



November 5, 2021

U.S. Department of Health and Human Services  
Office of the Assistant Secretary for Planning and Evaluation, Strategic Planning Team  
Attn: Strategic Plan Comments  
200 Independence Avenue, SW, Room 434E  
Washington, DC 20201

RE: Public Consultation on the Draft HHS Strategic Plan FY 2022-2026

Strategic Planning Team:

The Consortium for Citizens with Disabilities (CCD) Health and Long Term Services and Supports Task Forces write in response to your request for public comment on the Draft HHS Strategic Plan for FY 2022-2026. CCD is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.

We appreciate many aspects of this Strategic Plan, particularly the focus on addressing health inequities and disparities. We support HHS's adoption of the definition of underserved populations listed in Executive Order 13985: Advancing Racial Equity and Support for Underserved Communities through the Federal Government, which includes people with disabilities and other individuals who belong to underserved communities, such as Black, Latino, and Indigenous and Native American persons, Asian Americans and Pacific Islanders and other persons of color; members of religious minorities; LGBTQ+ persons; persons who live in rural areas; and persons otherwise adversely affected by persistent poverty or inequality. We also appreciate HHS's explicit recognition that people "may belong to more than one underserved community and face intersecting barriers."

Below we offer recommendations for ensuring the needs of people with disabilities are considered and addressed in specific objectives and strategies.

***Objective 1.1: Increase choice, affordability, and enrollment in high-quality healthcare coverage***

CCD approves of HHS putting choice, affordability, and enrollment as its first objective. For years, people with disabilities have struggled disproportionately with rising health care costs. The Affordable Care Act (ACA) and subsequent legislation have helped

level the playing field, by for example, limiting medical underwriting and insurance rescissions. The ACA also largely eliminated high-risk pools that had greatly increased premiums for people with disabilities, and created critical new pathways to affordable coverage for people with disabilities, such as Medicaid expansion and premium tax credits. Rough estimates suggest that 20 to 30% of Medicaid expansion adults have disabilities.<sup>1</sup> Before the ACA, many of these individuals would have had no access to affordable health care. Medicaid expansion has led to greater flexibility for people with disabilities in seeking employment as well. Evidence shows that people with disabilities have higher rates of employment in expansion states vs. non-expansion states and that overall employment rates increased in expansion states.<sup>2 3</sup>

Even after these important steps, there is still a long, steep pathway ahead to fully rectify disparities for people with disabilities. Over the past few years, restrictive enrollment and redetermination policies in some state Medicaid agencies led to dwindling enrollment for youth and adolescents. Access to robust Marketplace coverage has also been weakened by reductions in funding for Marketplace navigators and increased authorization of misleading short-term health plans that offer flimsy coverage, and rising deductibles and cost sharing.

### **Promote available and affordable healthcare coverage to improve health outcomes in our communities**

We support the strategy to enhance and support outreach efforts to inform eligible individuals of healthcare insurance options and related cost-saving opportunities. It is particularly important to ensure that people with disabilities are afforded effective support for enrollment through navigator support. People with disabilities often have more health care needs and must consider numerous factors when selecting insurance coverage, such as whether established providers are in network and whether multiple medications are covered with affordable cost-sharing. Therefore, it is critical that HHS continue to support robust access to free enrollment assisters who provide impartial assistance to people with disabilities in selecting a plan and enrolling in cost-sharing assistance, as well as Medicaid and CHIP if they are eligible. We applaud the Administration's expansion of the funding for the navigator program this year and recommend that it continue and that CMS encourage partnerships with local consumer based disability organizations to conduct outreach and enrollment to the disability community as locally trusted entities.

### **Empower consumers with choices for high quality healthcare coverage**

- We agree that reforms should emphasize transparency in relation to pricing, provider availability, cost-sharing, service availability, grievance and appeals, and

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<sup>1</sup> David Machledt, National Health Law Program, *Faces of Medicaid Expansion* (May 22, 2017), <https://healthlaw.org/resource/the-faces-of-medicaid-expansion-filling-gaps-in-coverage/>.

<sup>2</sup> Hall JP, Shartz A, Kurth NK, Thomas KC. Medicaid Expansion as an Employment Incentive Program for People With Disabilities. *Am J Public Health*. 2018 Sep;108(9):1235-1237. doi: 10.2105/AJPH.2018.304536. Epub 2018 Jul 19. PMID: 30024794; PMCID: PMC6085052.

<sup>3</sup> Hall JP, Shartz A, Kurth NK, Thomas KC. Effect of Medicaid Expansion on Workforce Participation for People With Disabilities. *Am J Public Health*. 2017 Feb;107(2):262-264. doi: 10.2105/AJPH.2016.303543. Epub 2016 Dec 20. PMID: 27997244; PMCID: PMC5227925.

all other elements of health coverage. However, transparency does not obviate the need for lower cost-sharing. As [our principles on health reform](#) make clear, health care coverage must be affordable for all people, including people with disabilities and others who have higher than average health costs. Ensuring that premiums are affordable is necessary, but insufficient to ensure affordable access to care. Deductibles and other cost-sharing must also be affordable. Premiums and out-of-pocket costs should be nominal or non-existent for low-income populations. First dollar coverage helps people with disabilities who need access to care and treatment on a routine basis have predictable and affordable co-pays. Deductibles and out-of-pocket caps should also be limited based on household income, recognizing that people with disabilities often have higher than average out of pocket medical expenses.

- We recommend policies that pursue cost-control mechanisms other than utilization management. Utilization management, such as prior authorization or step therapy, disproportionately impacts people with disabilities and chronic conditions who frequently need high-cost, high-intensity care and do not have lower-cost alternatives. Data shows that many insurers employ utilization controls such as step therapy via protocols that are more restrictive than the standard of care.<sup>4</sup> Many states eased or eliminated prior authorization during COVID-19, and this did not dramatically increase health care usage. Policymakers should analyze data from this experience and reconsider the frequent application of prior authorization as a barrier to needed services, rather than a tool to improve care quality.
- High-quality health care coverage must be comprehensive. In order to be comprehensive, we believe that any health care coverage must include robust coverage of Home and Community Based Services (HCBS), habilitation and rehabilitation services, behavioral health, prescription drugs, dental, vision, and hearing.
- We recommend that HHS commit to discontinuing any policies that apply premiums, high cost sharing, or other added conditions of eligibility in Medicaid and other health programs targeted at low-income populations. We appreciate that HHS has already rescinded guidance and most approvals related to work requirements from the prior administration. In prior administrations, several states have sought and received approvals for § 1115 projects that impose premiums, heightened cost sharing, work requirements or other waivers of key Medicaid protections that reduce access to care. Such waivers have no meaningful innovative or experimental value. We already know premiums (and high cost sharing) substantially reduce access to coverage and care, particularly for low-income individuals and families. Work requirements cause massive coverage losses – often due to administrative and reporting problems – and do not meaningfully increase employment.<sup>5</sup> Work requirements in different safety net

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<sup>4</sup> <https://www.healthaffairs.org/doi/abs/10.1377/hlthaff.2021.00822?journalCode=hlthaff>

<sup>5</sup> Robin Rudowitz & MaryBeth Musumeci, *An Early Look at State Data for Medicaid Work Requirements in Arkansas* (2018), <http://files.kff.org/attachment/Issue-Brief-An-Early-Look-at-State-Data-for-Medicaid-Work-Requirements-in-Arkansas>.

programs also disproportionately disenroll people with disabilities.<sup>6</sup> Moreover, many of these policies exacerbate health inequities.

- We recommend HHS not approve any waiver proposal (whether § 1115, § 1915, or § 1332) without analysis of its potential effects on marginalized communities and its plan to bolster health equity as part of the innovation. This concrete step would go a long way toward making HHS's Strategic objective on affordability, choice and enrollment more than just words on a page. We appreciate HHS's recent rule that strengthens § 1332 waiver guardrails on affordability, comprehensiveness, and coverage. In the past, these reviews have included a review of each proposals' effects on different subpopulations within the target group. This could serve as a starting point for a new commitment to incorporate a robust equity analysis as a required element for new waiver proposals of any kind. This analysis should include a determination of the proposed waiver's effect on community living for people with disabilities.
- We support the proposal to “monitor equitable and timely access to Medicaid and Children's Health Insurance Program (CHIP) providers and services.” People with disabilities rely on Medicaid for access to basic health care services and for services that ensure their functioning, independence, and well-being, including: nursing and personal care services, specialized therapies, intensive mental health services, special education services, and other needed services that are unavailable through other insurance. Access to these services is a matter of life, death, independence, and dignity for the millions of people with disabilities on Medicaid and the protections provided by the equal access statute are of particular importance to our community. CCD has long supported CMS taking regulatory action to enforce the provisions at 1902(a)(30)(A) to ensure that people with disabilities who rely on Medicaid have adequate access to health care and home and community-based services and supports by ensuring that service providers have adequate reimbursement rates. Too often the reimbursement rates do not reflect the actual cost of providing the services and supports. Inadequate reimbursement rates contribute to low wages and high turnover rates for the direct support professionals which is creating a nationwide crisis disrupting the lives of beneficiaries and putting their health and safety at risk. Such enforcement must include managed care and HCBS.

#### **Leverage knowledge and partnerships to increase health coverage enrollment**

- We appreciate that HHS will conduct research into the cost-effectiveness and affordability of insurance coverage for diverse populations. We believe such research is necessary to address health disparities. HHS should ensure that such research does not exacerbate discrimination by relying on discriminatory metrics like the Quality Adjusted Life Year (QALY). The QALY is a discriminatory

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<sup>6</sup> Andrew J. Cherlin et. al., *Operating within the Rules: Welfare Recipients' Experiences with Sanctions and Case Closings*, 76 Soc. Serv. Rev. 387, 398 (2002) (finding that individuals in “poor” or “fair” health were more likely to lose TANF benefits than those in “good,” “very good,” or “excellent health”) (attached); Vicki Lens, *Welfare and Work Sanctions: Examining Discretion on the Front Lines*, 82 Soc. Serv. Rev. 199 (2008).

measure based on the idea that disabled lives are less valuable and less worth living than non-disabled lives. CCD opposes the use of QALYs and related measures and supports an explicit ban on the use of QALYs in any health care policy that considers the value or effectiveness of treatments or health care.

***Objective 1.2 Reduce costs, improve quality of healthcare services, and ensure access to safe medical devices and drugs***

**Partner with providers to develop payment models and other incentives to expand options for quality care at lower costs**

- We welcome the opportunity to help “design innovative, targeted, value-based payment models to increase recruitment of providers that care for predominantly underserved populations and provide them with support to improve their awareness of the benefits of alternative payment models that aim to decrease health inequities.” It is important to note that value-based payments should have the primary goal of improving health, not punishing providers or patients for poor health. Many states have adopted (or attempted to adopt) Medicaid waiver programs that are designed to “incentivize” healthy behaviors. We strongly object to these programs. The use of high-cost sharing, utilization management, and other barriers is sometimes discussed as giving patients “skin in the game” to reduce their utilization of care. In reality, these programs only put greater burdens on people with disabilities and chronic conditions and limit their access to needed care. Alternative payment models and other efforts to control costs should seek to expand and improve access to care, not limit it.

**Implement and assess approaches to improve healthcare quality, and address disparities in healthcare quality, treatment, and outcomes**

- We recommend that HHS use the term “*services*” rather than “*treatment*” to encompass the full range of programs HHS oversees and non-medical services are particularly important to people with disabilities.
- CCD supports the strategy to promote and support implementation of the National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care by health professionals, health systems and organizations and in HHS programs to improve the quality of care and reduce health disparities by ensuring the provision of services that are respectful of and responsive to individuals' health needs, preferences, culture, and preferred language.
- With respect to quality measures, we recommend HHS adopt the “CMS Meaningful Measures” approach, with the addition of HCBS and LTSS.

**Strengthen patient safety improvements and access to affordable medications and medical products to reduce spending for consumers and throughout the healthcare system**

Prescription drugs are an essential aspect of daily life for many people with disabilities

and chronic conditions. As the administration considers policy proposals to reduce the cost of prescription drugs, we encourage policymakers to keep the needs of people with disabilities and chronic conditions at the forefront of all discussions. As our [Positions on Access to Prescription Drugs](#) state, we believe that all people should have access to treatment that is affordable, accessible, easy to navigate, and based on a physician-directed and person-centered treatment plan determined by the individual and their health care providers. We have several recommendations in order to achieve this goal:

- Strengthen rules and enforcement to prohibit discriminatory benefit design in formularies and other benefit designs that explicitly discriminate against people with disabilities, such as through placing higher prior authorization or cost sharing requirements on treatments for certain conditions or placing all drugs to treat a condition on the specialty tier.
- Do not weaken consumer protections (including Medicaid's broad outpatient prescription drug requirements and Medicare's six protected classes) or allow limitations on access to treatment to extract price concessions from manufacturers. Insurance practices like step therapy, prior authorization, cost-sharing designs, and tiered formulary design are used in negotiation with pharmaceutical manufacturers and other providers and manufacturers to extract discounts, but they directly harm people with disabilities and chronic conditions who have higher needs and higher costs.
- To the extent measures of cost-effectiveness or comparative effectiveness are used in determining drug formularies, utilization management, or cost sharing, prohibit the use of Quality-Adjusted Life Years and other similar metrics which discriminate against people with disabilities.
- Increase options for individuals to lower their out of pocket costs, including access to safe and effective generics, while not unduly restricting coverage of brand name drugs. Many people with disabilities may not be able to take a generic, due to drug interactions, side effects, ineffectiveness, or inability to obtain a list of all ingredients in the generic drug.

***Objective 1.3: Expand equitable access to comprehensive, community-based, innovative, and culturally-competent healthcare services while addressing social determinants of health***

**Support community-based services to meet the diverse healthcare needs of underserved populations**

- We strongly agree with HHS's strategy to support community-based services. It is critical that this strategy include supporting the right of people with disabilities to receive long-term services and supports at home and in the community.
- We appreciate HHS's plans to increase access to oral health care and ensure it is integrated with primary care. People with disabilities are more likely than the general population to experience barriers to good oral health, including lack of coverage, conditions and/or treatments that exacerbate oral health needs, and few accessible oral health care providers. For example, 62% of individuals with

disabilities under 65 on Medicare report that they have not seen a dentist in the last year. Therefore, we encourage HHS to take steps across Medicare, Medicaid and other sources of health care coverage to expand access. For example, people with disabilities on Medicare may need dental care before they can get a surgery or treatment. We urge HHS to expand access to such services under its existing “medically necessary” authority. In addition, to expand access for people with disabilities, it is critical that dentist offices are accessible and that providers are equipped and trained to serve them.

- We also support improving access to telehealth services in accordance with our [CCD Health Task Force Telehealth Principles](#).

### **Remove barriers to healthcare access to advance health equity and reduce disparities**

- As previously mentioned, we support strategies to integrate and promote CLAS. We note that cultural competency includes disability competence and accessibility, and that these competencies intersect with other cultural competencies including linguistically appropriate services. For example, documents that are translated into non-English languages also need to be made available in accessible formats in those languages.
- We urge HHS to ensure effective communication with people with disabilities, including by providing plain language versions and ensuring that internet communications are made screen reader accessible and adhere to the guidelines created by the Web Accessibility Initiative (WCAG).
- We strongly support increasing access to affordable and accessible housing. Housing is a primary social determinant of health, and for people with disabilities lack of accessible and affordable housing is also a barrier to HCBS. We urge HHS to collaborate with the U.S. Department of Housing and Urban Development (HUD) regarding targeting affordable, integrated, accessible housing to people transitioning from, or at risk of entering, institutions and carceral settings; and provide technical assistance to states about leveraging Medicaid for housing-related supports.
- We recommend that enhancing civil rights regulations and enforcement be a key strategy to advancing health equity and reducing disparities. In particular, we are encouraged that HHS is planning to engage in rulemaking on Section 1557 of the ACA. We urge quick action to not only restore the health care rights that have been gutted but also improve upon 1557 and other anti-discrimination protections for people with disabilities, including by ensuring that regulations implementing Section 1557 clearly outline key ways in which health insurance benefit design may discriminate based on disability.
- We urge the administration to continue to address discriminatory policies and practices by hospitals, health care systems, and state policies, including regarding Crisis Standards of Care, access to organ transplants, and other instances of disability discrimination. The administration should finalize the rulemaking that HHS’s Office for Civil Rights initiated concerning these issues.
- In developing patient safety bundles and decision aids for health conditions that disproportionately affect underserved populations, people with lived experience

must be consulted.

- We appreciate inclusion of disability status in data collection, but note that current approaches to defining and asking about disability status vary greatly to the point where comparisons across data sets are often impossible. Where possible we encourage HHS to use a more standardized, inclusive definition of disability, based on the ADA definition, and start from the six-question standard used by the American Community Survey. We also ask that HHS collect and report data on residential settings (i.e., whether someone lives in a congregate setting).

***Objective 1.4: Drive the integration of behavioral health into the healthcare system to strengthen and expand access to mental health and substance use disorder treatment and recovery services for individuals and families***

- We strongly support efforts to better integrate behavioral health and primary care and LTSS delivery. We urge expansions of models and programs to better integrate care for people with disabilities and chronic conditions, including people who are dually eligible for Medicare and Medicaid. We also agree with enhancing support for peer support specialists as part of the behavioral health workforce and community-based intervention services.
- In strengthening health equity research to ensure evidence-based treatments are available, we recommend HHS include disability status as a demographic category. Many people who have mental health disabilities also have other co-occurring disabilities. In research and development of programs and best practices, we urge HHS to work with people with lived experience, including people with co-occurring mental and non-mental health disabilities, and ensure that their perspectives are central in decisions concerning these services.

***Objective 1.5: Bolster the health workforce to ensure delivery of quality services and care***

- It is paramount to build the workforce with people with disabilities in mind. We support strategies to promote employment for people with disabilities throughout the healthcare workforce.
- HHS must work with states and stakeholders to develop strategies to address workforce shortages and high turnover in Medicaid HCBS programs in particular. Currently, the essential workforce that provides HCBS is severely underpaid due to inadequate Medicaid rates paid to providers. The result is a community service delivery system that a survey of over 3,000 providers in 26 states indicates is challenged by high direct care vacancy rates and an average turnover rate of 43%, with numerous states reporting turnover in excess of 50%.

***Objective 2.1: Improve capabilities to predict, prevent, prepare for, respond to, and recover from emergencies, disasters, and threats across the nation and globe***

**Leverage opportunities for improved collaboration and coordination to strengthen capacity for effective emergency and disaster readiness, response,**

## **and recovery**

- Often, people with disabilities are routinely overlooked and underserved before, during, and after disasters. This begins when people with disabilities are left out of emergency preparedness processes, which then disproportionately impacts them during disasters. The consequences have been catastrophic. It is essential that emergency management programs are developed with people with disabilities in mind. People with disabilities have unique needs, even with regard to disaster preparedness. They must have the necessary information and access to resources to enable them to make plans for and respond to emergencies. While recognizing that emergency preparedness begins with individuals, people with disabilities must have access to guidance, tool kits and other materials that are in accessible and understandable formats whether in written form or on line. With respect to health care in particular, maintaining access to prescription drugs and home- and community-based services (HCBS) are critical for people with disabilities. Interruptions in drug regimens or support with activities of daily living can be a matter of life and death.

### ***Objective 2.3: Enhance promotion of healthy behaviors to reduce occurrence and disparities in preventable injury, illness, and death***

- We urge HHS to ensure that public health promotion, such as promotion of physical activity, includes efforts to improve the health of people with disabilities.
- We call on HHS to end the use of wellness programs in employer-sponsored insurance, end the demonstration promoting wellness programs in Marketplace plans, and reverse the decision to allow issuers to include wellness programs in quality improvement activities. The past two administrations have promoted the use of “wellness programs” in commercial insurance. Health-contingent wellness programs that incur financial penalties or require disclosure of private information to employers discriminate against people with disabilities, and evidence now shows that they also do not improve health or control costs.

### ***Objective 3.3: Expand access to high-quality services and resources for older adults and people with disabilities, and their caregivers to support increased independence and quality of life.***

- We strongly support HHS naming expanding people with disabilities’ access to high-quality services to support increased independence and quality of life as an objective. As a threshold matter, we recommend HHS work to identify racial and other inequities in HCBS and develop specific strategies for addressing those inequities, including requiring states to develop equity plans for their HCBS programs, providing TA and funding for outreach to Black, Indigenous, and other communities of color, including non-native English speakers and LGBTQ+, and providers that serve them, and prioritize transition efforts in institutions disproportionately with residents from those communities.

**Enhance system capacity to address the health, health related outcomes, and social determinants of health for older adults and individuals with disabilities by developing processes, policies, and supports that are person centered and**

**provide quality care for older adults and individuals with disabilities, at home or in community-based settings.**

- We believe HHS should prioritize strong implementation of the HCBS Settings Rule, including by providing additional guidance, technical assistance (TA) to states, and ongoing monitoring, with a focus on the heightened scrutiny process.
- Particularly in light of COVID19 laying bare the risks of institutional and large congregate settings, HHS should provide guidance on how states can expand community-based services and housing, further *Olmstead* implementation in their Medicaid systems, and work with the Department of Justice to support their *Olmstead* enforcement activities.
- Work with states and stakeholders to develop strategies to address workforce shortages in Medicaid HCBS programs. Currently, the essential workforce that provides HCBS is severely underpaid due to inadequate Medicaid rates paid to providers. The result is a community service delivery system that a survey of over 3,000 providers in 26 states indicates is challenged by high direct care vacancy rates and an average turnover rate of 43%, with numerous states reporting turnover in excess of 50%.
- We support enhancing states' ability to implement Medicaid HCBS and incorporate standardized quality measures to assess and track the adequacy of the HCBS community integration on access, availability, quality, experience of care, health outcomes, and the workforce. We urge CMS to finalize and work with states to implement core quality measures for HCBS that emphasize person-centered services, compliance with the HCBS Settings Rule, equity in access to HCBS, and best practices. As previously mentioned, we recommend HHS adopt the "CMS Meaningful Measures" approach, with the addition of HCBS and LTSS.

**Ensure availability and equitable access and delivery of evidence-based interventions that focus on research, prevention, treatment, and care of older adults and individuals with disabilities.**

- We urge the Administration to direct resources to support multidisciplinary clinics to support patients and provide expert care to those with Post-Acute Sequelae of SARS-CoV-2 infection (PASC), myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), and other similar conditions. Multidisciplinary post-COVID clinics that can act as a comprehensive care center, providing access to multiple physician specialists, therapists, psychiatric services, and social work seem to be best at helping patients not only recover, but better understand their new diagnosis. These multidisciplinary clinics have started opening in academic medical centers, which have resources to support them, but are not available throughout the country.
- We urge HHS to use its leadership position and budgetary resources to ensure that this focus on Long COVID includes and benefits people with similar chronic illnesses, such as Chronic Fatigue Syndrome/Myalgic Encephalomyelitis, fibromyalgia, and dysautonomia, that have long gone under-diagnosed, under-researched, and under-treated, with devastating impacts on quality of life for people with these disabilities.

**Objective 4.4 Improve data collection, use, and evaluation, to increase evidence-based knowledge that leads to better health outcomes, reduced health disparities, and improved social well-being, equity, and economic resilience**

- We support HHS's strategies to improve data collection. In addition to key demographics HHS has identified, we recommend data collection also include residential setting and treatment setting.
- Having more comprehensive, directly collected data, and examining how the demographics intersect, will enable HHS to better identify compounding disparities for people with disabilities in access to and quality of care, services and supports.
- During the COVID-19 pandemic, people with disabilities, particularly those living in congregate settings, have faced higher risk of morbidity and mortality, often due to a conglomeration of risk factors: the hands-on nature of the services they need, the lack of effective protective equipment, and labor practices that often led to high turnover and staff interacting with multiple enrollees and increasing exposure risk. We also suspect, though there is little data, that people of color with disabilities have been especially hard hit by COVID-19. This attention to data is desperately needed both immediately to ensure that the COVID-19 response is addressing the needs of the disability community and all people, and longer term to move forward on building more equitable systems for delivering health care and long term services and supports.

Thank you for your time and attention. For more information, please contact Caroline Bergner, Director, Health Care Policy, Medicaid, for the American Speech-Language-Hearing Association at [cbergner@asha.org](mailto:cbergner@asha.org) and Natalie Kean, Senior Staff Attorney for Justice in Aging at [nkean@justiceinaging.org](mailto:nkean@justiceinaging.org).

Sincerely,

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