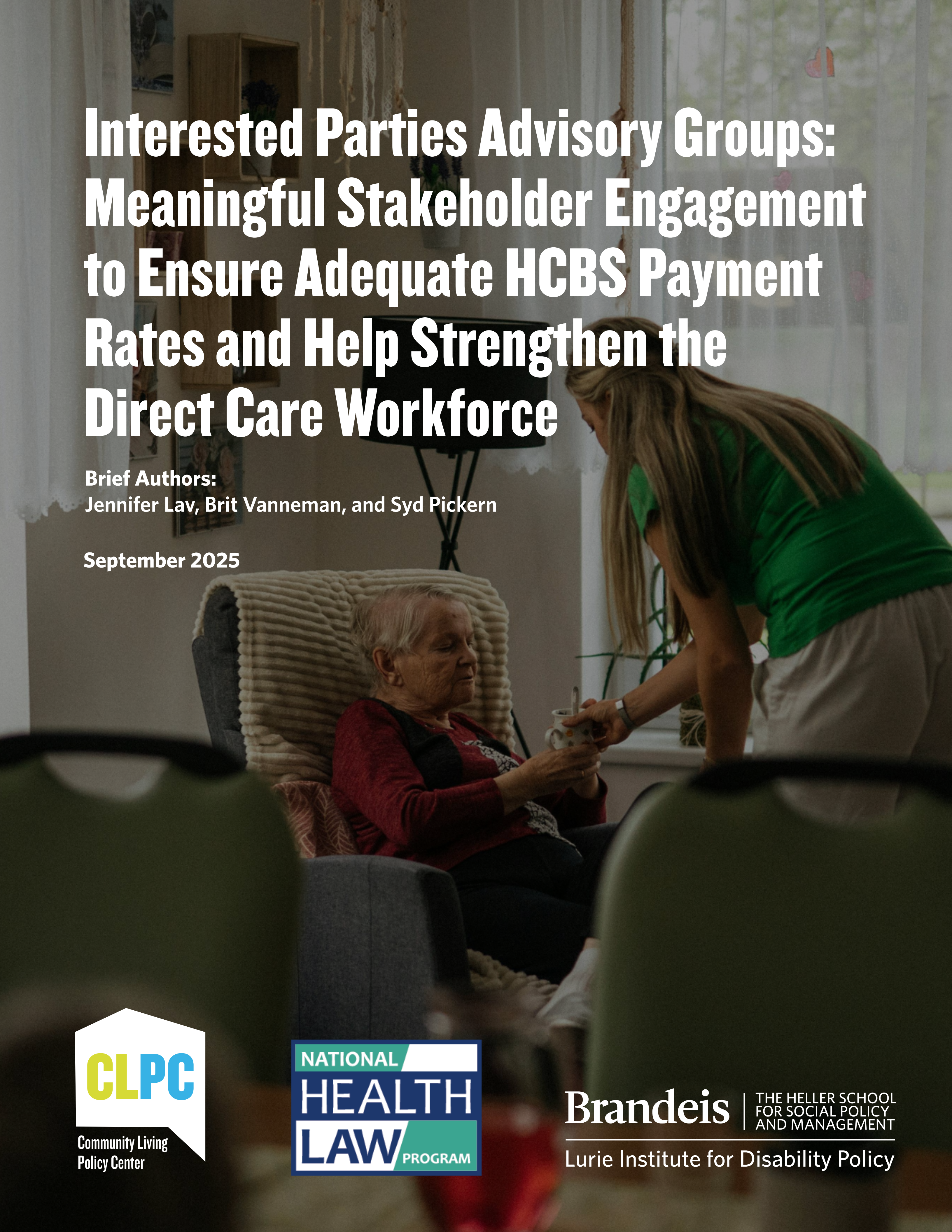

Interested Parties Advisory Groups: Meaningful Stakeholder Engagement to Ensure Adequate HCBS Payment Rates and Help Strengthen the Direct Care Workforce

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I. Executive Summary

The Interested Parties Advisory Group (IPAG) requirement, established under the Medicaid Access Rule, instructs states to establish a work group to advise on the adequacy of rates for direct care workers who provide home and community-based services (HCBS) for people with disabilities.[1] States must establish and begin convening IPAGs by July 2026. This issue brief prioritizes strategies to help states implement IPAGs in ways that advance the Access Rule's core objective: ensuring meaningful access to HCBS. By centering the experiences and needs of people with disabilities, states can also support more transparent and responsive rate-setting processes. In doing so, they can help secure adequate wages and develop strategies to strengthen the direct care workforce that supports people who use HCBS.

To inform this issue brief we conducted one-hour interviews with representatives from four organizations, using a consistent set of questions to guide each conversation. The organizations interviewed included consumer and workforce advocacy groups, provider associations, and labor organizations that represent the direct care workforce. These interviews focused on understanding the current landscape of the direct care workforce, drawing lessons from other advisory groups, and identifying best practices to strengthen the influence of these stakeholder groups – particularly in shaping rate-setting decisions with buy-in from all of the key rate-setting partners. We also hosted a convening with participants from state agencies and advocacy organizations invested in strengthening the direct care workforce to promote improved access to long-term services and supports (LTSS).

Additionally, incorporated perspectives from select organizational comments submitted during the Access Rule public comment period that both reflected and prioritized community integration, and drew on state laws, regulations, policies, and practices relevant to community input on rate setting for various types of HCBS. These qualitative activities, alongside our resource review, directly informed our recommendations for effective implementation of the IPAG.

II. Introduction

The Access Rule ("the Rule") is one of the most important regulations advancing Medicaid-funded Home and Community-Based Services (HCBS) of the last decade. HCBS services are an optional benefit, but all states have chosen to provide it. When states choose to cover HCBS (at their option), they must guarantee comparable access to the general population, pursuant to the "Equal Access Provision" in 42 U.S.C. § 1396a(a)(30)(A), which requires that states:

> "provide such methods and procedures relating to the utilization of such care and services and to assure that payments are consistent with efficiency, economy, and quality of care and are sufficient to enlist enough providers so that care and services are available under the plan at least to the extent that such care and services are available to the general population in the geographic area…".

The Rule aims to clarify how states should implement this statutory mandate. The Rule also builds on the foundation of the Affordable Care Act (ACA), which directs the Secretary of Health and Human Services (HHS) to issue regulations ensuring that all states develop delivery systems that support HCBS.[2] This includes ensuring an adequate number of qualified direct care workers to meet the needs of Medicaid enrollees living in the community.

Disability, aging, and workforce advocates, policymakers, and disabled and older adult communities played a central role in shaping the Rule. Their efforts helped secure a rulemaking process that centered the views of people with disabilities and older adults receiving HCBS, along with aging and disability networks. The final Access Rule is comprehensive, establishing new requirements related to the direct care workforce, access to HCBS, health and safety protections, quality measures, and other key areas. Its overarching goal is to strengthen individuals' ability to live independently in their communities, in ways that are meaningful to them and reflect their needs and preferences.

The key purpose of the Rule is to make it easier for individuals to access HCBS, and to do so, the rule addresses a major barrier to care: longstanding nationwide direct care worker shortages. Direct care workers provide essential support to people with disabilities and older adults by assisting with activities of daily living (such as bathing, dressing, eating, and mobility, or instrumental activities of living (such as meal preparation, medication management, transportation, and shopping). Individuals who provide behavioral supports, employment supports, or other services to promote community integration for Medicaid beneficiaries are also direct care workers.[3] Their services make it possible for individuals to live in their homes and communities, rather than in institutional settings, and are foundational to the delivery of Medicaid-funded HCBS as recognized in the Rule. Historically, wages for these essential workers have been extremely low which has led to frequent turnover and chronic labor shortages.[4] To strengthen the direct care workforce, the Rule requires states to establish an Interested Parties Advisory Group (IPAG) to advise on payment rates for direct care workers delivering self-directed and agency-directed personal care, home health aide, homemaker services, and habilitation services under state plan authorities, section 1915(c) waivers, and where applicable, 1115 demonstrations.[5]

The IPAG requirements do not solely aim to improve direct care worker wages so that workforce shortages no longer limit access to HCBS. They also seek to increase transparency and accountability and promote active community engagement in state Medicaid programs.[6] As the Rule emphasizes, "true engagement" requires the state to:

> "understand and honor strengths and assets that exist within communities; recognize and solicit the inclusion of diverse voices; dedicate resources to ensuring that engagement is done in culturally meaningful ways; ensure timelines, planning processes, and resources that support equitable participation; and follow up with communities to let them know how their input was utilized."[7]

This brief translates the requirements of the IPAG rule and stakeholder recommendations into actionable steps that states, advocates, and stakeholders can use to implement IPAGs effectively and advance access in Medicaid HCBS.

III. IPAG Purpose

As highlighted above, one of the biggest barriers to HCBS access is the chronic shortage of direct care workers, which has reached a crisis level.[8] Contributing factors include an increased demand for services—partly due to an aging population—and a variety of recruitment and retention issues, including inadequate pay and benefits for these workers.[9] Because a stable and reliable workforce is integral to access, the IPAG provision of the Rule helps to address the direct care workforce shortage.

The IPAG provision seeks to strengthen the direct care workforce by requiring states to establish a group to advise and consult on provider payment rates and direct compensation for workers.[10] By centering worker voices and community input, IPAGs present a monumental opportunity to address some of the most urgent challenges to hiring and retaining a stable workforce. Stakeholder interviews echoed the potential of IPAGs in three main categories:

1) Raising wages and expanding access

2) Shaping broader HCBS policy and workforce improvements

3) Advancing workforce training and credentialing.

Raising Wages and Expanding Access: A core focus of the IPAG is making sure wages are high enough that HCBS users can find a direct care worker when they need one; in other words, the IPAG is an important resource to the state in setting sufficient wages to allow equal access to HCBS. Stakeholders confirmed that their past advocacy to set adequate wages has sought to center direct care worker input in rate setting processes to encourage policies that reflect their experiences. Importantly, the Rule also centers people with disabilities who rely on the direct care workforce to receive HCBS. Interviews emphasized that CMS created a landmark opportunity by requiring an Advisory Group that puts both beneficiaries and "the direct care workforce at the forefront, making access and workforce interlinked issues." Given the complexity and importance of Medicaid rate-setting, particularly for services that direct care workers deliver, advocates agreed that input from both direct care workers and people with lived experience is crucial to a comprehensive assessment of rate adequacy.

Shaping Broader HCBS and Workforce Improvements: Stakeholders agreed that one of the most powerful ways states can benefit from IPAGs is by using the expertise of the group to address broader policies affecting HCBS access, including helping states better prepare for public health emergencies. A number of national stakeholders emphasized that the IPAG forms the infrastructure for states to examine issues that go beyond the direct care workforce and affect the entire HCBS workforce and access to services. They noted as one example that payment rates for direct care workers in institutional settings are often higher than those for HCBS workers, which can leave community-based care under resourced and less available, which shifts more individuals into institutional settings for care. As one stakeholder put it, "We view this as a means of…setting industry wide workforce standards that raise standards for everybody."

Advancing Workforce Training and Credentialing: Enhancing training and education opportunities for direct care workers is widely seen as a key strategy to increase worker recruitment and retention.[11] A number of stakeholders recommended that IPAGs could inform and develop training on self-management, person-centered communication, abuse prevention, and other essential competencies. They also saw a role for IPAGs to give feedback in credentialing systems, like setting statewide competencies and ethical guidelines; and potentially incorporating partnerships with universities to integrate workforce development with state education and training systems.

The following sections break down the membership and administrative components of the Rule's IPAG requirements and highlight key insights from stakeholders to aid state implementation of these advisory groups.

IV. IPAG Membership

A. Inclusive Stakeholder Engagement of IPAGs

> *"I think that what's most exciting about [the IPAG] is...bringing workers and advocates, and folks that care about the programs and care about workers into the process with the State."*

Stakeholders elevated the importance of IPAG member lived experience, and that individuals in the group reflect diverse perspectives, including those from medically underserved and marginalized populations. As a key stakeholder noted, the final Rule "underscores the importance of voices with lived experience."

The Rule requires the IPAG to include "at a minimum, direct care workers, beneficiaries, beneficiaries' authorized representatives, and other interested parties impacted by the services rates in question, as determined by the State."[12] In the preamble, CMS clarified that the positions and services described are a floor and that states could choose to have broader member representation.[13]

While stakeholders affirmed that states should retain flexibility over the number of IPAG seats to meet state-specific needs, they also agreed that the IPAG should be direct care worker-led and, at the minimum, include persons with lived experience, direct care workers, state Medicaid staff, small providers or provider associations, union representatives, family caregivers, and in states where applicable, representation from Managed Care Organizations (MCOs) and/or Program of All-Inclusive Care for the Elderly (PACE) organizations. Below, we discuss the importance of representatives from each of these groups in more detail:

Direct Care Workers: As defined by the final rule, direct care workers include personal care attendants, direct support professionals (DSPs), home health aides, registered nurses, licensed practical nurses, nurse practitioners, clinical nurse specialists who provide HCBS, licensed or certified nursing assistants, and "other individuals who are paid to provide services" that qualify as homemaker services, home health aide services, personal care services, or habilitation services.[14] These workers must be included on the IPAG. However, other qualifications are left to states.

Stakeholders urged that direct care workers who sit on IPAG should represent different levels of experience, lengths of time in the field, and geographical regions. As one stakeholder put it, “having the people who are actually doing the hands-on delivery at the table…is the crux.” Stakeholders emphasized that at least one seat should be reserved for a family caregiver to bolster representation of that perspective in the group. Stakeholders also recommended that all workers in the group should currently provide direct care as their primary role so that workers with recent lived experiences remain centered (as opposed to former workers or workers whose primary source of income is not from direct care).

Beneficiaries: According to a key stakeholder, the most important balance to strike is that between “workers and consumers [e.g. beneficiaries]” and the IPAG should seek to balance membership in favor of those two roles. To achieve this, several stakeholders suggested that states should consider reserving a minimum number of seats on the IPAG for beneficiaries. While CMS did not accept this recommendation in the final Rule, many commenters suggested that beneficiaries comprise at least 25 percent of the IPAG’s membership. Stakeholders further called for beneficiaries to reflect recipients of self-directed and agency-based HCBS. CMS urged states to prioritize individuals who are dually eligible for Medicaid and Medicare since they comprise a significant percentage of HCBS recipients.[15]

Beneficiary Groups, Advocacy Organizations, and Worker Representatives: To supplement beneficiaries’ input, stakeholders suggested participation of beneficiary groups, advocacy organizations, and worker representatives who may have more experience in developing and implementing policy. Stakeholders emphasized that these groups should reflect the particular needs and dynamics of each state. For example, some beneficiary groups and advocacy organizations may have a larger influence in certain states, and their inclusion could be important to move recommendations. Stakeholders also emphasized the need for at least one dedicated seat on the IPAG for direct care worker representative organizations, including unions and other worker advocacy groups.

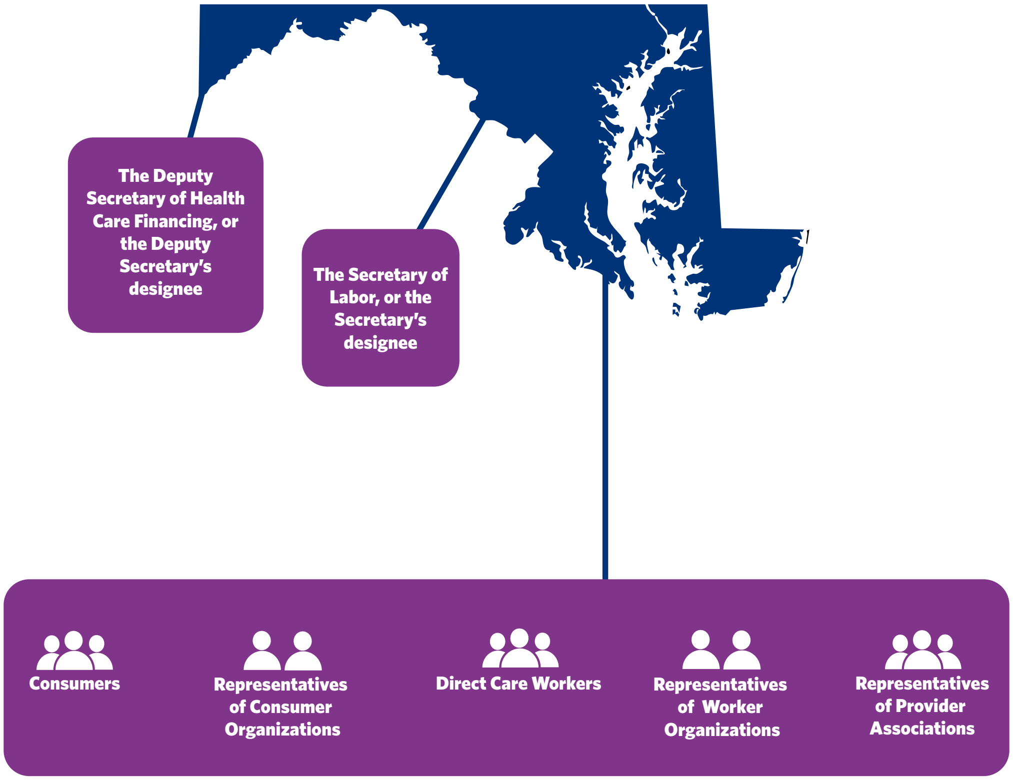
Providers: While the rules do not require IPAGs to include providers, stakeholders suggested that small providers or provider association representatives could help the group make sense of certain data during the data exploration phase, including provider surveys. A number of stakeholders called for providers on the IPAG to have at least two years of experience with direct care workers and/or beneficiaries and reflect both agency and independent provider models. Stakeholders emphasized the importance of maintaining a mission from both Medicaid beneficiaries and workers to maintain buy-in from the members that the IPAG was designed to elevate.

Managed Care Organizations: 37 states use Managed Care to provide at least some HCBS, and in these states, the process will be different to set sufficient wages for direct care providers.[16] Managed Care Organizations typically receive a “capitated” per-person rate from the state to provide care, and set their own fees and payments for individual services and contracted providers. Still, states can direct plan expenditures for certain providers through State Directed Payments, though only a few states have taken up this option for HCBS direct care services.[17] State Directed Payments allow states to “set parameters on how expenditures under managed care contracts are made by managed care plans to assist states in achieving their overall objectives for delivery system and payment reform and performance improvement.”[18] The recently passed HR-1 limits SDPs to roughly Medicare rates, but this is still an option – even a necessity – to make sure that state supported payment requirements actually reach direct care workers in states that use Managed Care to provide HCBS MLTSS.[19] Wisconsin has used SDPs in this way – to set a “uniform percentage increase established by the state for eligible [HCBS]…incorporated into the capitation rates.”[20]

Because of the unique role MCOs might play in providing HCBS, attendees from a Long-Term Quality Alliance (LTQA) led IPAG Workgroup recommended a particular approach for these states. In states with managed care programs,[21] collaboration between direct care workers and MCOs is necessary for a more integrated approach to workforce challenges. This is because the MCO may have access to unique data, and so that members do not have to communicate recommendations to each MCO. For example, in Indiana, the state's three major MCOs agreed to collaborate on workforce development. Each participated in the state's Direct Service Workers Advisory Board, which eventually raised rates for direct care workers in the state. Early involvement of the MCOs facilitated quicker buy-in on the group's recommendations.

Data Experts: All stakeholders urged the state make available a data expert to break down complex information for IPAG members, whether or not that expert is an official member of the group. An IPAG could include a data expert as a non-voting member of the group who does not participate in policy recommendations yet still serves as an important resource to group members. Alternatively, the Group could host a number of public meetings and invite data experts to teach members how to examine the data that the Group is expected to analyze. Public meetings are discussed in the IPAG Resources section below.

Maryland IPAG Legislation, Membership[22] Example:
(A) The Advisory Group Consists of:
    (1) The Deputy Secretary of Health Care Financing, or the Deputy Secretary's designee;
    (2) The Secretary of Labor, or the Secretary's designee;
    (3) The following members appointed by the Deputy Secretary of Health Care Financing, or the Deputy Secretary's designee:
        (I) Three consumers;
        (II) Two representatives of consumer organizations;
        (III) Three direct care workers;
        (IV) Two representatives of worker organizations; and
        (V) Three representatives of provider associations, of whom:
            1. Two shall be representatives of a residential service agency; and
            2. One shall be a representative of an employer trade association.



While not a specific requirement of the final Rule, members should not have conflicts of interest with the group's mission. In other words, nobody should "stand to receive financial benefit from the decisions of the group."[23] Finally, states should create principles for the IPAG to encourage broad representation. These principles could be modeled after Colorado's Home Care Worker Stabilization Board, which was adopted by Maryland in its IPAG legislation.[24] Stakeholders also offered input on recruitment and the application process to achieve these diversity goals.

B. Recruitment and Application Process

The Rule gives states limited guidance on the recruitment of IPAG members, stating only that "the process by which the state selects interested party advisory group members and convenes its meetings must be made publicly available."[25]

Stakeholders agreed that members of the IPAG should be recruited and selected through an application process. The application process should be accessible and designed with input from direct care workers and people with disabilities. At a minimum, stakeholders recommended that states have a plan for a broad recruitment strategy, establish clear eligibility criteria and an accessible application process, and convene a representative selection committee.

Advertising IPAG Recruitment: First, stakeholders suggested the state should advertise the IPAG with a recruitment announcement across a broad array of groups, including provider networks and disability rights organizations. Stakeholders highlighted the need for recruitment announcements to describe the purpose of the IPAG and the recruitment procedure in plain language with different multilingual versions.

Establish Clear Eligibility Criteria and Expectations: Second, several stakeholders said the state should establish clear eligibility criteria and expectations for participation in both the IPAG application process and the IPAG committee. Eligibility criteria should include qualifications for each member and clear timelines for decision-making. The availability of accommodations during the application process and expectations of time commitments are also important to communicate to applicants. The state might also consider establishing other opportunities for direct care workers and beneficiaries to stay engaged if not selected (e.g., provide notice of when meetings might be open to the public).

Multiple Avenues to Apply: Third, stakeholders suggested the state should provide multiple ways for interested individuals to apply, including a written application, electronic application, and a phone application. They recommended that the application should be short and in plain language (again with multiple language options). The application should also ask only for necessary personal information and focus on lived experience. After membership selection, applicants should be asked about any supports the applicant might need to participate.[26]

Diverse Selection Committee: Fourth, stakeholders emphasized the state's review team and/or selection committee should be diverse – including, where possible, a disability advocacy organization. In New Hampshire, an advocacy organization oversees the entire recruitment and application process. In Maine, it is the Long-Term Care Ombudsman. Either way, stakeholders advocated for scoring rubrics with clear evaluation criteria for candidates and that the selection process needs to balance lived experience and professional leadership.

Term Limits and Removal for Cause: Finally, while the Rule leaves the tenure of members up to states, many commenters on the proposed rule recommended term limits, where it makes sense (likely in larger states where access to beneficiaries and workers is more readily available), as well as using staggered terms so the IPAG does not have a high turnover rate all at once; and removal for cause procedures.[27]

V. IPAG Administration

The Rule requires that the IPAG convene at least every two years to make recommendations to the Medicaid agency about rates. To be successful, all stakeholders suggested that the IPAG should meet more frequently – most commonly, stakeholders recommended the IPAG should meet quarterly, with early meetings dedicated to trust-building, skill-building, and goal setting. Meetings should include training to help members understand data and develop leadership skills, especially for direct care workers and consumers.

To support full participation, stakeholders strongly suggested that the states pay for stipends, childcare, transportation, and meals during meeting times; provide accessible materials to group members; and use expert facilitators to guide inclusive and productive discussions about rate setting and access to care. Stakeholders must have access to "current and proposed payment rates, HCBS provider payment adequacy reporting information as described in 42 C.F.R. § 441.311(e), and applicable access to care metrics as described in 42 C.F.R. § 441.311(d)(2) for HCBS."[28]

A. Regular and Structured Engagement Mechanisms

The IPAG must meet regularly in order to solicit input, track progress, and align efforts with constantly evolving workforce needs. All stakeholders agreed that meeting every other year as the Rule requires is not sufficient, with a national stakeholder emphasizing, "drastic changes happen year to year in HCBS." One interviewee recommended that the IPAG meet at least quarterly and that they be able to convene on an ad-hoc, as-needed basis. Another suggested that if the larger group meets as infrequently as every two years, there should be sub-groups that meet more frequently, ideally quarterly.

Several stakeholders suggested that the first meeting should be used to define the group's purpose and expectations. Potential examples of these group activities include storytelling circles - so group members can share what brought them to participate in the group; co-creating community agreements or group norms; a vision exercise where group members define what success looks like; or a conversation among participants to reflect on how their identities or roles have shaped their perspectives.[29] Stakeholders also suggested an onboarding or orientation process for new members to reflect on how their work and experiences will contribute to the shared goal. An agenda for each meeting should be shared well in advance and any public meeting must comply with the state's public meeting requirements.

One interviewee suggested that after the introductory meeting, each meeting should include skill-building activities with expert facilitation to help group members review and process data. One example of this type of skill building is called a Data Walk.[30] Ongoing skill building opportunities like teamwork and public speaking should be available for direct care workers specifically. For example, direct care workers in one state asked for skill building workshops to more effectively participate in an advisory group and to help the group develop skills to drive policy change. IPAG meetings should include ongoing education for direct service workers by bringing in expert speakers on career development and advocacy.

Meeting in person vs. virtually: Stakeholders suggested that IPAGs alternate between virtual and in-person meetings to maximize accessibility. Virtual meetings are often critical to reduce travel burdens and out-of-pocket costs for participants, but stakeholders also recognized value in convening the group in-person. Conducting hybrid meetings could help address both needs.

Scheduling: Stakeholders emphasized that meeting schedules should accommodate direct care worker members' schedules, workers who often work irregular hours or juggle multiple jobs. If a group member is unable to attend an in-person meeting, a virtual or call-in option should be made available. Group members should be surveyed for availability after they are selected to join the group and a meeting time should be scheduled that preferences workers' schedules to the greatest extent possible, so they do not have to miss work.

B. Representation, Compensation, and Accessibility

To achieve representation and active participation in the IPAG, stakeholders recommended that the state provide access supports to IPAG members, such as stipends, transportation, childcare, technology access, and emphasized that all meetings must meet disability accessibility requirements including communications access and reasonable accommodations.

Stipends: Stipends reduce financial barriers to participation and compensate group members for their time, expertise, and lived experience. This is especially critical for direct care workers and family caregivers. Without stipends, low-income participants may be unable to participate due to lost wages. In Maine, advisory group members are paid $50 per hour and are also reimbursed for transportation and meals. According to a key stakeholder, stipends are "an important investment for sustained participation." The option of providing financial support is also included in the Medicaid Advisory Committee (MAC) and Beneficiary Advisory Council (BAC) regulations to facilitate Medicaid beneficiary engagement.[31] Stakeholders emphasized that states need to be mindful that stipends could affect members' Medicaid or other public benefits eligibility and should offer alternative supports where needed.

Transportation and Meals (or reimbursement): All stakeholders suggested that the state should reimburse transportation and meals to ease these participation burdens, especially for rural and low-income participants, and those participants who may not have access to a vehicle or public transportation. By covering transportation costs or providing travel support, geography and income will be less likely to determine who gets a seat at the table. Likewise, providing meals during in-person meetings shows respect for participants' time and well-being, and helps create a community-centered environment. Many individuals may be attending straight from work or other caregiving responsibilities, or have traveled long distances. The cost or time involved in securing food should not prevent full engagement or lead to distraction during meetings.

Child Care and/or Caregiver Support: Offering child care and/or caregiving support – either directly or through reimbursement – enables parents and caregivers to participate in meetings without having to choose between contributing and caregiving. This is especially critical for IPAG members with young children or caregiving responsibilities, who are often underrepresented in decision-making spaces and who have additional financial barriers to participation. This is another way to compensate for the real-world cost of participation.

Technology Accessibility: For both in-person and remote meetings, support for technology access is crucial. Organizers should help make sure that IPAG members have computer and internet access, to the extent possible, in addition to any necessary training on how to use certain tools. One stakeholder suggested making tablets or internet hotspots available for participants to use during their tenure.

Disability Access: States must facilitate group participation by ensuring that meetings are accessible to people with disabilities, reasonable accommodations are provided when necessary for accessibility and enable meaningful participation, communication with individuals with disabilities are as effective as with others, and that reasonable steps are taken to provide meaningful access to individuals with Limited English Proficiency.[32] Materials should be shared well in advance of meetings so IPAG members can review materials ahead of time and prepare to participate in meetings.

Orientation and Mentorship: Orientation sessions and peer mentorship programs can also support new members, especially those new to policy work or who may feel intimidated by technical language or formal meeting structures. Stakeholders noted that providing ongoing support to participants helps with retention, particularly among community members and frontline direct care workers.

Of note, the Rule states that federal reimbursement is available generally at the 50 percent matching rate for states for administration of the IPAG group, which should include these activities, unless the state believes its expenditures may qualify for a higher rate.[33] Lastly, the MAC and BAC regulations may be useful to review during the IPAG implementation process, starting at 42 C.F.R. § 431.12.

VI. IPAG Resources and Supports for Developing Recommendations

A. Tools to Assist IPAGs

As previously noted, the Rule requires states to provide the Advisory Group with payment rates, payment adequacy data, and access to care metrics so the IPAG can make recommendations. The state must also consider and respond to recommendations on proposed rate changes.[34] Stakeholder interviews illustrated, however, that to develop meaningful recommendations, Group members need access to additional resources to help inform their understanding of the complex rate-setting process and the data that they are charged with reviewing. The following resources and supports will help the IPAG develop comprehensive and robust recommendations.

Technical Assistance: A number of stakeholders noted that while direct care workers and beneficiaries bring valuable lived experience, they may need support to translate that experience into technical discussions and policy analysis. States already use a variety of internal staff and external consultants to develop rate-setting reports,[35] and these experts could provide the IPAG with a set of initial trainings on how rates are set and how to analyze rate data. As mentioned in the IPAG Membership section above, states could designate this resource a non-voting, but permanent member. This type of resource would also aid Group members in developing a meaningful understanding of the state's Medicaid policies, procedures, and subject matter, enabling the Group to serve a "bridging role between the data and the technical mechanisms, and the experience and expertise of the folks that are gathered together". In the same way, state officials and data experts could learn more about how data translates to experience in the actual context of receiving services.

Public Meetings: Public meetings are an opportunity to improve public participation and transparency. They can also provide an avenue to learn from experts in the rate-setting process, including state budget and benefits experts, actuaries, caregivers, and people with disabilities. The Rule's MAC/BAC regulations provide a useful example of how a state might choose to administer IPAG public meetings:

Make two meetings a year open to the public and include a dedicated time for the public to make comments;

Offer a rotating variety of meeting attendance options (in-person, virtual, hybrid);

Select meeting times and locations for maximum member attendance;

Create a policy for accommodations and accessibility of meetings; and facilitate with accessibility in mind;

Adequately notify the public of the date, location, and time of each public MAC meeting and any public BAC meeting at least 30 calendar days in advance of the meeting.[36]

Additional Resources: A number of stakeholders suggested that state Industry Standards Boards or Direct Care Worker Advisory Boards could serve as useful models for Advisory Groups when developing recommendations. These boards often bring together workers, employers, and government representatives to set workplace standards.[37] They make industry-wide recommendations on a broad range of interrelated workplace issues such as wages, training, and safety. For example, Colorado's Direct Care Workforce Stabilization Board conducts investigations, holds public hearings, and reports on its findings.[38] Stakeholders recommended that the Group could also utilize university partners for help with data collection and analysis.

B. Relationship Between IPAGs and Medicaid Advisory Committees

The Rule allows a state's MAC established under 42 C.F.R. § 431.12 to fulfill the IPAG's duties, if the MAC meets all of the requirements of the IPAG regulation.[39] However, the roles of both groups must be "distinct" and the existence of one group should not affect requirements with respect to the other.

While MACs may fulfill IPAG roles if necessary, stakeholders weighed the risks and benefits of combining the groups. Several stakeholders recognized the benefits of MAC regulations, and suggested that, at minimum, states look to mirror MAC best practices within their IPAGs, including by implementing CMS guidance,[40] state bylaws, and other best practices for advisory groups.[41] As one example, Maryland recently passed legislation (described above) mirrors a number of requirements from the state's MAC.[42]

Some stakeholders felt the risks of combining the groups outweighed the benefits, as the MAC is focused on a wide variety of issues and has a larger scope of work. Adding more responsibility to the group risks diluting its focus, potentially drowning out the core purpose of elevating direct care workforce issues.

Still, all stakeholders stressed coordination, and said strong collaboration channels should exist between IPAGs and MACs to align efforts and avoid duplication, especially acknowledging that participants may overlap with those on MAC. The IPAG can provide useful information to MACs and, according to a national key stakeholder, the "sufficiency of reimbursement rates is a fundamental component of access and Medicaid, and MAC oversees rec[commendation]s related to access."

VII. IPAG Data

Data Collection and Research for Policy Development

Data on rates is inconsistent, and only available in some states. Today, as a key stakeholder pointed out, there is simply no strong, unified data source that clearly shows what would stabilize the workforce and improve access. Every state approaches rate-setting differently, relying on different data sources and methodologies, which according to one stakeholder, only reinforces inconsistencies across the system. Complicating matters more, minimum wages can vary locally within states (most initial wages for many direct care workers hover around that amount). As a result of this confusing patchwork of data, for too long, direct care workforce rates have stagnated, sometimes remaining unchanged for years at a time. A well-supported IPAG can help states move toward more consistent, evidence-based approaches to collect data, including by improving the quality and transparency of data used in rate-setting.

In the final Rule, CMS requires states to provide IPAG members with "access to current and proposed payment rates, HCBS provider payment adequacy reporting information..., and applicable access to care metrics..."[43] CMS advises states to give as much context as possible to group members about this data, including "if and how inflation has factored in to a proposed rate," and whether there are any "costs imposed on providers beyond what is required under the payment adequacy metrics."[44] States must also make data available to the IPAG "with sufficient time... to consider them, formulate recommendations, and transmit those recommendations to the [s]tate."[45] Starting in July 2026, states are required to publish all Medicaid fee-for-service fee schedule payment rates on a website that is accessible to the general public.[46]

Resources like the Health and Human Services/Department of Labor HCBS Workforce Data Brief[47] and the National Core Indicators (NCI) Direct Care Workforce Survey[48] are good sources for identifying current wages. The state's Medicare wage data may also be a helpful comparator.

Other commenters on the Rule recommended these additional data sources or information (as summarized by CMS):

- "explain if and how inflation has factored into a proposed rate" as most wage rates are not typically indexed in any way.
- "costs imposed on providers beyond what is required under the payment adequacy metrics."
- "explanations and supporting information on how any proposed rates were calculated."
- "metrics required under the payment adequacy and reporting requirements provisions of the final rule."
- "clear, consistent definitions of the cost elements that are considered in establishing a rate."
- "public-facing reports that states are required to produce and publish."
- "data on turnover and vacancy rates."
- "median wages and historic trends in compensation."[49]

Apart from these sources, stakeholders recognized that IPAGs will need to pinpoint additional data sources the group will need to evaluate wage sufficiency and job quality across the workforce. LTQA's recent brief, Measuring and Monitoring the Adequacy of the Direct- Care Workforce and Impacts on Unmet Need: Landscape Scan of Data Sources and Opportunities for Future Research,[50] could be a helpful resource on this topic. Additionally, the IPAG should account for the time gap between when data is collected and when wage proposals go into effect, ensuring that "data lag" does not distort rate-setting.

The IPAG also offers an important opportunity to standardize and share rate-setting data across HCBS and even across states (where states are willing to share information publicly), leading to greater transparency and accountability, and less wage variation across settings. To make the most of this opportunity, IPAGs should prioritize a diverse and thoughtful data strategy that incorporates the following recommendations:

Look Beyond Bureau of Labor Statistics Data: A key problem is that many states over-rely on Bureau of Labor Statistics (BLS) data, which does not accurately capture the HCBS labor market. Because Medicaid Fee-for-service (FFS) often sets the floor for wages, the BLS data reflect already-suppressed rates and report only averages from all categories of direct care workers lumped together. This is problematic, according to stakeholders, for two reasons. First, when states use existing data to set new rates, the results will just reflect the historically low wages for this work. If current rates are insufficient, using them as a guide will not resolve the workforce shortage. States need to break this status quo by collecting and using better data. States could look to existing data that MCOs collect to set MLTSS rates (when not tied to FFS benchmarks) and incorporate living wage standards, to account for factors beyond wages alone.[51]

Second, analyzing direct care worker wages as a single rate oversimplifies important distinctions in training, qualifications, and job roles. For example, DSPs and community health workers may have more specialized education and training than home health aides (although with variation by state and program). States should disaggregate wage data by specific occupational classifications. This will help confirm that compensation data reflects the unique skills and responsibilities of each role, and will help the group achieve the goal one stakeholder described as "evidenc[ing] the sufficiency of rates for achieving livable compensation."

Disaggregate and Move Beyond Wage Data: Stakeholders from the LTQA IPAG Workgroup recommended that data should be disaggregated by provider type (such as agency-based, self-directed care, or paid family caregivers) and care setting. This allows states to identify and address disparities in areas like wages, quality, and staffing levels, and helps to make sure the IPAG can respond to unique challenges faced by different components of the direct care workforce. On top of rate studies and provider surveys, stakeholders agreed that more than wage data is needed to fully understand conditions and develop effective rates that promote recruitment and retention. Data collection should also capture non-wage factors that shape job quality, such as health benefits, paid leave, access to personal protective equipment (PPE), and support during emergencies.

Use Multiple Research Methods: Stakeholders suggested that states should supplement provider surveys with worker-led focus groups, job shadowing, and third-party evaluations to capture both qualitative and quantitative insights. The LTQA IPAG Workgroup emphasized the need to improve data collection across providers to generate a more consistent, meaningful picture of the workforce. LTQA Workgroup participants also recommended that direct care workers should be compensated for helping collect improved workforce data. For example, according to a stakeholder, Maine has paid direct care workers to help collect workforce data, ensuring an additional, worker-led perspective.

Track Access to Care: The final rule requires IPAGs to monitor data to confirm that Medicaid beneficiaries' access to personal care, home health aides, homemaker, and habilitation services is "at least as great as available to the general population in the general geographic area" and to guarantee an "adequate number of qualified direct care workers to provide self-directed personal assistance services."[52]

In addition to the data listed above, the IPAG should review other data that the Rule requires states to collect and publish. These measures include fee-for-service payment rates and bundled payment rates broken down by service.[53] The Rule also requires states to collect and submit information on HCBS waiver waiting lists (including average wait time and length of waitlist), reassessments of person-centered planning, and HCBS Quality Measures – data which the IPAG should review.[54] The IPAG could also review critical incident and/or grievance data to identify whether there are problematic trends related to access.

Most importantly, the IPAG must consider the data available in the state to determine if there are other sources that might reflect on access measures. For example, the rapid pace of private equity acquisitions of HCBS providers may have significant implications for wages and workforce stability. Additionally, this sector is highly dependent on labor from immigrants (one in three direct care workers providing HCBS identifies as an immigrant) and the current administration's federal policy decisions can directly affect the availability of these workers.[55] Tracking all of this data over time will help the IPAG identify whether increases in the rates paid to direct care workers are improving access to services.

Track Response to IPAG Recommendations: Finally, one-time data collection is not enough. A key stakeholder suggested that IPAGs should track data over time to assess the impact of IPAG-driven reforms. This tracking data could include turnover, unfilled vacancies, care quality, unfilled services hours, and surveying self-directed beneficiaries to see if they have had difficulty finding direct care workers to fulfill hours. Stakeholders also suggest that states should consider how to institutionalize these data practices through legislative action, through the IPAG directly, or by engaging with partners to build a sustainable infrastructure for data collection.

Building a strong data infrastructure is critical to setting fair rates and to finally making real progress on direct care workforce stabilization. Starting with a clear list of the types of data needed would be a major step forward, and stakeholders advise this list can be informed by the IPAG participants in the early, level-setting meetings.

VIII. Maximizing IPAG Findings

To expand the IPAG's impact, its recommendations should be read broadly and responded to by the state. Although states must make IPAG recommendations public within one month,[56] the regulation allows for wider sharing, including through public reports, legislative briefings, and stakeholder forums. This will help the Group's findings inform broader policy discussions and decisions.

Sharing Recommendations: Although the Rule requires the State Medicaid Agency to make recommendations publicly available and to consider them in specific circumstances, stakeholders emphasized the importance of increasing exposure to and expanding the use of the Group's findings. They highlighted that recommendations could be shared with other state entities critical to the development of direct care workforce incentives like Appropriations Committees, Health and Human Services Committees, and Legislatures. Maryland's IPAG legislation, for example, requires that the state share recommendations with the General Assembly and the Governor, in addition to the state Medicaid Agency. Stakeholders encouraged states to learn from their peers and share recommendations and reports with other states. In addition to the requirement to make recommendations publicly available, stakeholders suggested states could include public hearing processes with IPAG reports to increase accountability.

Responding to Recommendations: State Medicaid Agencies are not required to respond to the IPAG's recommendations in every instance.[57] However, the MAC regulations offer a useful model, as they require state Medicaid agencies to respond to the MACs recommendations and post MAC reports to the state's website.[58] This accountability tool makes the connection between MACs and IPAGs all the more meaningful. Ensuring that the IPAG is meaningfully linked to the MAC, so that IPAG recommendations are considered or integrated into MAC reports, would be one avenue to expand the important work of the IPAG as "part of a larger package of ensuring access." Additionally, stakeholders recommended requiring the state agency to formally respond to each IPAG report and explain any recommendations that were only partly implemented or rejected, to further improve accountability.

State Bills: There are a number of state bills that have codified the Rule's IPAG requirements or related provisions into state law.[59] Incorporating IPAG requirements into state legislation is useful for many reasons, including that it allows states to expand on the federal requirements and helps protect direct care workers and beneficiaries from federal regulatory rollbacks. In addition to specific IPAG legislation, states could also build direct care workforce improvements into related state legislation. A stakeholder explained that in Michigan, state advocates built direct care workforce infrastructure, including training opportunities and worker and consumer matching registries, into a bill reinstating collective bargaining rights for self-directed care workers in the state's Home Help program.[60]

National Representation and Visibility: To elevate the value of IPAG recommendations and the role of direct care workers' insights in shaping HCBS and workforce policies, states should encourage and support IPAG members to share their findings at national conferences and policy forums. These opportunities can amplify the impact of the IPAGs vital work and inform the national conversation.

IX. Conclusion

States are standing up IPAGs at the same time they face unprecedented budget pressures, including the largest Medicaid cut in history and new constraints under H.R.-1.[61] Some protections for direct care workers and paid family caregivers are being rolled back, while states are already reducing provider payments in response – threatening to make HCBS even more scarce. Yet, demand for these service will only continue to grow. In this environment, the role of IPAGs is more important than ever: they provide a critical forum for safeguarding access, elevating beneficiary and workforce voices, and ensuring that policy decisions strengthen rather than weaken the HCBS system.

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Endnotes

1 HCBS provide health and daily living supports that allow people to receive treatment at home or in their community, rather than in an institutional setting like a nursing home. They cover medical care (nursing, therapies, durable medical equipment, case management) as well as human services supports (personal care, transportation, homemaking, and more). HCBS are delivered by direct care workers, licensed health professionals, community-based providers, and, in many states, even certain family members who qualify as paid caregivers.

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