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Centers for Medicare and Medicaid Services
U.S. Department of Health and Human Services
Attention: CMS–2404–NC
P.O. Box 8013
Baltimore, MD 21244–8013

Delivered Electronically

Ref: 42 CFR Part 440: [CMS–2404–NC] RIN 0938–ZB33. RFI: Federal Government Interventions to Ensure the Provision of Timely and Quality Home and Community Based Services.

The HCBS Advocacy Coalition appreciates the opportunity to respond to the Centers for Medicare and Medicaid Services (CMS) Request for Information (RFI) on federal government interventions to ensure the timely provision of quality home and community based services (HCBS). We appreciate the significant strides CMS has made to promote community integration for persons with disabilities and seniors. Expansion of HCBS options – including the Money Follows the Person (MFP) Program, 1915(i) HCBS State Plan Option, 1915(k) Community First Choice (CFC) Option, Balancing Incentive Program, and options for self-direction – have greatly increased the numbers of people able to live in their own homes and communities instead of institutions. Equally important, the 2014 HCBS Settings Rule help ensure that individuals living and receiving HCBS can truly experience the benefits of community life as intended by these programs. Moreover, the Americans with Disabilities Act’s promise of community access and integration for all is closer than ever, and it is important that CMS continue to help states move forward without delay.

The HCBS Advocacy Coalition is a partnership of organizations that supports the full inclusion of people with disabilities and aging populations in all aspects of community life. We believe that strong implementation of the new HCBS Settings Rule is critical to achieving systems change that results in truly integrated settings and services that promote truly inclusive lives in the community. We work collaboratively to ensure that implementation fulfills the Rule’s intent and spirit by assisting stakeholders in every state in understanding and engaging in implementation of the Rule. For more information about our coalition, see www.hcbsadvocacy.org.

We applaud CMS’s recognition that there is much more the agency can and must do to ensure the provision of timely and quality HCBS. As noted in the RFI, the voluntary nature of Medicaid HCBS options has resulted in significant differences in the availability of HCBS by population and by state, with far too many people being isolated in institutions and other segregated settings due to the lack of HCBS. At the same time, it is complex for states to navigate the various HCBS options and determine how to best combine multiple authorities to accomplish the goal of increasing services. Participants themselves need a sufficient well coordinated array of service options and the confidence that they will be able to find available well-qualified providers of these services.

We are pleased to offer the following comments and recommendations in response to the RFI:

A. What are the additional reforms that CMS can take to accelerate the progress of access to HCBS and achieve an appropriate balance of HCBS and institutional services in the Medicaid long-term services and supports (LTSS) system to meet the needs and preferences of beneficiaries?

Address Medicaid's Institutional Bias: One of the biggest barriers to ensuring that all people who can and want to live in the community have access to HCBS is the fact that states must provide institutional services to eligible individuals but HCBS is optional. Over 500,000 people are on waitlists for HCBS waivers – individuals who choose to wait for HCBS despite the fact that they could access institutional services now. In short, Medicaid's institutional bias misaligns with the fact that the vast majority of Medicaid participants prefer HCBS over institutional services, which also are more expensive. We recommend that CMS:

- Develop a pilot program and/or work with states to develop programs that would offer HCBS to any individual prior to admission to an institutional setting, like the “Pilot Comprehensive Long-Term Care State Plan Option” proposed in the President’s Budget or the expanded definition of “nursing facility” proposed in the RFI;
- Ensure states are implementing the requirements of Preadmission Screening Resident and Review (PASRR), requiring certain individuals to be assessed for and offered community services prior to admission to a nursing facility. Consider expanding the requirements of PASRR to additional populations (e.g., individuals with physical disabilities or with traumatic brain injuries) through a pilot program, 1115 demonstration, and/or working with Congress; and
- Work with Congress to reverse Medicaid’s institutional bias

Continue and Expand Medicaid Authorities that Incentivize HCBS: Over the last decade, states have been given the option of participating in Medicaid authorities that help them expand their HCBS programs, including the Money Follows the Person (MFP) Program, the 1915(i) HCBS State Plan Option, 1915(k) Community First Choice (CFC) Option, and the Balancing Incentive Program. We recommend that CMS:

- Work with Congress to re-authorize and fund the successful MFP program. MFP provides assistance, support and funding to help individuals with intellectual and developmental disabilities, individuals with physical disabilities, and older adults who want to transition to their own homes or a community residence instead of living in an institution. Since 2005, the program has assisted more than 51,000 people to move out of institutions and has proven to be a critical strategy for states to expand their HCBS programs. Unfortunately, individuals with psychiatric disabilities in institutional settings have generally not been eligible for this program. We recommend that any re-authorization expand to include this population;
- Provide technical assistance to states about the 1915(i) authorities to expand state uptake. We appreciate CMS’ recently-released guidance about expanding 1915(k) CFC and believe similar technical assistance related to expansion of 1915(i) would

- continue this important effort. In addition, we support the proposals in the Presidents' Budget to expand eligibility for 1915(i) and CFC;
- Expand access to HCBS for children with serious mental health needs. We support the proposal in the President's Budget to expand eligibility for 1915(c) waiver services to children eligible for Psychiatric Residential Treatment Facilities. Alternatively, we encourage CMS to work with Congress to renew its PRTF demonstration grant;
 - Work with Congress to re-authorize the successful Balancing Incentive Program, which incentivized states heavily invested in institutional services to rebalance towards investment in HCBS; and
 - Work with Congress to ensure that these successful programs continue to be options for states if Congress makes any significant changes to the Medicaid program.

Address the Lack of Affordable, Integrated Housing: The lack of affordable housing is one of the primary causes for people with disabilities remaining “stuck” in institutional settings. Medicaid has an institutional bias related to housing – Medicaid covers room and board in an institutional setting but cannot be used to pay for rent in the community. We recommend that CMS:

- Develop pilot programs, create a demonstration (potentially through the Innovation Accelerator Program) and/or allow states using 1115 demonstrations to use cost-savings to provide rental subsidies to HCBS participants who could not otherwise afford to live in the community;
- Work together with the US Department of Housing and Urban Development (HUD) to expand access to affordable housing that is integrated in the community to people with disabilities, particularly individuals who are in or at risk of entering institutional settings;
- Ensure that the programs that CMS and HUD oversee and the regulations they issue support the principle that all individuals with disabilities can live in their own home with supports. To this end, individuals with disabilities should have access to housing other than group homes or congregate arrangements that are primarily for people with disabilities.

Address the Lack of Opportunities for Employment of People with Disabilities: The vast majority of people with disabilities want to work yet are unable to access services and supports they need to reach this goal. Research has shown that people with disabilities who are employed use less Medicaid services (including crisis and emergency room services) and are healthier. Medicaid funds “day services” for hundreds of thousands of people with disabilities. Yet despite recent rules governing HCBS programs requiring that they provide opportunities for competitive integrated employment, almost all of HCBS funding for day services currently goes towards services *other than* employment. For example, in Medicaid systems supporting people with intellectual and developmental disabilities, only 13% of funding nationally goes towards employment and the rest towards day services like day habilitation programs. See *State Data: The National Report on Employment Services and Outcomes* (2014), available at http://www.statedata.info/sites/statedata.info/files/files/statedatabook_2015_F.pdf. Lack of employment opportunities for people with significant disabilities is such a significant problem that Congress created a federal advisory committee – the Advisory Committee on Increasing

Competitive Integrated Employment for Individuals with Disabilities – to make recommendations to Congress and the Labor Secretary about strategies to reduce barriers and increase job opportunities. CMS was a member of the Committee. In September 2016, the Committee submitted a final report to Congress and the Labor Secretary, with numerous specific recommendations aimed at CMS. We recommend that CMS:

- Review the recommendations in the Advisory Committee report and begin working on implementation;
- Provide guidance and technical assistance to states on strategies to incentivize competitive integrated employment, including allowable outcome-based payment methodologies and how the various Medicaid authorities (including state plan services) can be used to provide services to help individuals access employment; and
- Develop pilot programs, create a demonstration (potentially through the Innovation Accelerator Program) and/or work with Congress to create a new Medicaid authority to incentivize supported employment services over other day services and/or provide support for people moving from segregated day services to competitive integrated employment. These programs could be modeled after the 1915(k) Community First Choice and/or the Money Follows the Person Program.

Ensure All HCBS Services Offer People the Benefits of Community Living: The HCBS Advocacy Coalition strongly supports CMS’ 2014 HCBS Settings Rule. The Rule provides requirements to ensure that all HCBS services provide participants access to the benefits of community living. The Rule is a culmination of multiple rule-making processes and the input of thousands of stakeholders, reflecting decades of advancements and bi-partisan solutions to provide people with disabilities and seniors access to the community. We recommend that CMS:

- Continue providing technical assistance to states on successful implementation of the Rule and options for funding HCBS;
- Continue to ensure that all HCBS settings meet the Rule’s strong standards as CMS evaluates “presumptively institutional” settings through its “heightened scrutiny” process. Only settings that provide meaningful community integration and access should be eligible for HCB funding.
- Continue to engage disability and aging stakeholders in implementation of the rule and provide technical assistance to the federally-funded networks of disability and aging organizations to assist with engaging state-level stakeholders;
- Utilize the federally-funded nationwide protection and advocacy (P&A) systems, that already exist in every state and are experienced at monitoring for abuse and neglect of individuals with disabilities in institutional and community settings, to supplement CMS mechanisms for ensuring safe, quality HCBS settings in compliance with the Rule;
- Ensure transparency in implementation in the rule, including continue to require meaningful public comment and publicly posting CMS decisions on plans;
- Continue implementing the Rule in a manner that accomplishes its goal, which is to ensure that HCBS provide people with meaningful access to all aspects of community life;
- Continue to hold to high standards regarding full compliance with the rule for all residents as states submit settings for heightened scrutiny; and

- Provide additional technical assistance and guidance about the Rule’s provisions around person-centered planning and informed choice.

Ensure Portability of Services: We encourage CMS to explore strategies for incorporating “Medicaid Benefits Portability” into the Medicaid program in order to allow individuals accessing HCBS in one state to continue to access HCBS in another state in the event the individual relocates (that is, becomes a resident of the new state). This would support continuity of HCBS service delivery to these individuals, who may otherwise face long waiting lists for regaining access to services or even be re-institutionalized, and afford them the same freedom of economic, educational and employment mobility as those who do not require HCBS support. Any strategies should ensure that portability does not negatively impact access to services for individuals who may already be on waitlists for services in the new state.

Answers To Select Specific Sub-questions:

1. *CMS is interested in receiving comments on the following potential interpretation of current law. The term “nursing facility” is defined in section 1919(a) of the Act. Under this definition, a nursing facility must be primarily engaged in providing skilled care and rehabilitation to residents with medical necessity for those services. In contrast, nursing facilities provide health-related care and services, that is, those services that are not skilled nursing or rehabilitation services, "to individuals who . . . require care and services . . . which can be made available to them only through institutional facilities". In other words, the statutory nursing facility service definition could provide a basis for states to offer the mandatory nursing facility benefit only to individuals eligible for nursing facility coverage whose assessed need cannot be met by HCBS. If the individual’s needs can be met by HCBS, Medicaid reimbursement would not be available for health-related care and services provided in a nursing facility in those circumstances. Because this concept intersects with other requirements such as institutional eligibility rules and the choice of institution as an option for section 1915(c) waiver participants, the idea may best be implemented under the flexibility of a section 1115(a) of the Act demonstration authority.*

We support any CMS actions to reduce or eliminate the institutional bias of Medicaid funding. As we understand the proposal, the interpretation of the term “nursing facility” as stated above would provide an important step in this direction by offering people access to HCBS as a strategy to divert unnecessary institutional placement. We also think it is critical that any broadening of the definition of nursing facility be carefully implemented so it does not have an unintended impact of increasing the number of people entering nursing facilities. If CMS pursues this option, we think it is critical that the new definition include a requirement that states offer sufficient and adequate HCBS to people who meet this nursing facility level of care and provide options counseling to individuals and their families about HCBS before a person enters a nursing facility.

2. *Are there particular flexibilities around Medicaid requirements for LTSS that states would be interested in using 1115 authority to support?*

We recommend that CMS add a new requirement for 1115 waiver demonstrations that involve people with disabilities or older adults, such as managed LTSS demonstrations. Any such new or renewed 1115 waivers must include specific strategies to incentivize or improve HCBS. Such incentives could include, for example, demonstrations that reinvest cost-savings to help participants access integrated, affordable housing (addressing the institutional bias that allows Medicaid to pay for room and board and institutions but not rent in the community), allow for increased funding for supported employment services over other Medicaid-funded day services, or provide incentives for transitioning people out of institutions or segregated day services.

Currently, some 1115 demonstrations impose new conditions that discourage enrollment and access to care. For example, several Medicaid expansion demonstrations provide new potential pathways to HCBS, but include waiting periods, premiums, disenrollment with lockouts for failure to pay, and high cost sharing. States repeatedly have proposed work requirements as a condition of eligibility, which can make Medicaid impractical for low income individuals without transportation, child care, and other supports. The cost-sharing and premiums can make Medicaid coverage too costly. Waiting period and lockouts simply create more churning and gaps in care.

We urge CMS to zealously enforce its stated policies and the words of the Social Security Act's § 1115, and to not approve 1115 waiver applications that include provisions that clearly do not promote the objectives of the Medicaid program. In particular we recommend:

- CMS not approve 1115 waivers that require Health Expense Accounts (HEAs) These HEAs create an unnecessary and costly added layer of bureaucracy. For example states would need to track enrollee incomes to adjust premiums, calculate monthly statements tracking expenses, collect monthly payments, especially people with no credit cards or checking account who might need to pay for a money order that can be more expensive than the premium. And the red tape keeps people from getting care they need. For example, in Indiana a large number of HIP 2.0 members think that preventive care is charged to their deductible, and so these individuals may avoid cost-effective screenings. There are simpler, more efficient, and cheaper ways to get people covered so they can get care when they need it and to encourage them to get recommended preventive services.
- CMS should not approve an 1115 demonstration that seeks to waive a Medicaid provision, if the effect of the waiver has already been thoroughly tested and demonstrated. For example, more than nominal premiums and cost-sharing for low income beneficiaries have been redundantly studied and consistently shown to *depress* enrollment and create additional barriers to care. A heightened copay, therefore, offers no positive experimental value and would undermine the objective of the Medicaid Act to furnish medical assistance for enrollees.
- CMS should require that state 1115 renewals explain the full breadth of what it tested with respect to the population with the previous demonstration project, the results of those tests, how the lessons learned from that project have affected the new proposal, and

what new experiments will be conducted regarding this population with the new project. Those lessons must be based on accurate and relevant data.

- CMS should not approve an 1115 waiver that seeks to reduce or eliminate EPSDT services. No feature of an 1115 application can be approved if it is inconsistent with the objectives of the Medicaid Act. Congress designed Medicaid with clear requirements to cover EPSDT for children and youth under age 21. These statutory provisions have been repeatedly amended and strengthened over the years, as research repeatedly documents that poverty-level children and youth need a range of enabling and developmental interventions. Young people are one of the core populations of the Medicaid program and to diminish EPSDT – the most essential and enduring feature of coverage for children and youth – is clearly inconsistent with the objectives of the Medicaid program.
 - HHS should not approve any waiver permitting a state to condition Medicaid eligibility on compliance with work search activities. Work search requirements are an illegal condition of eligibility in excess of the Medicaid eligibility criteria clearly enumerated in Federal law. Although states have flexibility in designing and administering their Medicaid programs, the Medicaid Act requires that they provide assistance to all individuals who qualify under federal law, and courts have held additional eligibility requirements to be illegal. Section 1115 cannot be used to short circuit the Medicaid protections, because work search requirements can in no way promote the objectives of the Medicaid Act or demonstrate anything. From a practical stand point, work requirements applied to health coverage get it exactly backwards. An individual needs to be healthy to be able to work, and a work requirement can prevent an individual from getting the health care they need to be able to work. We note finally that in almost any system in which eligibility is conditioned or attached to work search, there are likely to be serious violations of nondiscrimination laws, as persons with disabilities may end up with fewer benefits or higher costs due to their condition or the lack of adequate systemic supports to foster their employment.
 - HHS should not approve waiver of Non-Emergency Medical Transportation (NEMT) under an 1115 authority. These waivers can only be approved if they have a valid experimental purpose and promote the objectives of the Medicaid Act. There is no valid experimental purpose to not providing transportation to medical appointments – it is clear that beneficiaries will lose access to care. Furthermore, reducing access to care for poor beneficiaries, including ones in isolated rural communities that lack any public transportation, clearly contradicts the objectives of the Medicaid Act. To the extent HHS has approved such waivers in Indiana and Iowa, we believe that the evaluations of those pilots revealed a persistent need for NEMT among Medicaid expansion enrollees, clear signs of poor understanding of the benefit and ineffective delivery, and a disparate impact on people of color.
3. *What types of benefit redesign (such as a package of benefits) would improve the provision of LTSS?*
- Continue to advance options, such as 1915(i), that allow the provision of HCBS services

even if beneficiary needs have not yet risen to an institutional level of care. HCBS as a “preventive measure” before an institutional level of care is required is both desirable for beneficiaries and cost-effective. Providing services earlier could help prevent beneficiaries from developing higher-intensity and more expensive care needs, including potentially avoidable inpatient admissions and emergency room visits.

- Assist states to identify methods for coordinating across waiver and state plan services and include a section on HCBS applications regarding how the HCBS program will interact and coordinate with other HCBS programs and state plan services.

B. What actions can CMS take, independently or in partnership with states and stakeholders, to ensure quality of HCBS including beneficiary health and safety?

Establish Common HCBS Quality Measures that Look at Integration, Health and Safety, and Consumer Satisfaction: We believe it is critical that CMS continue its efforts to establish common quality measures for HCBS. We believe quality measures must look at a broad array of outcomes that are important in a persons’ life – from health and safety (including access to needed healthcare services) to integration (like opportunities to participate in community activities, work in competitive integrated employment, and live in housing that is integrated in the community with a choice of a roommate) to self-determination and choice (including whether the person was supported to express their personal goals and choices in service planning, chose their living arrangement, and had a choice of daytime activities) to consumer satisfaction factors. We recommend that CMS:

- Work with ACL and DOJ to identify effective HCBS Quality Measures based on DOJ’s *Olmstead* enforcement work and ACL’s work around person-centered planning;
- Ensure that quality standards do not unnecessarily reduce HCBS participants’ rights to the normal human experience of taking risks and the dignity and growth that accompanies these risks. One way to do this is to individualize quality procedures and create them as a standard part of the person-centered planning process. The CMS guidance on the 2014 HCBS rule and promoting community integration for individuals who “wander” offers good recommendations on how to individualize safety and protections in HCBS settings;
- Encourage or require states to begin stratifying HCBS quality data by common demographics to help identify, track, and reduce health disparities over time;
- Strongly reinforce the existing MLTSS regulation expectation to identify each enrollee with special health care needs (and develop an individualized person-centered self-directed plan of services and supports); and
- Encourage the use of National Quality Forum endorsed, CAHPS trademark, CMS-AHRQ developed HCBS experience survey; National Core Indicators; Aging and Disability; and Council on Quality and Leadership Personal Outcome Measures. This would allow state choice and encourage comparative cohorts of states using one or more of these existing measures.

Require States to Set More Specific Standards for Beneficiary Health and Safety and Increase CMS Monitoring: Ensuring that states have in place effective strategies to ensure the health and

safety of HCBS participants is critical. The assurances that states are currently required to provide to CMS, including in appendix G of the 1915(c) waiver application, are too high level and do not receive detailed enough scrutiny from CMS during the waiver application review process. This has been borne out in multiple state reviews where HHS' Office of the Inspector General has documented that the assurances on health and safety made in the application have not in fact been implemented by states. Given the foundational nature of basic health and safety in HCBS systems, we recommend that CMS:

- Develop a common set of specific health and safety elements that must be included in state HCBS monitoring processes.. CMS should require that states regularly document that these health and safety requirements are being effectively implemented. States, at a minimum, should have effective:
 - *Real-time critical incident reporting systems* with clear definitions of “critical incidents” and criteria for “serious risk” of “critical incidents;” that is managed by an entity independent of providers; requires regular training of providers in using the incident reporting system; has criteria to triage incidents by level of harm and has required response times; investigative findings include specific action steps to prevent future similar incidents; and requires regular trending of data to identify systemic issues and/or on-going issues with particular providers;
 - *Systems to promptly report, investigate, and address abuse, neglect and serious harms* that clearly defines “abuse and neglect” by level of severity; have clear rules about who are mandatory reporters and provides training on mandatory reporting duties; lays out appropriate response times for initiating an investigation and starting protective proceedings based on the level of severity; requires investigative findings to include a mitigation plan; have clear criteria when cases are referred for criminal investigations and prosecutions or fraud; and requires regular trending of data to identify systemic issues and issues with particular providers and
 - *Mortality review systems* that report all unexpected deaths to an independent entity based on clearly defined standards of “unexpected” deaths; conducts a preliminary investigation to identify any suspicious circumstances; conducts a full investigation (including interviews with staff, review of records, and autopsy reports) when suspicious circumstances are present; requires investigative findings include a mitigation plan; and requires regular trending of data to identify systemic issues and issues with particular providers.
- Promptly address any evidence of state violations of health and safety assurances. CMS should actively work with states to develop Corrective Action Plans (CAPs) using best practices from other states. CMS should require that states' CAP process is transparent to the public and that states engage stakeholders in CAP development and implementation, including considering how to leverage external monitoring by Protection and Advocacy organizations and Long Term Care ombudsmen; and
- CMS should ensure that Protection and Advocacy (P&As) have immediate access to all surveys and reports, along with supporting information, prepared by CMS, its regional offices, and state Medicaid agencies regarding deficiencies identified in home and community based waiver settings.

Establish a Common Federal Definition for Competitive, Integrated Employment and Data

Collection Requirements: The September 2016 report to Congress and the Labor Secretary from the Advisory Committee on Increasing Competitive Integrated Employment for Individuals with Disabilities made a number of specific recommendations aimed at improving the quality and outcomes of Medicaid-funded day services. These include:

- Establish a common definition for competitive, integrated employment based on the definition in the Workforce Innovation Opportunity Act and the Americans with Disabilities Act. States should be required to use this definition to measure “employment” in their HCBS systems; and
- Establish minimum outcome measures that states must collect for individuals receiving services supporting employment .

Ensure Strong Implementation and On-going Monitoring by CMS of the HCBS Settings Rule as a Strategy to Improve the Quality of HCBS: The HCBS Advocacy coalition supports strong implementation of the HCBS Settings Rule. We believe this rule is critical to improving the quality of HCBS systems and improving the outcomes for HCBS participants. We strongly encourage CMS to view implementation and ongoing monitoring of states implementation of this Rule as critical to its quality efforts.

Leverage Federally-Funded Disability and Aging Networks and other Stakeholders as Part of Quality Monitoring: We believe it is critical that CMS do a better job leveraging the federally-funded disability and aging networks as part of its monitoring of the quality of state HCBS systems. We recommend that CMS:

- Recognize and promote collaboration across aging and disability stakeholders through its grant and contract activities;
- Use the P&A Network as part of the CMS panoply of independent quality enforcement strategies and provide funding to allow the P&As to monitor disability service systems receiving Medicaid or Medicare funding. P&As are established in every state and territory and already knowledgeable about existing Medicaid and Medicare programs. P&As are trained in how to monitor disability service systems and how to design corrective action plans.
 - Support of funding for P&A HCBS quality and access oversight would include, funding for the P&As to provide oversight and monitoring to ensure the full implementation of the 2014 Rule governing HCBS settings and services
 - Support of funding for the protection of the rights of Medicaid beneficiaries served by managed care entities. This was the recommendation of the National Council on Disability (NCD), an independent federal agency charged with advising the President, Congress, and other federal agencies on disability policies. NCD called on Congress to fund a P&A health advocacy program after a series of national focus groups and forums made clear that beneficiaries with disabilities experience unique barriers to care and due process violations as a result of managed care utilization controls.
- Support the Independent Living Centers, the Developmental Disabilities Councils, P&As and the University Centers for Excellence to be part of the technical assistance available to states, individuals with disabilities, providers and other stakeholders to ensure full adherence to the 2014 rules governing HCBS settings and services. Examples could include: development of assessment tools; identification of and training on practices to

promote person centered services; and training on the rule and best practices for compliance, etc.; and

- Require that HCBS quality and outcome measures rely not only on administrative data, but also on direct feedback from residents in these settings and that collection of this feedback includes the use of assistive technology and other measures to protect privacy and minimize bias.

C. What program integrity safeguards should states have in place to ensure beneficiary safety and reduce fraud, waste and abuse in HCBS?

The RFI focuses primarily on potential fraud and abuse in personal care programs, including self-directed personal care. Our recommendations on this topic are as follows:

Continue to Support and Incentivize Options for Self-Direction: Self-direction (also known as consumer-direction) grew out of a desire by people with disabilities and seniors to have more control and choice over the services they receive and who provides them. Self-direction started as a small pilot program. Due to the evidence of positive consumer outcomes and satisfaction, it has dramatically expanded over the last decade to become a mainstream service delivery model. As of 2016, every program in the country offers at least one self-direction program. Individual enrollment in self direction programs has grown steadily since their inception. Preliminary data from a national inventory on self-direction performed in 2016 shows over 1 million individuals self-directing their services in publicly-funded programs. An AARP survey found that 75% of adults 50 years of age and older would prefer to manage services themselves rather than receive care from agencies (Gibson, 2003), thereby showing a strong preference for self-directed services over traditional services.

Self-directed services are effective. A Public Policy and Aging Report published by the Gerontological Society of America in December 2016 is dedicated to self-direction in Long-Term Supports and Services. Throughout this issue, qualitative and quantitative data support that individuals largely prefer self-direction over traditional models of service delivery, self-direction is cost-effective, and self-direction is a strategy to address workforce issues.

We recommend that CMS ensure that incentives remain for states to expand options for self-direction options in their HCBS programs. As more and more states are moving their system for long-term services and supports into managed care, we think it is critical that CMS ensure options for self-direction are available in managed LTSS systems. We encourage CMS to create standards and/or work with states to create standards that require or incentivize managed care organizations to design, implement and operate high functioning self-direction programs, including genuinely offering the option to eligible beneficiaries in a way that ensures individuals have the purchasing power and flexibility to select the services and providers they need.

Use Quality and Robust Financial Management Services As a Strategy To Assist Consumers and Ensure Program Integrity: We understand that HHS' Office of the Inspector General has raised concerns about program integrity in personal care programs. We believe that Financial Management Services (FMS) in self-direction are an important tool for ensuring programs that

offer robust individual choice and control also maintain serious financial integrity. FMS entities ensure that workers are paid in compliance with tax and labor law and that payments are only made on participants' behalfs when the expenditure is approved in the individual's budget, allocation or plan of care. FMS entities are also able to overlay a myriad of other payment controls and program business rules on individual and worker enrollment and timesheet and invoice processing. We applaud that CMS requires provision of FMS in Medicaid waivers with self-direction.

Often, there is a perception that with more individual control, there must be more fraud. The data has not borne this to be true in self-direction. "More than 25 home care demonstrations, including the National Long-Term Care Channeling Demonstration of the 10 states, provided strong evidence that home care recipients did not experience safety or quality problems at higher rates than comparison or control group members." (Applebaum, Mahoney, 2016). Nonetheless, we believe the best way to address risks of fraud is by ensuring quality and robust Information and Assistance services offered in self-directed programs. Information and Assistance in self-direction generally refers to those functions that support individuals to self-direct, including Support Brokerage and FMS. Applied Self Direction, the new home of the National Resource Center for Participant-Directed Services (NRCPDS), has identified key practices in FMS that effectively prevent and detect fraud in self direction. By requiring particular functions from FMS in self-direction, states and MCOs can ensure programs with limited fraud, yet high levels of participant choice and control. We encourage CMS to develop incentives or standards for states and MCOs to establish key FMS controls aimed at detecting and preventing fraud in self-direction.

When developing these fraud controls, however, we urge CMS not to require the use of electronic visit verification (EVV) as strategy to address potential fraud. EVV can have negative unintended impacts on the independence of people with disabilities and older Americans. First, the systems incorrectly assumes that people with disabilities and seniors who use attendant services are homebound; they typically require a home ("land line") phone to verify that an attendant has arrived or finished a shift. Most people today use PCS services throughout the community, and many people only have cell phones not land lines. EVV systems would impose a *de facto* homebound requirement on Medicaid PCS service users and could violate their privacy by providing geo-tracking data to the government on their location. Moreover, EVV systems may be less secure and less effective in prosecuting fraud than non-electronic systems which provide transparency, require multiple sign-offs and have verified signatures. Finally, a requirement to use EVV systems will impact the determination of whether a state or MCO is a joint employer in self-directed programs under the Fair Labor Standards Act (FLSA), leading to significant financial implications.

D. What are specific steps CMS could take to strengthen the HCBS home care workforce, including establishing requirements, standards or procedures to ensure rates paid to home care providers are sufficient to attract enough providers to meet service needs of beneficiaries and that wages supported by those rates are sufficient to attract enough qualified home care workers?

Ensure Provider Rates are Adequate for Participant Access to HCBS: The lack of competitive wages and benefits for direct care and personal care workers in HCBS is creating a significant crisis for many states' HCBS systems. Across the country, state Medicaid agencies have failed to budget adequate rates that will result in competitive wages for HCBS direct service providers (DSPs) and personal care attendants. Provider agencies report huge turnover and vacancy rates, creating an inability to provide needed services to people they serve and creating unsafe situations due to insufficient staffing. In some cases, providers are closing their doors completely. As a result, HCBS participants are unable to access the services for which they are eligible and need due to a lack of provider capacity. This is particularly a problem for people with complex behavioral and medical needs. To address, this, we recommend that CMS:

- Expand the Medicaid access rules to explicitly measure LTSS and include waiver and demonstration programs; and
- Use the waiver approval and renewal process to work with states to ensure sufficient capacity to needed services, particularly for people with complex and/or significant support needs.

While it is not feasible for CMS to actually set wage floors for specific types of workers in Medicaid programs, we do believe that as part of its access requirements, state Medicaid agencies in setting rates should be required to assess marketplace conditions affecting workers in particularly labor-intensive HCBS services such as community residential and home care programs. Such an assessment should follow along the lines of the Department of Labor's recent wage and benefits survey instrument, using Bureau of Labor Statistic (BLS) data that compares wages and benefits and turnover rates over multiple entry level occupations, including direct care workers, home health aides and personal care workers. We recommend that CMS should require that state Medicaid agencies consult the results of such an assessment before finalizing rates that translate into wages and benefits for these affected workers.

Support Direct Support Professionals: To be successful, it is critical that Direct Support Professionals (DSPs) working with people receiving HCBS supports have the competence, confidence, ethical decision making skills and guidance necessary to provide quality support, receive compensation that is commensurate with job responsibilities and have access to a career path aligned with ongoing professional development. Paying a living wage that exceeds poverty thresholds and minimum wage comparisons is the first and most important step to ensure an adequate supply of workers to meet the needs of Medicaid beneficiaries.

Use Expansion of Self-Direction as a Strategy to Address Workforce Shortages: Self-direction has proven effective at tapping an otherwise unrepresented labor pool in the home health workforce. Self-directing individuals do not have to rely on agency home care workers and instead often hire friends and family, who may be interested in the job due to the personal relationship they have with the individual. Studies have shown that self-directing participants were more likely to receive paid care than those assigned to agencies. This was because with worker shortages in many states, self-directing individuals could hire family members and friends to provide needed services (Kietzman, Benjamin, 2016). We encourage CMS to work with states, MCOs and stakeholders to ensure that self-directing individuals are able to tap into the workforce of friends and family members. Self-direction has repeatedly shown that these

worker relationships produce quality outcomes and this approach increases the labor supply for self-directing individuals.

Finally, self-direction can lead to better rates of pay for workers. There often lower overhead costs in self-direction than in traditional services, leading to a larger share of the funding being available to go towards wages. Additionally, in self-directing models where the consumer can set the rate of pay (i.e., budget authority models), the individual may choose to pay a higher rate of pay as a strategy to avoid worker turnover, while still maintaining budget neutrality. We encourage CMS to help states and managed care organizations understand how budget authority in self-direction encourages individual control and worker satisfaction.

The HCBS Advocacy Coalition appreciates the opportunity to respond to this Request for Information and hopes that CMS will continue its work to ensure that people with disabilities and seniors have timely access to the quality HCBS that help them live full and meaningful lives in their communities. Thank for you considering our input about how to achieve this important goal.

Submitted by:

American Network of Community Options and Resources (ANCOR)

Association of People Supporting Employment First (APSE)

Association of University Centers on Disability

Autistic Self Advocacy Network

Center for Public Representation

Collaboration to Promote Self Determination

Council on Quality and Leadership

Human Services Research Institute

Institute on Disabilities at Temple University

National Association of Councils on Developmental Disabilities

National Disability Rights Network

National Down Syndrome Congress

National Health Law Program

TASH

The Arc of the United States