

Disability Rights Education & Defense

Fund



November 20, 2017

Submitted via email to: CMMI_NewDirection@cms.hhs.gov

Ms. Seema Verma
Centers for Medicare & Medicaid Services
Department of Health and Human Services
P.O. Box 8016
Baltimore, MD 21244-8013

Re: Informal Request for Information Seeking New Direction to Promote Patient-Centered Care and Test Market-Driven Reforms

Dear Administrator Verma,

The Disability Rights Education and Defense Fund (DREDF), founded in 1979 by individuals with disabilities and parents of children with disabilities, is a leading national law and policy center that works to advance the civil and human rights of people with disabilities through legal advocacy, training, education, and public policy and legislative development.¹ We are committed to increasing accessible and equally effective healthcare for people with disabilities of all ages so they can live productively in their communities, free of persistent health disparities that affect the length and quality of their lives. We greatly appreciate the opportunity to respond to the Center for Medicare and Medicaid Innovation's (CMMI) Request for Information (RFI) on the future direction of the Innovation Center.² We hope to serve as a partner for the Innovation Center as it creates new models that improve healthcare quality, lower costs, and empower consumers, and develops guiding principles for establishing new models

I. Introduction

As we outlined below, people with disabilities face unique challenges in the Medicare and Medicaid programs. By partnering with disabled beneficiaries and their advocates, we believe CMMI can make substantial improvements in patient care consistent with the forward-thinking principles laid out in this RFI. We agree with CMMI that transparent, small-scale models with patient-centered and provider-focused designs can meet the complex needs of vulnerable patient populations, including people with disabilities and multiple chronic conditions.³ The common thread among the delivery models that we

¹ See more about our work at <https://dredf.org>.

² See <https://innovation.cms.gov/Files/x/newdirection-rfi.pdf>

DREDF also wishes to acknowledge the substantial research, writing, and thought contribution of Joe Liss, a student at Yale Law School, in our comments, as well as the Solomon Center for Health Law and

raise and support here are that they all have existing or unexplored potential to increase integration of long-term services and supports with acute and preventive healthcare. We also take this opportunity to affirm those guiding principles that are especially consistent with the values and needs of the disability community.

In particular, we think that increasing clinician flexibility, especially as part of the primary care-focused Accountable Care Organization (ACO) models, to coordinate and provide both medical and non-medical services at home and in the community has the potential to improve healthcare quality and reduce long-term healthcare costs. In this respect, DREDF envisions ACO models that can follow and build on the best integration practices developed in the dual eligible financial alignment demonstrations, for which we also express support below. With respect to ACOs, we specifically ask CMMI to:

- Increase the availability of upfront investments in ACOs that provide services at home and in the community, where patients want them most;
- Measure ACOs on and reward ACOs for their ability to keep beneficiaries in the community, which lowers healthcare costs and improves patient quality-of-life;
- Tear down legal and regulatory barriers that inhibit cooperation and the free flow of information between ACOs and home health agencies (HHAs), community organizations, and community-based care providers.

We also see potential in the development of PACE models directed at younger people with disabilities provided that there are sufficient guardrails and monitoring mechanisms to ensure patient-centered, individualized community-based care that comports with the prior solicited goals of younger people with disabilities. DREDF also sees great significant benefit in recognizing specialty physician models as APMs when the models focus less on narrow specific diagnoses, and more on functional limitations among patient populations, allowing providers to focus on providing and coordinating the multiple levels of medical and LTSS interventions that such patients need to stay in the community. CMMI policies that will support these models include incorporation functional impairment information within electronic health records (EHRs), and establishing ways to informally solicit and incorporate feedback from the disability community and advocates within the model development process.

II. Relevant Principles

As discussed below, we recommend that CMMI pursue the above design changes, models, and policies consistent with principles that are both laid out in the RFI and central to the disability community. In particular, DREDF stresses the importance of fully-informed beneficiary choice, which for the disability community automatically imports the need for fully accessible modes of communication for individuals with vision, hearing, and other communication disabilities. In addition, we emphasize the need for transparency, patient-centered care **with strong consumer protections**, systems

Policy at Yale Law School, at <https://law.yale.edu/solomon-center>. Any errors or omissions in this response are entirely attributable to DREDF.

³ Ibid, Section II, Subsection A: "Guiding Principles"

testing and readiness (emphasizing network adequacy and continuity of care), as well as oversight of all prior principles.

We hope to serve as a resource in a continued dialogue between CMS, providers, and patients about how to improve the Medicare and Medicaid programs through CMMI's important work. Please do not hesitate to reach out to me at syee@dredf.org or by phone at 510-644-2555 with any questions.

The Challenge

Americans with disabilities make up one of the United States' largest minorities. More than 25 percent live in poverty and only about 20 percent have gone to college.⁴ Sixty-five percent of non-elderly disabled Medicare beneficiaries have a cognitive or mental impairment, compared to less than 30 percent of elderly Medicare beneficiaries.⁵

People with disabilities want to live at home in the community, where they can continue to have social, economic and cultural opportunities, control over multiple aspects of their lives, and feel safe and comfortable *if they have appropriate community-based services and supports*. However, the complex needs of people with disabilities and chronic conditions and the frequently uncoordinated efforts of Medicare, Medicaid, state and local public assistance, local community services and private charities make getting access to necessary services at home a daily challenge. Thirty-five percent of non-elderly disabled Medicare beneficiaries have Medicaid coverage as well and must learn how to navigate the myriad rules of both insurance programs. Furthermore, non-elderly people with disabilities have Medicare spending that is more than \$3,000 per capita higher than elderly beneficiaries; importantly, these higher costs are either borne privately or by Medicaid in conjunction with the Medicare program. And a full 21 percent of non-elderly disabled beneficiaries have no supplemental health insurance coverage, as compared with only 12 percent of elderly Medicare beneficiaries.⁶

Lawmakers and researchers have noted that disability is both a cause and a consequence of poverty as people with disabilities receive lesser education and fewer economic opportunities, while low-income individuals and families experience social determinants of health such as lack of housing, healthcare, and food security that leave them at greater risk of acquiring disabilities.⁷ Breaking the cycle similarly involves meeting the health and health-related needs of people with disabilities so that they can live productive lives, including employment for many younger people with disabilities. Integrated care is already a goal in many federal and state public programs – including in many of CMMI's current models – and should be a featured goal in all the private programs in which the federal government invests.

Prioritizing Home and Community-Based Services (HCBS)

⁴ See <https://dredf.org/about-us/>

⁵ See <https://www.kff.org/medicare/issue-brief/medicares-role-for-people-under-age-65-with-disabilities/>

⁶ Ibid

⁷ US Senate, Committee on Health, Education, Labor and Pensions, Majority Committee Staff Report, "Fulfilling the Promise: Overcoming Persistent Barriers to Economic Self-Sufficiency for People with Disabilities," September 18, 2014.

Services delivered at home and in the community allow people with disabilities of all ages to live in their home and remain integrated with their communities. In particular, many state Medicaid programs offer home and community based services (HCBS). While the types of services offered differ substantially across Medicaid programs nationwide,⁸ disabled Medicare beneficiaries without Medicaid may lack access to a menu of community-based services and supports, which can include meal preparation, transportation assistance, supervision, and other assistance with simple and complex activities of daily living. According to the Medicaid and CHIP Payment Access Commission (MACPAC), “Recent data on Medicaid’s [Long-Term Services and Supports] expenditures suggests that efforts to promote HCBS are producing their intended results,” including decreasing costs and keeping beneficiaries in home-based care settings that they prefer.⁹ In 2014, Medicaid spent \$80.6 billion in HCBS.¹⁰

As CMS notes on its website, however, HCBS programs face many challenges, including access to providers, access to qualified caregivers, caregiver turnover, and caregiver burnout.¹¹ For the disability community, there are also concerns around maintaining autonomy, achieving reliable caregiving back-up systems for personal assistance, and the constant need to find and maintain suitable accessible housing where personal assistance services can occur. CMMI has already identified “a critical gap between clinical care and community services in the current health care delivery system,” and introduced the Accountable Health Communities (AHC) model to attempt to fill that gap.¹² As the Department of Health and Human Services (HHS), CMS, and CMMI well know, many issues substantially affecting health and healthcare have their complex roots far from the hospital or physician office. Research from the Robert Wood Johnson Foundation (RWJF)¹³ and Centers for Disease Control and Prevention (CDC),¹⁴ among others, has made clear both that care in the community is vital to improving health outcomes in an efficient manner and that we have a great deal to learn about which strategies have the greatest impact. HHS has faced this issue head-on by making addressing social determinants of health one of its Healthy People 2020 goals.¹⁵ Given the need to improve whole-patient, community-based care and the opportunity for Medicare and Medicaid savings from better beneficiary health, a new wave of small-scale models present an unparalleled opportunity to allow individual clinicians – cooperating with their patients – to try numerous strategies to improve home-based care and see which have the greatest impact on cost and quality outcomes while prioritizing patient-centered care and consumer choice.

We support CMMI’s renewed focus on encouraging innovative, patient-centered, and provider-led models. Given substantial patient demand for remaining in the community

⁸ See <https://www.macpac.gov/subtopic/home-and-community-based-services/>

⁹ Ibid

¹⁰ See <https://www.medicaid.gov/medicaid/hcbs/index.html>

¹¹ See <https://www.cms.gov/Outreach-and-Education/American-Indian-Alaska-Native/AIAN/LTSS-TA-Center/info/hcbs.html>

¹² See <https://innovation.cms.gov/initiatives/ahcm>

¹³ See <https://www.rwjf.org/en/library/research/2016/10/defining-and-measuring-a-culture-of-health.html>

¹⁴ <https://www.cdc.gov/socialdeterminants/>

¹⁵ See <https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-of-health>

and the large opportunities that lie beyond the four walls of medical facilities, new CMMI models and modifications to existing work should change incentives to reward whole patient, community-based care.

III. Policy Proposals

As part of what we hope will be an iterative and inclusive model development process, we outline, below, several ways to leverage existing models and to create new ones to incentivize high quality care through community-based services. People with disabilities will benefit from patient-centered care that breaks down regulatory barriers and allows clinicians to care for the whole patient. We hope that beyond these ideas, disabled beneficiaries can engage with CMMI to make sure models meet patient needs.

A. Informally integrate beneficiaries and their advocates into the complex and heretofore opaque model development process

The average CMMI model must overcome substantial bureaucratic hurdles on the way from a simple idea to a deployable, measurable change to the existing healthcare incentive structure.

- First, from a design perspective, CMMI staff must do heroic work getting even the best ideas off the ground. Building a deployable model is particularly challenging, given the well-documented complexity of Medicare's arcane policies,¹⁶ even small changes to which could have large impacts on vulnerable patient populations.¹⁷ CMS' data systems continue to rely, at least in part, on COBOL,¹⁸ a computer programming language developed prior to 1960 and well-documented in the Museum of American History.¹⁹
- Second, models face myriad bureaucratic hurdles. Any model must undergo internal CMMI review, review across CMS, review across HHS, and review by the Office of Management and Budget (OMB) and other government-wide partners. While such review assures models are as comprehensive as CMMI can make them, it makes quick deployment an ongoing challenge.

¹⁶ See The House Ways and Means Committee's *Modernizing Medicare for the 21st Century* at https://waysandmeans.house.gov/UploadedFiles/Combining_A-B_Medigap_White_Paper.pdf; the Committee for a Responsible Federal Budget's *Modernizing the Medicare Benefit* at <http://www.crfb.org/blogs/modernizing-medicare-benefit>; the Robert Wood Johnson Foundation and Health Affairs' *Restructuring Medicare* at http://healthaffairs.org/healthpolicybriefs/brief_pdfs/healthpolicybrief_95.pdf; and the Kaiser Family Foundation's *Modifying Medicare's Benefit Design* at <https://www.kff.org/medicare/report/modifying-medicare-benefit-design-whats-the-impact-on-beneficiaries-and-spending/>. DREDF cites these source to recognize gaps and issues within Medicare's structure and operation, not to endorse the specific policy prescriptions proposed in every report.

¹⁷ See <http://www.medicareadvocacy.org/medicare-benefit-redesign-proposals-to-restructure-could-hurt-more-than-help/>

¹⁸ See CMS Pricer guidelines at <https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/PCPricer/Guidelines.html> and a CMS solicitation documented on a third-party site at <https://www.g2xchange.com/statics/solicitation-cms-seeks-cobol-programming-support-for-cms-nch-data-repository-mqa-and-medpar>.

¹⁹ See <http://americanhistory.si.edu/cobol/afterward>

As such, CMMI faces two main challenges when it comes to incorporating patient feedback in the model design process:

- First, patients – and, frankly even experienced advocates – can experience difficulty grasping the complex issues CMMI faces deep in the intricacies of its design work.
- Second, CMMI is limited in how much information it can release before complex models reach the end of thorough government vetting.

However, we agree with CMMI that only patient-centered models can effectively engage clinicians to provide patients the services they need where and when patients need them. In order to help CMMI obtain patient feedback while respecting the complexity of CMMI's work and the thoroughness of government review, we recommend that CMMI develop an informal patient review process:

- First, at the beginning of the model development process, reach out to patient advocacy groups and ask them to help find a diverse panel of beneficiaries in CMMI's target patient population; for example, if developing a model in oncology, disability advocacy groups can help locate cancer patients, including cancer patients with other disabilities such as mental health, mobility, or developmental disabilities, or other chronic conditions with functional needs, such as Deafness. Individuals from diverse socioeconomic, geographic, and ethnic backgrounds may face different challenges or benefit from interventions tailored to their communities. Engaging a variety of advocacy groups will help CMMI find a broad cross-section of patients with both expected and unexpected comorbidities that are exacerbated by the interplay of disability with a variety of other personal characteristics.
- Second, CMMI staff can ask – either in person or in writing – both targeted and open-ended questions to better understand what patients are currently missing or concerned about in their medical care. For example, some patients may face issues of coordination among multiple specialists, while others may be more concerned about patient and caregiver education or support. Such informal focus groups can help CMMI understand what issues beneficiaries in their target patient population(s) think are most important, which can help inform model quality measures, participant application requirements, and evaluation questions. Focus groups can also help CMMI to identify unknown additional barriers faced by specific subgroups within the patient population that are sufficient to interfere with CMMI's goals for the project
- Third, CMMI can ask advocacy organizations to help reconvene informal focus groups as CMMI encounters new design problems or focuses on disease categories (e.g. narrowing a cardiovascular model to focus on particular heart conditions).²⁰ Each focus group will remain informal and questions can stay at a high-level.

²⁰ DREDF advocates for CMMI to incentivize payment models that will focus on interventions needed by people with functional impairments common across a number of diagnostic categories, but recognizes that there is also benefit to models that focus on evidence-based acute and medical interventions for particular diseases. Nonetheless, we strongly believe that such models need to recognize the diversity of patients that experience any specific disease, and not establish a falsely homogenous patient population.

- Finally, CMMI can release factsheets with each new model or model update explaining how it incorporated informal beneficiary feedback, in ways both large and small, and how ongoing feedback can be provided.

As we emphasized above, such focus groups do not require CMS to give away any operational details or pledge to undertake any particular action. Additionally, advocacy organizations can help connect CMMI with diverse affected beneficiaries, maximizing the returns CMMI gains from its investments in outreach work. Finally, CMMI can use simple accessible factsheets to help consumers, including LEP consumers with disabilities, understand how their voices were heard and how ongoing feedback can be provided. Thus, CMMI can create a complete, informal feedback loop that helps to assure the development of models with patient concerns at the center.

B. Increase the availability of upfront investments in Accountable Care Organizations (ACOs) that provide services at home and in the community, where patients want them most

Providers looking to help patients by providing both medical and non-medical services at home and in the community face at least two known and substantial constraints: Rigid regulations prohibit Medicare from paying for such services and provider investments in improving patient well being take time to pay off. By expanding the availability of up-front investments in ACO infrastructure, CMS can help clinicians provide the type of care that clinicians want to provide and that patients need to receive.

CMMI's Advance Payment ACO model provided 36 physician-led Medicare Shared Savings Program (MSSP) ACOs with up-front payments to invest in improving care quality. While the model recouped \$38 million in advanced payments through ACO shared savings and showed reductions in certain key spending categories, such as inpatient care, the model did not immediately work as intended. CMMI had yet to recoup \$30 million in advanced payments as of its final evaluation report, and no performance year showed costs significantly lower than in comparison groups. Evaluators concluded that "[t]ransforming multiple physician-led practices into a cohesive entity to improve quality and reduce Medicare spending growth is a process that may take longer than the evaluation period."²¹ CMMI has continued to refine its initial advance payments work through the ACO Investment Model, which particularly targets ACOs in rural areas.²²

We think CMMI can make key changes to the advance payments concept – building upon its ACO Investment Model work – that will help improve results:

- Increase the performance period to at least five years to allow more time for investments in improved care quality to mature;
- Require provider participants to participate in an Advanced Alternative Payment Model (Advanced APM), such as the Medicare ACO Track 1+ Model,²³ which will

²¹ See pages viii through xi at <https://innovation.cms.gov/Files/reports/advpayaco-fnevalrpt.pdf>

²² See <https://innovation.cms.gov/initiatives/ACO-Investment-Model/>

²³ See <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Value-Based-Programs/MACRA-MIPS-and-APMs/Medicare-Accountable-Care-Organization-ACO-Track-1+-Model-Webinar-slides.pdf>

allow CMMI to recover a portion of advance payments even from participants with higher-than-expected costs through downside risk;

- Target high-cost beneficiaries who are likely to gain the most benefits by assigning advance payments based on the number of beneficiaries who commonly experience health and health disparities (e.g., live in rural areas, are low-income, and/or are disabled), rather than assigning advance payments based simply on practice size or total patient panel; and
- Require model provider participants – as part of their application – to work with both public and private providers of community assistance and services (e.g. independent living centers, aging and disability resource network organizations) in their area on a strategy to understand and care for the whole patient.

Providers know that, among the nation’s most vulnerable Medicare beneficiaries, there are enormous opportunities to decrease costs and improve quality simultaneously. However, success will require an up-front investment backed both by a substantive plan of action that leverages existing community resources and a strategy for CMMI to see a real return on its investment. Currently, government-dictated payment categories and coding restrict provider flexibility to truly meet patients where they are and discourage firsthand provider consultation with patients on their broader health-related needs. CMMI’s commitment to flexible, patient-centered models provides a tremendous opportunity to break through this logjam and allow clinicians to invest in broader community-based care.

C. Measure ACOs on and reward ACOs for their ability to keep beneficiaries in the community, which lowers healthcare costs and improves patient quality-of-life

DREDF’s work with and among the disability community, including many individuals who are Medicare and/or Medicaid beneficiaries, has made one thing clear: Americans with disabilities of all ages prefer to live in the comfort and safety of their communities, with appropriate services and supports. At home, beneficiaries have access to friends and family, community activities, and their own possessions. They have control over their own schedules and patterns of life in the same way as people without disabilities. They have greater capacity to avoid the drain on assets and feelings of isolation that come with institutional living. Therefore, one obvious measure of any primary care-focused model’s success is the ability to both keep patients in and return patients to their communities.

Among the roughly 30 quality measures on which MSSP ACOs will be evaluated in 2017, there are at least two measures of readmissions and three of hospital admissions.²⁴ CMMI uses many of these quality measures in the ACO 1+ Model, as well as the Next Generation ACO Model and the ACO Investment Model. In other words, across these models, CMMI recognizes the advantages of avoiding institutional settings of care. However, neither the Center for Medicare’s MSSP nor CMMI’s many ACO models measure the base outcome of keeping patients in the community with

²⁴ See <https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/sharedsavingsprogram/Downloads/MSSP-QM-Benchmarks-2016.pdf>

appropriate services and supports, or the prior necessary condition of accurately assessing and providing the level of services and supports needed by beneficiaries.

Therefore, we recommend that CMMI add measures similar to the following to its ACO models and connect performance to increased shared savings payments:

- Risk-adjusted change in percentage of beneficiaries who spend fewer than ten days in institutional settings during the year;
- Risk-adjusted percentage of disabled beneficiaries who spend fewer than ten days in institutional settings during the year;
- Risk-adjusted percentage of beneficiaries who are both disabled and dual eligible who spend fewer than ten days in institutional settings during the year; and
- Risk-adjusted percentage of beneficiaries who spend fewer than ten days in an institutional setting in a year among those who spent at least ten days in an institutional setting in the prior year.

We believe that CMS possesses sufficient claims data – through admission and discharge dates for claims for payment under the Inpatient Prospective Payment System (IPPS) and Inpatient Rehabilitation Facility (IRF) payment system, as well as from claims for payment under the Skilled Nursing Facility Prospective Payment System (SNF PPS) per diem payments – to calculate these claims-based measures. We only propose ten days and using risk-adjusted percentages as a starting point. Moreover we assume CMMI both would structure such quality measures to reduce the risk of cherry-picking, and would incorporate provider reporting and CMS monitoring elements to discourage cherry-picking of beneficiaries who have a history of institutionalization, since those are the beneficiaries who would most benefit from explicit community quality measures, and who offer the greatest potential cost savings when served appropriately in the community. We urge CMS and CMMI to expeditiously review what measure parameters would be most effective and informative, and we urge CMS and CMMI, especially in the early years of using these measures, to try out a variety of claims based measures. Additionally, as CMS improves the Transformed Medicaid Statistical Information System (T-MSIS)²⁵ and as CMS refines its Medicare location of services claims data, we urge CMMI to also integrate days spent in non-Medicare covered long-term care facilities into the above measures.

In summary, patients want to remain in their homes, and we urge CMMI to both measure which ACOs – and other primary-care focused models – are succeeding in helping beneficiaries to meet that goal and to reward those clinicians who do.

D. Tear down legal and regulatory barriers that inhibit cooperation and the free flow of information between ACOs and home health agencies (HHAs), community organizations, and community-based care providers

For some disabled beneficiaries in the community, home health agencies (HHAs) provide essential medical services. However, HHAs face role restrictions and myriad state and federal regulatory requirements that make it tough to provide the highest

²⁵ See <https://www.medicaid.gov/medicaid/data-and-systems/macbis/tmsis/index.html>

quality care for vulnerable beneficiaries.²⁶ Furthermore, given the limits on what non-medical services HHAs can provide, local private and public agencies as well as privately hired personal care assistants have stepped into the breach to help family members care for disabled loved ones.

ACOs share with HHAs the goals of keeping patients in the community and making sure patients have sufficient resources to maintain preventative and other healthy behaviors between visits (e.g. medication adherence, regular meals, physical activity) that improve outcomes and decrease medical costs. However, even under current CMS and HHS Office of the Inspector General (OIG) waivers, ACOs may be limited in their ability to share data with or make payments to HHAs and other, non-CMS enrolled community-based organizations (e.g. independent living centers, private charities). HHAs and local community-based groups outside the ACO's formal network are still essential to providing excellent beneficiary care.

For example, Next Generation ACOs – which are among the most advanced in the CMMI portfolio – may only distribute shared savings payments to ACO participants and preferred providers. Further, the Next Generation ACO waiver document fails to discuss data sharing and electronic health records at all.²⁷

We urge CMMI to expand waiver authority with the delivery of community-based services in mind. In particular, we urge CMMI to either change or clarify its rules so as to:

- Provide clear procedures for medical providers inside and outside the ACO to share electronic health record information (using uniform and blanket patient permission forms where possible);
- Provide clear procedures for ACO participants to share non-medical information about patients with, and receive non-medical information from, community-based organizations from which the patient is already receiving assistance;
- Help ACOs pay HHAs to provide additional, more complex health maintenance and personal assistance tasks needed by beneficiaries but that Medicare does not currently cover, even while HHAs continue to bill Medicare under fee-for-service (FFS) for covered services;
- Allow ACOs to pay as needed for public and private community-based organizations to provide personal assistance services, such as personal care and chore assistance, that Medicare does not cover, but that are essential to an individual with disabilities staying safely in the community; and

²⁶ See, for example, HHA regulations in Massachusetts (<http://www.mass.gov/eohhs/docs/masshealth/regs-provider/regs-homehealthagency.pdf>), licensing requirements in Michigan (http://www.michigan.gov/lara/0,4601,7-154-63294_72971_75375---,00.html), the Connecticut Department of Public Health's rules on HHA licensure (http://www.ct.gov/dph/lib/dph/agency_regulations/sections/pdfs/title_19_health_and_safety/phc/chapter_iv/19-33_home_health.pdf), and rules and regulations for HHA in Pennsylvania (http://www.health.pa.gov/migration/documents/bcplc/hha/rules_regulations.pdf).

²⁷ See <https://www.cms.gov/Medicare/Fraud-and-Abuse/PhysicianSelfReferral/Downloads/Amended-ACO-Model-Waivers.pdf>

- Consider how ACOs, in partnership with HHAs or community-based service organizations, could address transitional and permanent housing needs since housing is such a critical social determinant of health.²⁸

By removing regulatory barriers, CMMI can help ACOs build broader community-based networks that help care for the whole patient. We note that – to varying degrees and extents – CMS and OIG’s current waivers may allow ACOs to undertake some of these payment transfer and data sharing tasks; where that is the case, we urge CMMI to make those flexibilities clearer to both ACO participants and potential community partners. ACL, CMS, and others – for the dual-eligible financial alignment initiatives – have worked to develop best practices around health plans and community-based partners, which could also prove useful in the ACO context and should be made available.

While, as discussed above, upfront investment and changes to quality measures that focus on community-based services will have a more substantial and direct impact, reducing regulatory barriers with home-based and community-provided services in mind can improve care quality and lower costs.

E. Incentivize the Identification of Functional Impairment Information in Electronic Health Records²⁹

In 2014, an estimated 53 million people with disabilities over age 18 lived in the United States, or 23 percent (23%) of the population. An estimated 14 percent (14%) of people within the adult U.S. population have a complex activity limitation that affects their ability to participate in society, including maintaining a household, working, and pursuing hobbies. People with disabilities or complex activity limitations are likely to be at greater risk for health and health care disparities than the general population.³⁰

Research has shown that people with disabilities are more likely than the general population to experience difficulties or delays in getting the health care they need, not have had an annual dental visit, have high blood pressure, use tobacco, or be overweight. Women with disabilities are more likely not to have had a mammogram in the past two years or to have been screened for cervical cancer in the past three

²⁸ P. Braveman, M. Dekker, S. Egerter, T. Sadegh-Nobari, and C. Pollack, “Housing and Health,” Robert Wood Johnson Foundation, May 2011, <https://www.rwjf.org/en/library/research/2011/05/housing-and-health.html>.

²⁹ DREDF has written extensively on this issue, most recently in the Issue Brief, “The Case for Including Functional Limitation Measures in Electronic Health Records,” March 2016. This section of our comments is primarily taken from the Issue Brief

³⁰ Complex activity limitation affects their ability to participate in society, including maintaining a household, working, and pursuing hobbies; see Altman, Barbara & A. Bernstein, Disability and Health in the United States, 2001-2005” (Hyattsville, MD: National Center for Health Statistics, 2008). Complex activity limitation is captured through four measures: any limitations in social or leisure activities, any difficulty or inability to work, self-care limitation (reflected by any ADL or IADL limitation), and an overall combination measure, which reflects any individual or combination of limitations in the first three measures.

years.³¹ They also have higher death rates from breast cancer than women without disabilities. Studies show that people with disabilities also die from lung cancer at higher rates than the general population.³² Health and health care disparities among people with disabilities can be attributed in part to complex barriers to care that contribute to difficulties or delays in getting needed health care and increase the likelihood of poor health outcomes. Identified barriers include lack of provider awareness and training, lack of accessible medical offices and facilities, and a dearth of accommodations such as accessible medical and diagnostic equipment, lifting assistance, or Sign Language interpreters. Certain inflexible policies also create barriers to care such as the inability of a provider to extend a patient visit to ensure time for lifting assistance on to an exam table or effective communication for someone with a speech or cognitive limitation.³³

A 2015 study has shed additional light on these problems by analyzing in some detail the underlying causes of health disparities among people with disabilities. Authors found that, "Population-level differences in health outcomes...are related to a history of wide-ranging disadvantages, which are avoidable and not primarily caused by the underlying disability."³⁴ Another recent study illustrates certain of these avoidable disadvantages. In 2014, 256 specialty providers were asked if they would accept a referral of a large patient who used a wheelchair and required transfer assistance. The study revealed that 22 percent (22%) of the specialty provider offices could not accommodate this patient, 4 percent (4%) were architecturally inaccessible and 18 percent (18%) couldn't assist the patient to transfer onto an exam table. Gynecology was the subspecialty with the highest rate of inaccessible practices (44%).³⁵ Such lack of accessibility and impairment-related accommodation is commonplace not only among specialty providers, but also among primary care practices, diagnostic centers and facilities, clinics, and hospitals. These barriers frequently prevent patients from obtaining needed care and treatment.³⁶

In light of the changing regulatory landscape and a growing understanding of the underlying causes of health and health care disparities among people with disabilities, it is increasingly important to consistently identify and record physical, mental and/or cognitive functional limitations in electronic health records (EHR). This data is required

³¹ Sze Y. Liu, Melissa A. Clark, "Breast and Cervical Cancer Screening Practices among Disabled Women Aged 40–75: Does Quality of the Experience Matter?" *Journal of Women's Health* 17(8) (2008):1321–1329.

³² Ellen P. McCarthy, Long H. Ngo, Richard G. Roetzheim, Thomas N. Chirikos, Donglin Li, Reed E. Drews, Lisa I. Iezzoni, "Disparities in Breast Cancer Treatment and Survival for Women with Disabilities," *Annals of Internal Medicine* 145.9 (2006):637–45; Lisa I. Iezzoni, Long H. Ngo, Donglin Li, Richard G. Roetzheim, Reed E. Drews, Ellen P. McCarthy, "Treatment Disparities for Disabled Medicare Beneficiaries with Stage I Nonsmall Cell Lung Cancer," *Arch Phys Med Rehabil*, 89.4(2008):595–601.

³³ National Council on Disability, "The Current State of Health Care for People with Disabilities," September 30, 2009.

³⁴ Gloria L. Krahn, Deborah K. Walker, Rosaly Correa-De-Araujo, "Persons with Disabilities as an Unrecognized Health Disparity Population," *American Journal of Public Health* 105 S2 (2015): S198-S206.

³⁵ T. Lagu, N.S. Hannon, M.B. Rothberg, A.S. Wells, K.L. Green, M.O. Windom, K.R. Dempsey, P.S. Pekow, J.S. Avrunin, A. Chen, and P.K. Lindenauer, "Access to Subspecialty Care for Patients With Mobility Impairment: A Survey," *Annals of Internal Medicine* 158 (2013):441-446.

³⁶ National Council on Disability, "The Current State of Health Care for People with Disabilities," September 30, 2009.

in order to understand and plan for the prevalence of functional limitations among the patient population and to be able to cross reference it for research and policy purposes with population health and other demographic information such as race/ethnicity, gender, age, and LGBT status. Including functional limitation queries in the EHR would significantly benefit research into the health care disparities experienced by people who have intersectional bases for discrimination and unequal treatment such as disability and another demographic characteristic because such cross-analysis cannot currently be carried out without reliable information about the prevalence of functional limitation.

Moreover, the medical diagnostic codes that are presently included in medical records do not offer a solution because a single diagnostic code can be associated with wide variance in functional capacity and does not correspond to or represent the level or degree of a given individual's functional limitation. Information on functional need is critical to trigger provider administrative processes that result in needed accommodations before and during a patient's health care visit such as lifting assistance, assignment to an exam room with an adjustable height exam table, an ASL interpreter, or extended exam time.

Several years ago, LifeLong Medical Care, a Federally Qualified Health Center located near San Francisco, in Alameda County, California, decided to embed functional impairment questions in the health center's registration form in order to alert primary care staff that some patients required accommodations so they could receive maximum benefit from health care. These questions are included in the clinic's electronic health record and can be flagged in individual patient records.

Jan. – Dec. 2015	Unduplicated Patient Count
Language Interpreter Needed	633 ³⁷
Long Appointment Only	26
Sign Language Interpreter	NA
Mobility Assistance	2281
None	30555
Support for Low Vision or Blindness	39
(blank)	62
Grand Total	33596³⁸

TABLE 1. LifeLong Medical Care Disability and Language Assistance Data – 2015

Table 1 sets forth some categories of information that LifeLong collects and data showing the number of patients requesting certain spoken language or disability

³⁷ LifeLong includes a query about language interpretation needs along with disability accommodation questions in the EHR.

³⁸ LifeLong Medical Care also collects information on patients who require Sign Language interpreters, but that data was not available at the time this Issue Brief was finalized.

assistance or accommodations who visited either one of LifeLong's ten primary care clinics, health care practitioners located at several supportive housing sites, a dental practice or two school-based sites in Alameda County during 2015.

According to LifeLong, during 2015 about 9 percent (9%) of unduplicated patients who visited the various sites in Alameda County indicated that they needed some type of language or disability assistance or accommodation. (LifeLong also collects data on patients who need Sign Language Interpreters, but that data was not available at the time this Issue Brief was being written.) About 7.5 percent (7.5%) indicated a solely disability-related accommodation need, excluding Sign Language interpreters. LifeLong records show that 22 individuals had more than one disability or language accommodation need.³⁹ These data are important because they likely represent the first time that functional limitation questions not only have been embedded in electronic health records, but that also identify some specific areas of disability assistance patients require in the clinical setting. While more study is needed to understand how LifeLong uses the identified functional accommodation information, and indeed whether these are the best questions to ask to collect the needed information, these early data highlight the importance of initiating the inquiry and embedding responses in patient records so clinic staff can plan and prepare adequately for patient visits.⁴⁰

Furthermore, we know from extensive reports from the disability community that unless the need for disability accommodations is proactively recorded in the patient's medical record, provider offices simply cannot or will not provide required accommodations, thus denying access for some people with disabilities to even the most common health measures such as weight measurement and routine prevention procedures such as cervical cancer screening.⁴¹ By recording the presence of a functional limitation, providers can more readily prepare for visits by such patients and take steps to ensure that they receive appropriate diagnostic tests and needed treatment and care.

DREDF strongly supports including either the American Community Survey (ACS) set of six disability questions or other equivalent functional limitation measures in electronic health records. While this information is necessary purely from the standpoint of providing effective medical services to people with disabilities, as outlined above, it will also be both easier to obtain with, and invaluable for, the integration of LTSS services within primary and specialist healthcare models. Many healthcare providers tend to prioritize diagnostic information given their training and acute care orientation. LTSS providers prioritize functional impairment information, which is typically achieved through the observed and reported need for assistance with basic and instrumental activities of daily living. In an integrated healthcare model where primary/specialist and

³⁹ Email communication with Kathryn Stambaugh, Geriatrics Service Director, LifeLong Medical Care, Berkeley, California, March 10, 2016, unpublished data.

⁴⁰ DREDF is currently engaged in further analysis and research on the actual impact of the disability questions on how patient care is delivered and experienced.

⁴¹ Intended as an advocacy and educational tool, DREDF produced a video series entitled **Healthcare STORIES** that features people with disabilities telling their personal stories about their health care experiences. The narrators describe the barriers to care they experience when health care providers are not adequately prepared for their visit and when necessary accommodations are not provided. The series can be viewed at: <http://dredf.org/healthcarestories/2014/02/05/barriers%e2%80%8e-solutions/>

LTSS professionals are working together, LTSS providers will help ensure that accurate and current functional limitation data is maintained in the EHR of a person with a disability, which will in turn enable primary/specialist providers to receive electronic alerts on the need for accommodations that will in turn assure that a beneficiary receives effective preventive and acute care interventions when needed. An EHR that contains LTSS information also sets the stage for far better care coordination across the broad range of medical, social, and behavioral health needs that must be met before people with disabilities and chronic conditions can avoid costly institutionalization and sustainably remain in the community.⁴² Some models, such as the ACOs, already allow the model entity to financially invest in care coordination in innovative ways.

F. Maintain benefits guardrails and incorporate beneficiary cooperation when designing any PACE flexibility model

The PACE Innovation Act of 2015 (PIA) provided CMMI the flexibility to test expansion of the PACE model to beneficiaries under age 55 and to those who do not require a nursing home level of care.⁴³ We strongly support PACE's goal of keeping beneficiaries who could be sent to nursing homes in the community, and we think PACE organizations could serve as an opportunity to allow the private sector to explore how best to provide non-medical community-based services that contribute greatly to younger beneficiaries with disabilities' overall health and quality of life. However, we are concerned that PACE's capitated payment model gives PACE organizations disincentives to assure patients get necessary care, or encourages fiscal incentives in the delivery of care that will run counter to expressed consumer choice and patient-centered care. The PACE Protocol and ongoing state and federal monitoring assure that patients receive such needed interventions.⁴⁴

Therefore, we recommend that CMMI and other partners within CMS and HHS both assure that guardrails and monitoring remain in place and incorporate beneficiary feedback into creating any PACE model. We also recommend that innovative PACE models for younger people with disabilities maintain a primarily focus on those individuals who **do** require a nursing home level of care since these are individuals with significant medical, LTSS, and coordination needs, but that the models also be given some degree of flexibility that will allow them to take on a minority percentage of individuals who may stop short of a nursing home level of care but who experience ongoing risk factors in their lives that may make higher or variable levels imminent. Similarly, PACE models should be given some flexibility to accommodate individuals with significant disabilities and degenerative conditions who may on occasion need to enter a nursing or rehabilitation facility for a longer period of time to stabilize functional capacity, but who retain the capacity and strong desire to return to the community. A

⁴² B. Chernoff, "How Coordinated Care Improves Lives and Manages Costs" Scan Foundation Perspectives on Aging with Dignity, January 2016. See http://www.thescanfoundation.org/sites/default/files/perspectives_how_coordinated_care_improves_lives_and_manages_costs_january_2016.pdf

⁴³ See <https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/PAPE/PAPEInnovationAct.html>.

⁴⁴ See 81 FR 54667 at <https://www.federalregister.gov/d/2016-19153/p-68> 81 FR 54669 at <https://www.federalregister.gov/d/2016-19153/p-86>.

patient-centered care PACE care model will place individual wishes and health assessments above arbitrary rules that allow beneficiaries to be dropped from a PACE program.

We specifically recommend that, for any PACE organizations participating in a model under PIA, CMS (1) maintains and increases monitoring activities, such as site visits and other evaluations; (2) works with PACE organizations to advertise to patients and their caregivers where they can report problems at their PACE organizations and provide patients and caregivers a way to track whether and how CMS has responded to those concerns; (3) develop progressive remediation compliance plans and penalties for PACE organizations found to be non-compliant with consumer choice and patient-centered care standards; (4) establishes built-in mechanisms to safeguard continuity of beneficiary care and LTSS services during periods of leadership or financial transition in the PACE organization; and (5) apply protections that CMS has built into its HCB settings rule to model participants.⁴⁵ While we understand that CMS did not directly apply the HCB settings guardrails to PACE organizations,⁴⁶ we think many of the protections included in those guardrails to ensure that community-based settings do not establish institutional and collective policies and practices of operation are equally applicable to the PACE organizations in their capacity as providers of community-based services.

Additionally, we recommend that CMMI and other CMS partners incorporate feedback from beneficiaries and their advocacy organizations into discussions and decisions about any PACE model. For example, CMS should solicit feedback on the outcomes younger beneficiaries with disabilities would like to see from PACE; find ways to measure those outcomes; and hold PACE organizations accountable for the results. CMS should also work with beneficiaries to determine what issues they most frequently have when interacting with PACE organizations and build protections against those concerns into any PACE model. Finally, we recommend that CMS directly enquire after all beneficiaries who elect out of PACE during the model to make sure that PACE organizations did not push those beneficiaries out; refuse to cover needed services (e.g. drugs or nursing home care); or otherwise encourage less healthy beneficiaries to seek care from other provider types.

We think PACE can provide coordinated, community-based care that helps beneficiaries, but beneficiaries' concerns must be at the forefront of any PACE model development efforts.

G. Recognize as APMs specialty physician models that propose a focus on patient populations with functional limitations

DREDF also sees significant benefit in recognizing specialty physician models as APMs when the models focus less on narrow disease-specific diagnoses, and more on functional limitations among patient populations, allowing providers to focus on providing and coordinating the multiple levels of medical and LTSS interventions that

⁴⁵ See 79 FR 2948 at <https://www.federalregister.gov/d/2014-00487/page-2948>.

⁴⁶ See <http://www.npaonline.org/summary-cms-final-rule-hcbs>.

such patients need to stay in the community. For example, a specialty physician model could have the aim of maximizing functional independence and capacity to remain in the community for individuals with mobility disabilities and complex musculoskeletal impairments. Patients could be assigned to specialist providers or provider groups in the areas of orthopedics, rehabilitation such as physiatrists who would be in overall charge of the model, working with LTSS providers and care coordinators to help keep assigned patients functional and active in their homes. Eligible beneficiaries would not have to have a specific diagnoses. Rather qualification could be based on a flexibly applied range of health characteristics such as having a mobility disability and needing a nursing home level of care, have functional impairment levels of quadriplegia, or one of a number of diagnoses or chronic conditions that affect musculoskeletal strength. The model would ultimately save money by improving patient health and outcomes through intensive outpatient treatment and appropriate LTSS interventions rather than institutionalization.

Quality measures could include the percent of patients who remain in the community, a reduction in hospital admissions and readmissions, as well as patient satisfaction scores. One means of evaluation could involve offering an opportunity for relevant provider specialists to sign up for the model. Those specialists would then be randomized into treatment and control groups. Control providers would be paid to report data only on patients with comparable ADL and IADL scores, while treatment providers would enter the program and work with a provider team that includes LTSS providers and access to care coordination. The incentive would arise from providing upfront payments to each practice in the form of a monthly fee (billed through a CCM-like HCPCS code) that would cover additional outpatient services. CMMI would then reconcile total spending (including the outpatient fee) against risk-adjusted benchmarks (calculated using prior year data and location-specific trend factors) for those patients. CMMI would pay savings to those practices that managed to keep total costs below predicted costs and meet quality goals; and CMMI would recover funds from practices whose actual spending exceeded predicted costs or who did not meet quality goals. Episodes of care could last for a defined period of time.

H. Continue to Support Dual Eligible Financial Alignment Demonstration

The Medicare-Medicaid Financial Alignment Initiative (FAI) is currently in the middle of a multi-year implementation period and cannot be characterized as a “new direction,” but DREDF strongly calls for ongoing CMMI support of the FAI since many of the state demonstrations under the FAI feature the patient-centered care and beneficiary empowerment, choice, and outcome improvements emphasized by the RFI. In particular, many of the demonstrations have sought to achieve integration not only of Medicare and Medicaid services in ways that will benefit dual-eligible beneficiaries, but also LTSS and medical care. Multiple stakeholders, including states, plans, providers, and consumer advocacy groups have placed very significant resources designing, implementing, refining, and monitoring the demonstrations. The data already gathered, as well as data still to be gathered as best and promising practices are tested over a period of years with a patient population that has disproportionately high levels of care needs and costs within both Medicare and Medicaid, cannot be easily replicated.

Rather than reinvent the wheel, DREDF recommends that CMMI recognize and help disseminate information and practices from the RAI demonstrations among potential qualifying Advanced Payment Model participants and other prospective providers and plans. CMMI should encourage existing and potential model design participants to integrate LTSS components needed by beneficiaries with disabilities into CMMI model proposals. The FAI demonstrations are a vital source of information about different LTSS integration practices, outcome data, and the evolution and implementation of standards for soliciting and meeting patient needs and preferences. Ultimately, people with disabilities will have genuine choice when they can choose among different provider models that may differ in details of healthcare delivery, but that uniformly adhere to a core set of principles respecting patient autonomy, encourage the free flow of accessibility information, and recognize key consumer rights such as grievance and complaint rights. The FAI demonstrations have, to varying degrees of success, established these goals for themselves and can serve as invaluable models on how to meet the needs of beneficiaries with complex conditions and disabilities.

Conclusion

People with disabilities and chronic conditions can present unique challenges for the Medicare and Medicaid programs. By partnering with disabled beneficiaries and their advocates, we believe CMMI can make substantial improvements in patient care consistent with the forward-thinking principles laid out in this RFI. As outlined above and with the goal of increasing the availability of services in the community, we recommend that CMMI pursue the following design changes, models, and policies:

- Informally integrate beneficiaries and their advocates into the complex and heretofore opaque model development process;
- Increase the availability of upfront investments in Accountable Care Organizations (ACOs) that provide services at home and in the community, where patients want them most;
- Measure ACOs on and reward ACOs for their ability to keep beneficiaries in the community, which lowers healthcare costs and improves patient quality-of-life;
- Tear down legal and regulatory barriers that inhibit cooperation and the free flow of information between ACOs and home health agencies (HHAs), community organizations, and community-based care providers;
- Include functional impairment information within the electronic health record;
- Maintain benefits guardrails and incorporate beneficiary cooperation when designing any PACE flexibility model;
- Recognize as APMs specialty physician models that propose a focus on patient populations with functional limitations; and
- Continue to support duals initiatives and push the information discovered there, especially around the critical nature of LTSS integration and findings on assessing and satisfying unmet care needs.

We hope to serve as a resource in a continued dialogue between CMS, providers, and people with disabilities about how to improve the Medicare and Medicaid programs through CMMI's important work. Such an iterative process will hopefully include both formal opportunities for comment and informal opportunities to get real consumers and their day-to-day concerns in front of CMMI staff and leadership. We share with CMMI's dedicated staff the passion for improving the lives of beneficiaries with disabilities and members of our community each and every day.

Again, we sincerely value CMMI's work and the opportunity to comment on this RFI. We look forward to doing even more to improve care quality through patient-centered models of care. Please do not hesitate to contact me at 510-644-2555 or syee@dredf.org with any questions.

Sincerely,

A handwritten signature in black ink, appearing to read "Silvia Yee", with a horizontal line underneath the name.

Silvia Yee