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January 9, 2017

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
Comments in response to 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.

Community Catalyst respectfully submits the following comments to the Centers for Medicare and Medicaid Services in response to the Home and Community Based Services RFI.

Community Catalyst is a national non-profit advocacy organization dedicated to quality affordable health care for all. Since 1998, Community Catalyst has been working to build the consumer and community leadership required to transform the U.S. health system. Our new Center for Consumer Engagement in Health Innovation is a hub devoted to teaching, learning, and sharing knowledge to bring the consumer experience to the forefront of health. The Center works directly with consumer advocates to enhance their skills and power to establish an effective voice at all levels of the health care system. We collaborate with innovative health plans, hospitals, and providers to incorporate the consumer experience into the design of their systems of care. We work with state and federal policymakers to spur change that makes the health system more responsive to consumers. We have been working to improve home and community-based services (HCBS) for consumers for the last five years, producing tools for consumer advocates to use in state-based advocacy as well as tools for use by other stakeholders.

We appreciate CMS' commitment to ensuring that seniors and people with disabilities have better access to quality HCBS funded by Medicaid. We look forward to continued partnership with CMS toward achieving this goal, in accordance with the Supreme Court Olmstead ruling and the often-stated preferences of consumers who need these services to thrive in their communities. We believe there are many additional steps that can be taken to address the institutional bias in Medicaid that leaves too many people served at great cost in nursing homes rather than in their homes and communities.

We offer comments in each of the four areas laid out in the RFI:

A. Reforms to accelerate access to HCBS

- **Promote new 1115 waivers**

We strongly support using 1115 waivers to offer preferential access to HCBS as an alternative to nursing facility care. We encourage CMS to explicitly announce to state Medicaid officials that it welcomes such 1115 waiver proposals to achieve greater rebalancing by combining various waiver and state plan amendment options. CMS is already effectively using this mechanism to encourage states to propose innovations in substance use disorders services and could easily adopt this for HCBS. The waivers could be structured to promote state use of rate incentives that promote rebalancing long-term services and supports (LTSS) from institutional to community based services. The waivers could also include mechanisms to use cost savings to help address the lack of affordable housing that is needed to help people stay in the community. CMS is already encouraging housing options in other waivers and could explore additional ways to promote housing options in 1115 waivers.

- **Protect consumer choice of settings**

We are concerned about the suggestion in the RFI to change the definition of nursing facility service so that states could offer nursing home coverage only to those whose needs cannot be met by HCBS. We worry that this change could violate requirements for person-centered care by taking away consumer choice of the best location to meet their needs. It could also potentially limit eligibility for HCBS since HCBS eligibility generally is based on the consumer needing a nursing facility level of care.

- **Enhance supports for transitions from an institution to an HCBS setting**

Under the Money Follows the Person (MFP) program, 43 states plus the District of Columbia received special Medicaid funding to facilitate consumer transitions from nursing facilities into community settings. MFP programs successfully facilitated transfers from institutions for more than 50,000 people. But MFP statutory authority expired in 2016. We urge CMS to work with Congress to reauthorize and fund MFP. But in the absence of that action, we recommend CMS provide transition assistance to states through existing HCBS authorities.

- **Promote and provide TA to states to adopt the HCBS state plan option and the Community First Choice (CFC) option**

Both of these options support rebalancing but has not been widely adopted. We applaud CMS' recent guidance to states on CFC as an important step forward. We have been concerned by previous attempts to repeal the CFC option as part of repeal of the Affordable Care Act and urge continued support of this important program.

- **Reject waivers of Non-Emergency Medical Transportation (NEMT)**

NEMT is essential to enable low-income consumers to participate in community activities and access community-based services. NEMT waivers are particularly

problematic for consumers in isolated rural communities where public transit is scarce or nonexistent. We urge CMS to disapprove any additional waivers, given threats to vulnerable consumers.

- **Ensure consumers can retain their homes during short nursing home stays**

Too frequently, consumers lose their homes during a relatively short stay in a nursing facility. Current Medicaid regulations give states an option to provide an income deduction for housing expenses when a physician has certified the consumer will be able to return home within six months. We recommend two changes: make these deductions mandatory and ensure the deductions are sufficient. Currently, many states cap deductions at levels too low to cover consumers' costs to maintain a house or apartment.

B. Oversight and quality measurement

- **Require state HCBS oversight councils with a majority of consumers or consumer representatives**

We recommend that CMS require these councils in every state, allowing them to be combined with LTSS oversight or advisory councils where those already exist. These councils can provide the eyes and ears on the ground to inform state officials and CMS about the quality of HCBS and help shape improvements. They can ensure that HCBS fully reflects consumer goals, preferences and needs.

To ensure these councils are fully effective, we recommend CMS require states to:

- Offer consumer members supports to facilitate their participation, such as transportation assistance, interpreters, personal care assistants and other reasonable accommodations, including compensation
- Provide staff support to the committee
- Ensure transparency of the meetings, including publication in advance of the agendas and locations of upcoming meetings, prompt release of minutes of the meetings and annual reports about changes resulting from the council's recommendations
- Include cross-disability representatives, consumer advocacy groups and legal services providers who represent the constituencies served
- Engage the councils in policy development, program administration and oversight, with a special focus on quality and consumer outcomes

- **Provide rigorous oversight of state HCBS quality programs and intervene as needed to ensure quality and the safety of consumers**

We recommend CMS carefully review state quality programs and require annual reporting of key measures of system and consumer problems and outcomes. We suggest this include rates of consumer problems reported to state oversight, ombudsmen or other external sources, including those arising from consumer grievances and appeals; number of denials and reductions in service; number of cases of neglect or abuse; rates of preventable events including ambulatory-sensitive admissions, readmissions, preventable

ER visits and hospital complications; prevalence and reduction of health disparities; extent of system rebalancing from institutional care to HCBS; and rates of consumer self-direction. All reporting should be disaggregated by age, race, ethnicity, primary language, gender identify, sexual orientation and disability.

We also urge CMS to host regular meetings with stakeholders from each state, including Protection and Advocacy Agencies, Centers for Independent Living, Area Agencies on Aging, Legal Aid groups and other consumer health advocates.

- **Promote development and state use of performance measures focused on consumer-reported outcomes and experiences**

We urge CMS to support standardized HCBS performance measures that focus on consumer-reported outcomes and experience, particularly regarding quality of life, including consumers' ability to maintain independence and meaningfully participate in work, relationships and community activities, as well as live in their preferred setting. This would go beyond the measure development that CMS is already supporting. CMS could draw on the recently published National Quality Forum report, Quality in HCBS to Support Community Living, which lays out measure concepts and recommendations by domain. We urge CMS to focus on the domains of Consumer Leadership in Systems Development, Community Inclusion and Equity which are critical to ensuring HCBS consumers are able to live with as much independence and community participation as possible.

While standardized measures are in development, we urge CMS to encourage state experimentation with use of measure concepts laid out in the report, especially those drawn from these validated surveys: HCBS experience survey; National Core Indicators - Aging and Disability; Money Follows the Person Quality of Life; and Council for Quality and Leadership Performance Outcome Measures. These surveys make use of broad measures for social connectedness, relationships and meaningful community activities.

C. Program integrity safeguards for personal care services

As consumer advocates, we are always concerned about ensuring adequate consumer protections. We see these as crucial elements in achieving person-centered care. We believe that perpetrators of fraud, waste and abuse should be held accountable, and we believe that engaging consumers as partners in detecting and reducing fraud, waste and abuse is fundamental to achieving reduction in this problem.

However, we also believe that the scale/scope of this problem is overstated, and that enforcement of current standards, including those included in the Affordable Care Act[i] can sufficiently address the problem. We oppose restrictions that would limit the option of consumer-directed care.

We offer the following recommendations:

- **Let states set standards for personal care aides**

  Registering workers is already underway in states in a number of ways and should be left up to the states to devise the best way to identify and support personal care aides. This could include criminal background checks, requiring training certification, assigning provider identifications for billing, and creating service registries that can work as intermediaries to support consumers and families (see Section D below).

- **Expand skills training for consumers using self-direction**

  Under the current financial alignment demonstrations, health plans enrolling dually eligible adults needing LTSS must offer self-direction as an option. This requires care managers to provide information to the consumer and to support them if they choose this option. The Administration for Community Living and the National Resource Center for Participant Directed Services have materials and offer technical assistance to stakeholders on what is needed to help consumers. This technical assistance should be expanded.

D. Strengthening the HCBS home care workforce

Community Catalyst appreciates that CMS, in seeking input on ways to strengthen the home care workforce, outlines a number of key areas that are important to stability and growth of that workforce. Recruiting and retaining workers is essential to meet the needs of the growing numbers of consumers of HCBS. This workforce has been demonstrating signs of workforce instability, including high turnover and vacancy rates, for some time[ii].

Nearly 90 percent of older adults want to stay in their home as they age.[iii] And right now, family caregivers are the backbone of our in-home LTSS system. The ratio of family caregivers to older adults, however, is on a sharp decline. In 2010, the ratio was more than seven potential caregivers to every one person in the high-risk years of 80-plus. In 15 years, that ratio will be four to one, and by 2050, it is expected to be only three to one.[iv] To fill this tremendous gap, we must significantly strengthen the home care workforce.

There are well-documented factors that affect meeting this demand, including low pay, scarce benefits, a lack of supervision, inadequate training, high turnover and the lack of career advancement opportunities.[v] An Institute of Medicine report titled "Retooling for an Aging America: Building the Healthcare Workforce[vi], issued over eight years ago, made a number of recommendations to address these issues and improve the workforce, such as increasing economic incentives, improving the work environment and broadening the labor pool. **We suggest CMS review these recommendations as it considers both short- and long-term strategies to strengthen the workforce.**

- **Level the playing field on rates**

  CMS asked for input on using rate methodologies to strengthen the provider infrastructure and ensure beneficiary access to services. We encourage the agency to look at ways to level the playing field between institutional rates and HCBS rates, and take

into account appropriate labor costs when establishing the rates. Reimbursement can also be used to generate competitive pressures that push quality up and costs down by providing financial rewards or incentives for high productivity or superior performance with respect to staffing adequacy and stability.

- **Improve workforce training**

Another area of importance to consumers is access to a quality, knowledgeable workforce. Ultimately, poor training and inadequate training systems reduce the ability to meet consumer needs and increase turnover. High turnover costs squander scarce public dollars, further diminishing quality of care. We recommend that CMS encourage the use of person-centered, competency-based curricula, such as what the state of Michigan developed under the federal PHCAST grant[vii] for inclusion in new employees' orientation. The Massachusetts PCA Workforce Council offers a good model that includes independent living principles, training on lifting, basic body mechanics, and obligations to address fraud and abuse.

CMS should encourage additional training in specialty areas, such as dementia care, where behavioral interventions and communications skills are essential. Another area for special training is end-of-life care. There are model training programs run by Centers for Independent Living that could be used.

- **Increase use of intermediaries**

Another area for improvement is the HCBS infrastructure. As the country moves toward a decentralized model of service delivery, much greater responsibility is being placed on consumers and their families for meeting their HCBS needs. However, little infrastructure is in place to provide needed supports to consumers, workers, or family caregivers, including infrastructure that helps consumers and providers identify each other and interface. Multifaceted intermediaries are needed to support consumers and workers in consumer-directed programs, as well as family caregivers, by providing services such as service registries, training for consumers and family caregivers, access to back-up and respite services, and one-stop/single points of access to information and resources. There are numerous models in operation across the US[viii], with model programs such as the Oregon Home Care Commission Registry and Referral System.[ix]

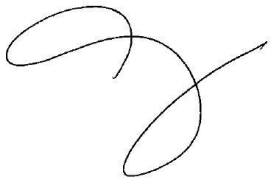
- **Collect data on the direct care workforce**

Finally, we recommend that CMS collect a more robust set of data on the direct care workforce,[x] such as: (1) numbers of direct service workers (full time and part time), (2) stability of workforce (turnover and vacancies), and (3) average compensation of workers (wages and benefits). This information would enable states and CMS to assess the magnitude of their workforce issues, design appropriate policy responses to ensure that consumer needs will be met, and assess the impact of new policies and/or trends on consumers over time. The need for this data was cited in the recent National Quality Forum (NQF) report.[xi] NQF's longer term recommendation is to support the development

of processes and infrastructure to collect data on the workforce and to link this data to the consumer receiving care.

Thank you for the opportunity to provide input on HCBS improvements and for keeping consumers a priority. Please contact Alice Dembner (adembner@communitycatalyst.org), senior policy analyst for long-term services and supports, with any questions about these comments.

Sincerely,



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[i] Patient Protection and Affordable Care Act. (2010, March 23). Public Law 111–148, §§ 5102(a); 5507(a), from http://www.gpo.gov/fdsys/pkg/PLAW-111publ148/pdf/PLAW-111publ148.pdf

[ii] A survey of home care agency staff in Pennsylvania found a turnover rate of 44% (University of Pittsburgh, 2007, The State of the Homecare Industry in Pennsylvania, Prepared for the PA Homecare Association); a review of 13 state and 2 national studies of in-home care for people with intellectual and developmental disabilities found an average turnover rate of 65% (Hewitt and Larson, 2007); a study of agency-employed home care workers in Maine found a turnover rate of 46% (L. Morris, 2009, Quits and Job Changes Among Home Care Workers in Maine, The Gerontologist, 49(5): 635 -50).

[iii] *AARP Public Policy Institute and National Conference of State Legislatures, In Brief, Aging in Place: A State Survey of Livability Policies and Practices.* 2011 December. athttp://assets.aarp.org/rgcenter/ppi/liv-com/ib190.pdf

[iv] *AARP Public Policy Institute, The Aging of the Baby Boom and the Growing Care Gap*. 2013 August. at http://www.aarp.org/home-family/caregiving/info-08-2013/the-aging-of-the-baby-boom-and-the-growing-care-gap-AARP-ppi-ltc.html

[v] *Retooling for and Aging America: Building the Health Care Workforce, Institute of Medicine,* 2008, at http://nationalacademies.org/hmd/reports/2008/retooling-for-an-aging-america-building-the-health-care-workforce.aspx

[vi] *Retooling for an Aging America: Building the Health Care Workforce, Institute of Medicine,* 2008, at http://nationalacademies.org/hmd/reports/2008/retooling-for-an-aging-america-building-the-health-care-workforce.aspx

[vii] http://www.michigan.gov/documents/osa/Michigan_PHCAST_BTBQ_Final_Report_December_18_2014_477161_7.pdf

[viii] http://phinational.org/policy/resources/phi-matching-services-project

[ix] https://or-hcc.org/

[x] https://www.medicaid.gov/medicaid/ltss/downloads/workforce/monitoring-dsw.pdf

[xi] *Addressing Performance Measure Gaps in Home and Community-Based Services to Support Community Living: Priorities for Measure Development, Interim Report,* June 15, 2016 at www.qualityforum.org