to urban areas; fewer Medicaid administrators articulated this point.

Approachability (Informational Access, Knowledge of Service Availability, Health Literacy²⁸)

Communications infrastructure

Stakeholders reported that the communications infrastructure in rural environments was inadequate for communicating and coordinating the availability of HCBS. One patient advocate described the challenge as “just getting the word out to people that the waivers are available, especially in some of our very rural, underserved areas.” This contrasted with 1 agency manager’s description of “a proliferation of marketing in more suburban areas.”

Stakeholders noted that many rural persons had limited or no access to the Internet, where they might learn of HCBS services. This was problematic given shifts toward web-based HCBS infrastructure, including informational outreach, applications for benefits, and locating services. Rural residents might also have limited cellular phone or landline connectivity, restricting their ability to contact distant administrative offices or services. One provider noted a lack of communications infrastructure in tandem with limited technological skills:

There’s many sections of the state that have little or no Internet access. My particular crowd of people that I serve, they don’t have computers. We’re talking people who have next to nothing and they don’t have the ability to access [the internet], let alone the understanding of how to use it. I do think that the state through this process is relying heavily on Internet use and on-line access and [consumers] don’t have the ability to do that.

This *approachability*-related challenge dovetailed with limited available services in rural areas (*availability and accommodation*). One advocate explained that although there was increased advertising of HCBS service availability (ie, increased *approachability*), they were wary of promoting a service that was potentially not available in rural areas:

We’re really working hard to try to let people know these services are out there... but you kind of pull back a little bit, if we’re going to a very rural part of the state... I don’t want to tell somebody something’s available and come to find out, it’s really not available in their area.

Acceptability (Concordance Between Available Services and what is Socially and Culturally Acceptable to the Population Served²⁸)

Perceived rural culture and norms

Stakeholders commented on a rural culture of informal caregiving. For example, one agency manager conjectured that rural persons were constitutionally different (“it seems like the people are hardier”) from suburban or urban persons. This stakeholder speculated that rural persons “don’t ask for help that much, as opposed to maybe in the suburban cities where maybe you’ve got more people working, more double spouses working, and they can’t take care of their parents.”

However, perceptions that rural persons had a cultural preference for informal caregiving also could reflect adaptation to HCBS deficits. Specifically, rural communities may rely on informal caregiving (eg, provided by families and neighbors) because of gaps in HCBS. This is supported by the remarks of one service agency manager who reported that it was a common perception that rural persons tended to rely on informal supports. The stakeholder further commented, however, that to them it was unclear whether a tendency to use informal supports was a choice or a necessity:

One of the things we’ve heard repeatedly, as well, is folks in rural communities tend to be the same way, as far as using family and using internal sources for the aging-in-place experience.

Whether they’ve had to or chosen to is another matter, I don’t know.

Availability and Accommodation (Ability to Access Services when and where Needed, Distribution of Services²⁸)

Availability of HCBS providers

Stakeholders reported that caregivers, providers, and specialty care were disparately concentrated in urban/suburban areas and limited in rural areas. One stakeholder commented:

Two-thirds of our state area really only has less than one-third of our state population. It really is rural. Services are inconsistent when they’re available. Somebody may have to drive 100 miles to see a particular specialist whereas in other areas of the state, those services are much more readily accessible.

Transportation

Stakeholders perceived that limited or nonexistent transportation in rural areas contributed to rural disparities in HCBS. One Medicaid administrator explained:

In our urban communities, we have some fairly robust medical and informal transportation resources for an individual, that helps them remain at home and navigate life outside of an institution, that we do not have in rural areas. So I think that probably is one of those things that makes a difference.

Transportation deficits may further marginalize rural populations, such that their need is not visible to provider agencies or policymakers who allocate resources. One stakeholder’s response demonstrated the paradox of transportation deficits and rural older adults’ inability to attend adult day meetings, thereby potentially obscuring the demand for HCBS:

I don’t know [whether there are rural disparities], to be honest with you... because they don’t come to adult day meetings and [there are] not too many adult day [care centers] in the rural environment of [omitted state name], because of transportation, mainly. Yet, there’s a high proportion of elders in the woods of [state], the rural areas. But I don’t feel like I could answer that properly.

Availability of informal supports

As noted in *Acceptability*, stakeholders reported the perception that rural persons were more likely to endorse informal caregiving, potentially out of necessity. However, social and economic circumstances might limit the availability of informal caregiver supports. In responding to a question about rural differences in HCBS access or utilization, 1 Medicaid administrator explained the need for informal supports to enable HCBS utilization:

In a community where we have not fully recovered from the economic downturn, the availability of caregiver support, informal caregiver support, does impact the ability of someone who would prefer to receive their services through [HCBS program name]; or if there is a [HCBS] site in that area, [the ability to] receive their services from [HCBS program] is impacted by the availability of someone to support that individual in-home.

Affordability (Financial Capacity for Services²⁸)

Business viability and the HCBS workforce

The *availability and accommodation* factors that limited access to HCBS for beneficiaries also challenged the affordability of providing HCBS in the rural context—specifically, the recruitment and retention

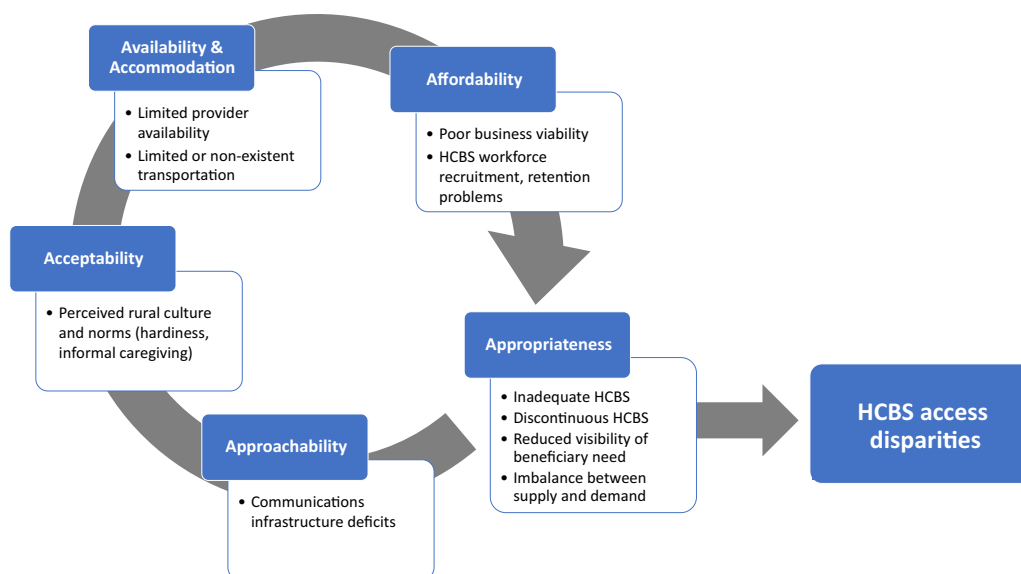


Fig. 1. Supply-side barriers to HCBS access for rural populations. Framework adapted from Levesque et al.²⁸

of a caregiving workforce. Stakeholders, particularly service agency managers and patient advocates, perceived that there was insufficient patient volume in rural areas to make the business of HCBS financially viable for agencies or caregivers. Rural geography required paid caregivers to travel long distances to reach individual patients. One patient advocate noted, “it might be more expensive for them just to get somebody to the house, than it is for them once they’re there to provide the service.” This advocate elaborated:

There are no provider agencies. Getting somebody to come to your house at \$8 an hour when that’s not even going to fill your tank up, when they’re probably driving 50 miles just to get to the house, families are taking that \$8 because they don’t have a provider agency. And then on top of that, they’re having to supplement \$2 an hour worth of pay, just so that individual can get to the job. . . . It’s not a living wage for anybody at all.

A service agency manager pointed out that the same factors negatively impacted the availability of back-up paid caregivers:

You don’t have backup staff that can fill in when the [HCBS] caregiver is sick. . . . because there’s not enough hours to go around.

Patient advocates also reported that due to travel and low wages for HCBS, potential caregiving employees had better employment opportunities in other industries (eg, retail stores). An advocate framed caregiving as less desirable, in light of the pay and job duties:

[A national retail chain] is paying \$15 an hour as a starting rate for anybody who signs on and works for them. And we’re not paying that for CNAs [certified nursing assistants] who drive their own car and go out and do odd work and are pretty much in someone’s home unsupervised.

These problems with workforce viability and retention affected the availability of care for beneficiaries. Direct-care workforce shortages meant that patients were sometimes left waiting for services after receiving HCBS approval. As 1 Medicaid administrator explained,

It’s often a challenge for beneficiaries or sometimes a challenge for beneficiaries of those programs to—even though they’re approved for services—get access to the caregivers or the level of professional caregiver needed to deliver those services.

Workforce limitations also presented problems for established beneficiaries. Because it was not financially viable for agencies or their employees to have redundant caregivers available, beneficiaries could face gaps in care coverage, or caregiver turnover. For example, 1 service agency manager explained: “The problem is not access to care getting started, [it’s] more access to continuing care.” This manager referenced one client’s experience as an example:

A lady we have served multiple times in the community of [rural community], and we will find a caregiver that is more than willing to go and provide care, but it’s typically 15 to 20 hours a week is all that she requires. . . . We don’t have another caregiver, because you can’t have multiple caregivers for 1 client that’s only receiving 15 or 20 hours a week. So, we try to find another. . . caregiver. If we’re not successful to doing that in a short period of time, they will re-broker to another provider. This lady has been re-brokered so many times, [our agency has] had her 3 times. Now, who suffers during that? The client.

Discussion

This study is the first to provide multi-stakeholder insights into rural-urban disparities in access to HCBS in an era of rebalancing efforts. Our analyses sought to examine how supply-side factors manifest in the context of HCBS, and the unique challenges posed by an increasing policy emphasis on HCBS over institutional LTSS. Medicaid administrators, service agency staff, and patient advocates provided system-level perspectives on barriers to rural HCBS, and the types of barriers identified were relatively consistent across stakeholder types.

Figure 1 summarizes our findings and presents a revised model of Levesque and colleagues’ supply-side barriers²⁸ that we adapted to rural HCBS. *Approachability* manifested as limitations in the communication infrastructure of rural environments, meaning that potential beneficiaries had limited access to HCBS program information and were likely to experience challenges in coordinating care. *Availability and Accommodation* manifested as limited availability of providers in rural areas and transportation challenges (both distance and lack of transportation services). This had implications for workforce recruitment and retention, especially given the economic context of caregiving employment (eg, low wages). *Acceptability* manifested as

stakeholders' perceptions of rural persons' "hardier" constitutions and cultural inclination to use informal supports, despite the many reasons why these supports might be unavailable to provide consistent care. *Affordability* manifested as limited business viability and problems with recruiting and retaining an HCBS workforce, due to low reimbursement, dispersed patient need, and long driving distances. As a proximal outcome (*Appropriateness*, ie, concordance between demand/need and supply; quality of services), HCBS access was inadequate and discontinuous. There was inhibited visibility of beneficiary need, and an imbalance between HCBS demand and supply. Taken together, these factors contribute to the distal outcome of HCBS access disparities among rural populations.

We also expanded on the supply-side concept of *affordability* as originally described by Levesque et al: "Affordability reflects the economic capacity for people to spend resources and time to use appropriate services."²⁸ We reframed *affordability* to more directly reflect a supply-side (ie, infrastructure-related) dimension of health care access, and also because Medicaid's purpose is to make services accessible to persons who otherwise could not afford them. Instead, we posit that HCBS *affordability* represents the business viability for HCBS care. A revised definition that we propose is "the economic capacity for agencies and providers to spend resources and time to provide appropriate services."

Stakeholders noted that a lack of transportation and rural geographic expanses contributed to HCBS access disparities. The availability of care may be limited in rural areas, necessitating travel by providers and consumers over long distances.^{15,19} A particularly insidious effect of transportation barriers is that spatial isolation of beneficiaries can contribute to a perceived lack of demand, which in turn perpetuates lower funding for new services. Telecommunication advances (eg, the Internet) might ameliorate some of this invisibility and connect providers and policy makers with beneficiaries.¹⁵ However, our stakeholders identified limitations in both Internet access and technology literacy.

Similarly, stakeholders indicated that limitations in rural telecommunications likely contributed to HCBS disparities. Given the shift toward electronic platforms for enrollment and coordination in health care more generally, this finding is especially relevant for outreach strategies. Limitations in Internet access or technological literacy have implications for dissemination of information about HCBS to potentially eligible beneficiaries, and for care coordination. This infrastructure limitation, paired with the aforementioned instability and dearth of the rural caregiving workforce, means that beneficiaries and their families are likely to face challenges in accessing HCBS services without additional telecommunications resources or more traditional media outreach (eg, mailers, radio) in these areas.

Stakeholders also highlighted the limited availability of HCBS providers and caregivers. In the rural environment, where patients are geographically dispersed, workforce conditions such as low wages are likely to have a greater impact on the rural workforce. Factors such as the lower "baseline" availability of care workers in rural areas also have implications for current rebalancing efforts. For example, fewer home health workers in rural regions meant that changes in Medicare policy potentially had a differential and negative impact on rural settings following the Balanced Budget Act of 1997.³⁰ Our stakeholder reports align with research documenting consumers' beliefs that personal attendants are in short supply, are underpaid, and that this impacts care worker retention and quality of care.^{31,32} To facilitate rebalancing efforts, HCBS policymakers may need to address higher wages, better job training, and improved employment trajectories. The need for HCBS continues to grow, given more rapid population aging in rural areas.^{5,33,34}

Relatedly, stakeholders also perceived that transportation problems and dispersed clients meant that providing HCBS was not viable from a business perspective. This parallels previous findings from 1

state related to disability services and rehabilitation.¹⁸ It is also congruent with findings that the availability of assisted living settings is driven primarily by business considerations, and these residences are more available in densely populated higher-income areas and less available in rural areas.^{35,36} When these residences do exist in rural settings, they may be unaffordable and offer less privacy or fewer services than those in metropolitan settings.³⁵

Our findings contribute to the growing body of research on rural health disparities. For example, our study elucidates supply-side factors such as limited transportation, lower provider availability, and structural factors that contribute to rural differentials in HCBS access. These are cross-cutting issues for health disparities as well.^{15,17–19,21} Our analysis contributes to disparities research by documenting administrators', providers', and patient advocates' perspectives. These are less represented in existing literature, which has primarily documented patient and caregiver experiences.

Our findings also have several limitations. First, interviews were conducted within 14 states that were eligible to apply for BIP; findings may not be representative of all states. Our interviews were not designed to make cross-state comparisons in HCBS disparities with regard to BIP vs non-BIP states. However, they provide insight into rural challenges in the context of a large and recent policy initiative (ie, BIP). Additionally, states were ineligible to apply for BIP if their HCBS spending was more than 50% of Medicaid LTSS expenditures¹¹; the rural landscape of HCBS may be different in states that have already achieved this spending benchmark. Second, although we conducted 40 interviews, these individuals were stratified across 3 stakeholder types. We do not suggest that these interviews capture the totality of stakeholder perspectives; rather, these perspectives identify pressing areas to consider in future research. Third, because we were focused on supply-side factors, we did not interview HCBS consumers. Rural consumers may have distinct perspectives that are not reflected in our interviews with nonconsumer stakeholders. Relatedly, we did not examine disparities across the types of beneficiary needs, though any disparities by chronic condition or functional needs are likely to be further exacerbated for rural populations. Fourth, we did not explicitly differentiate the types of HCBS, and research suggests that there is likely variation in access barriers across HCBS types.³⁷ Finally, we note that the designations of "rural" vs "urban" are social constructs that are not dichotomous and are not operationalized consistently across research studies.^{21,31,38} Respondents defined rural and urban boundaries subjectively within their own state.

Conclusions and Relevance

Our findings suggest that rebalancing efforts may have unintended consequences. Groups may not benefit equally^{3,16} from policy interventions such as BIP if there are barriers to the existence or growth of HCBS. Further, policies emphasizing HCBS over institutional LTSS may have unintended negative effects on rural persons by limiting the institutional LTSS safety net. In examining nursing home closures and potentially disparate impacts in rural environments, Tyler et al¹⁶ draw a cautionary parallel to the era of psychiatric institution closure—because of a lack of community-based services in situ, persons with psychiatric conditions faced potential homelessness after they were deinstitutionalized. If institutional LTSS becomes less available because of rebalancing efforts, rural areas without current HCBS alternatives (and further, with structural barriers that impede the development and growth of HCBS) are likely to suffer. More proximally, efforts to rebalance must account for the social and structural contexts of rural HCBS, or they may inadvertently exacerbate disparities. Addressing these challenges requires comprehensive policy approaches with the collaboration of stakeholders (eg, addressing rural provider shortages, and working conditions for caregivers) to respond to the unique challenges of access to HCBS in rural areas.¹

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Appendix

Disparities Questions Excerpts*

Interview Topic	Medicaid Admin		Service Agency Staff		Patient Advocate	
	BIP	Non-BIP	BIP	Non-BIP	BIP	Non-BIP
I'm particularly interested in any differences that might have existed between groups in access to HCBS or use of HCBS.	X	X	X	X	X	X
<ul style="list-style-type: none"> Can you describe any differences between groups in terms of their access to or use of HCBS? For example, differences between racial/ethnic groups, or between different communities such as the disability community and the behavioral health community? How about geographic differences, such as between rural vs urban areas? How about differences related to family structure, eg, whether a beneficiary has a spouse or children Are there any other differences among demographic groups in terms of access or utilization of HCBS during the pre-BIP period that you think are important for me to know? 						
Are some groups in your state more likely than others to use HCBS instead of institutionalized care? If so, why?	X	X	X	X	X	X
What are the key factors that determine whether or not someone is able to receive HCBS in your state?		X		X		X
<ul style="list-style-type: none"> What kinds of things may make it more difficult for people to access HCBS? What kinds of things may make it easier for people to access HCBS? 						
In what ways has the availability of HCBS (eg in certain areas) affected beneficiary utilization?		X		X		X
What are some ways your agency, or the State has tried to address these disparities in access? What challenges have you faced in trying to address them?				X		X
<ul style="list-style-type: none"> To the extent that access has been improved, to what extent has the system (or your agency) been able to absorb the additional demand or utilization? 						
Now that BIP has ended, in what ways would you say access to or use of HCBS has changed?	X		X		X	
<ul style="list-style-type: none"> Earlier, you mentioned some differences in access and use of HCBS between certain groups. In what ways would you say BIP has addressed those differences? To the extent that access increased, to what extent has the system been able to absorb the additional demand or utilization? 						
Is there anything else that you think is important for us to know? [if BIP: about the implementation or impact of BIP in (state)?]	X	X	X	X	X	X

*Because the discussion guides were tailored for BIP vs non-BIP states, as well as stakeholder type (eg, Medicaid administrators vs patient advocates), there are 6 versions of the discussion guide. However, the questions that were germane to health disparities were similar across discussion guides (eg, Are there differences across groups in their access to HCBS in your state?).