



Leadership Council  
of Aging Organizations

March 9, 2026

Dr. Mehmet Oz  
Administrator  
Centers for Medicare and Medicaid Services  
U.S. Department of Health and Human Services  
Washington, D.C.

RE: Community Engagement Requirement Implementation for Caregivers, Older Adults,  
and People with Disabilities or Serious or Complex Conditions

Dear Administrator Oz:

The undersigned members of the Leadership Council of Aging Organizations (LCAO) express our concern about the potential impact of community engagement requirements on older adults and caregivers providing essential care to older adults. We offer recommendations for implementing these new requirements to minimize harm to older adults, people who need care, and those who provide it. LCAO is a coalition of 68 leading national nonprofit organizations working throughout the country to provide direct services to older adults, strengthen communities, and advance the health and well-being of older adults and those caring for them. Since 1980, LCAO has worked with all Administrations and Congresses on a bipartisan basis to help the United States realize the opportunities and meet the challenges of a growing older adult population.

H.R. 1 establishes new community-engagement requirements for most Medicaid expansion adults ages 19–64, requiring states to verify that enrollees are working, in school, in training, or volunteering. We are particularly concerned that Medicaid work requirements could jeopardize care for older adults, people with disabilities, and the people providing their care, which includes both family caregivers (paid and unpaid) and non-family, paid caregivers (i.e. direct care workers). While the statute includes exemptions for medically frail individuals and family caregivers, experience from past work-requirement programs shows that exemptions often fail to function as intended. Older adults, people with disabilities, and caregivers routinely lose coverage not because they are ineligible, but because the systems designed to identify and protect them are too complex, too restrictive, or overly dependent on incomplete data sources.

Steady employment can be especially challenging for many Medicaid beneficiaries. Among older adults aged 50 and over, 64% experienced or witnessed age discrimination at work.<sup>1</sup> Among Medicaid expansion enrollees aged 50-64 who are not working, 17% identify as

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<sup>1</sup> Choi-Allum, L. (2022). *Workforce trends: Older adults & age discrimination*. AARP Public Policy Institute.  
<https://www.aarp.org/pri/topics/work-finances-retirement/employers-workforce/workforce-trends-older-adults-age-discrimination/>

caregivers and 86% report having a health condition that limits their ability to work.<sup>2</sup> People with disabilities and serious or complex health conditions, particularly those with mental health conditions and/or substance use disorders, face additional hardships due to their disability including unstable housing, stigma and discrimination in the workplace, and limited access to reliable transportation. Losing Medicaid due to work requirements means losing access to crucial treatment, worsening the conditions and health outcomes for millions of Medicaid beneficiaries.

Given these challenges, Congress provided explicit exemptions for several groups including medically frail individuals and caregivers. Federal guidance must ensure that exemptions are readily available for these groups to prevent widespread improper and unintended coverage loss. In this letter, we address barriers to obtaining exemptions faced by older adults, people with disabilities including individuals living with mental health (MH) conditions and substance use disorders (SUDs), and caregivers including both family caregivers and direct care workers. When older adults and people with disabilities lose Medicaid, their health declines and may need more support from family caregivers and direct care workers. Likewise, loss of Medicaid not only has adverse health consequences for family caregivers and direct care workers themselves; it also limits their ability to provide care to older adults and people with disabilities. Our concerns and recommendations to reduce barriers to coverage for these groups follow.

### **Medically Frail Individuals**

Exemptions based on medical frailty should reflect variations among people with disabilities and people with complex or serious health conditions, should not be contingent on an individual's current or past work history, and should not require documentation unavailable to most individuals.

Medicaid is the primary payer for disability services like MH and SUD.<sup>3</sup> Of the 6.1 million people 50 to 64 enrolled in Medicaid,<sup>4</sup> 57 percent have a physical health condition and more than one in five have a diagnosed MH condition or SUD.<sup>5</sup> For these beneficiaries, work reporting requirements may create particular barriers to health coverage and service access. Moreover,

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<sup>2</sup> Tavares, J., & Cohen, M., (2025). *What are socio-demographic characteristics of Medicaid expansion population compared to non-expansion Medicaid population age 50 to 64?* [Analytic brief]. LeadingAge LTSS Center @UMass Boston. <https://www.ltsscenter.org/wp-content/uploads/2025/04/Differences-between-Expansion-and-Non-Expansion-Medicaid-Beneficiaries-April-2025.pdf>

<sup>3</sup> Medicaid and CHIP Payment and Access Commission. (n.d.). *Behavioral health*. Retrieved February 4, 2026, from <https://www.macpac.gov/topic/behavioral-health/>

<sup>4</sup> Shah Goda, G., Nevo, L., & Frank, R. G. (2025). *How proposed changes to Medicaid are expected to impact near-elderly Americans*. Brookings. <https://www.brookings.edu/articles/how-proposed-changes-to-medicaid-are-expected-to-impact-near-elderly-americans/>

<sup>5</sup> Mathers, J., Tolbert, J., Chidambaram, P., & Cervantes, S. (2025). *5 Key facts about Medicaid expansion*. KFF. <https://www.kff.org/medicaid/5-key-facts-about-medicaid-expansion/>

both MH conditions<sup>6</sup> and SUDs<sup>7</sup> increase the likelihood of co-occurring physical illnesses. Similarly, coping with numerous barriers to full participation in society can adversely affect the mental health of people with disabilities.

Thus, access to Medicaid coverage is crucial for people with disabilities and complex or serious health conditions. To preserve Medicaid, CMS must provide states with guidance to ensure this population is exempt from community engagement requirements as required by law. H.R. 1 mandates that individuals in any of the following categories for medically frail are exempt:

- blind or disabled (as defined in Section 1614 of the Social Security Act)
- with a physical, intellectual, or developmental disability that significantly impairs their ability to perform one or more activities of daily living (ADLs)
- with an SUD or a disabling mental disorder
- with a serious or complex medical condition<sup>8</sup>

Given the breadth of and variation within these groups, we urge CMS to adopt the following recommendations:

CMS should ensure states are applying a comprehensive definition of medically frail consistent with the statute. Disabilities and health conditions are highly varied and complicated, making it hard to define. Terms like “disabling mental disorder,” “substance use disorder,” and “serious or complex medical condition” should be defined broadly to reflect the chronic, fluctuating nature of disabilities and other health conditions. States should also be permitted to use a variety of methods to identify an individual who meets the medically frail exemption, promoting both the simplicity of administration and the best interests of the Medicaid enrollee.

What constitutes assistance with ADLs is also very broad. Hands-on assistance is just one way to assist with performing ADLs. Guidance should specify that the medically frail exemption is not limited to individuals who need hands-on assistance, but also those who need cueing, reminders, supervisory help, or other assistance to perform ADLs. Relatedly, many people with disabilities need assistance with instrumental activities of daily living (IADLs), such as communicating, managing medications, and accessing transportation. Health and functional limitations should not be limited to ADLs to qualify for the exemption.

Although some medically frail individuals may have a work history, CMS should clarify that states may not use ability or inability to work as criteria for the medically frail exemption, such

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<sup>6</sup> Momen, N. C., Plana-Ripoll, O., Agerbo, E., Benros, M. E., Børghlum, A. D., Christensen, M. K., Dalsgaard, S., Degenhardt, L., de Jonge, P., Debost, J.-C. P. G., Fenger-Grøn, M., Gunn, J. M., Iburg, K. M., Kessing, L. V., Kessler, R. C., Laursen, T. M., Lim, C. C. W., Mors, O., Mortensen, P. B., . . . McGrath, J. (2020). Association between mental disorders and subsequent medical conditions. *New England Journal of Medicine*, 382(18), 1721–1731. <https://doi.org/10.1056/NEJMoa1915784>

<sup>7</sup> American Addiction Centers. (2025). *Health risks of substance abuse*. <https://americanaddictioncenters.org/health-complications-addiction>

<sup>8</sup> An act to provide for reconciliation pursuant to title II of H. Con. Res. 14. Pub. L. No. 119- 21, § 71119, 139 Stat. 72, 312 (2025) (codified at 42 U.S.C. § 1396a(xx)(9)(A)(ii)(V)).

as by requiring an individual to attest or otherwise prove they are unable to work or by using an individual's past or current work status to disqualify them from exemption. Notably, H.R. 1 referenced the Social Security definition of disability, which uses the inability to work "substantial gainful activity" as the criteria, as just one category for the medically frail exemption. All the other categories make no reference to inability to work. Requiring individuals to attest to their inability to work not only is inconsistent with the statute, but also disincentivizes enrollees from even attempting to work. Further, an enrollee who meets the medically frail exemption should receive such exemption even if they are working. As previously stated, the exemption is based on the functional or health status of the beneficiary. States may have access to payroll or other data showing an exempt individual is employed, but that information is moot if the person meets the criteria for medically frail.

States should streamline the redetermination process by allowing individuals who have already been identified as medically exempt to simply attest that their circumstances remain unchanged, rather than requiring new documentation at every renewal. They should also adopt regulations that ensure individuals are screened for all applicable exemptions and granted the longest-lasting one. In addition, CMS should facilitate the ability of states to incorporate short-term hardship exceptions, consistent with those outlined in H.R. 1, for people who must leave their community for extended periods to receive inpatient hospital care, nursing facility services, intermediate care for individuals with intellectual disabilities, inpatient psychiatric treatment, or other services of comparable acuity, including community-based alternatives such as Assertive Community Treatment, mobile crisis services, inpatient substance use disorder treatment, and Psychiatric Residential Treatment Facilities. States adopting these hardship exceptions should also establish processes to ensure that individuals experiencing such circumstances are automatically evaluated for—and, when appropriate, transitioned into—exemptions for those who are medically frail or have other special medical needs.

## **Family Caregivers**

Family caregiver exemptions must be consistent with the RAISE Act definition and not depend on documentation unavailable to most individuals.

There are more than 63 million caregivers providing essential care and support, with that number continuing to rise as the population ages.<sup>9</sup> Family caregivers play an essential role in helping older adults and people with disabilities and other health conditions live safely in their homes and communities. Without these caregivers' support, many individuals would face unnecessary institutionalization, higher healthcare costs, and a significant loss of independence.<sup>10</sup> Since family caregivers supply essential—and, usually, unpaid—labor, they must not be subject to an onerous or complicated exemption process. There is no single,

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<sup>9</sup> AARP Public Policy Institute & National Alliance for Caregiving. (2025). *Caregiving in the United States 2025*. <https://www.aarp.org/content/dam/aarp/ppi/topics/ltss/family-caregiving/caregiving-in-us-2025.doi.10.26419-2fppi.00373.001.pdf>

<sup>10</sup> National Academies of Sciences, Engineering, and Medicine. (2016). *Families caring for an aging America* [Consensus study report]. <https://www.nationalacademies.org/publications/23606> (Citation from pp. 185–186)

integrated system for identifying or certifying someone as a caregiver. Imposing complicated paperwork requirements or demanding documentation caregivers are unlikely to possess undermines the very support structure they provide and heightens the risk that both the caregiver and the person receiving care will lose access to care.

H.R. 1 exempts family caregivers from community engagement requirements and explicitly adopts the RAISE Family Caregivers Act definition of family caregiver: “any adult with a significant relationship to a person with a chronic condition, disability, or functional limitation who provides a broad range of assistance.”<sup>11</sup> This definition does not limit caregiving to parents of minor children or spouses caring for partners, but includes adult children supporting aging parents, neighbors helping friends with mobility limitations, and individuals providing ongoing assistance to loved ones who may not have a formal diagnosis or may not identify as disabled. Congress deliberately added this inclusive definition for purposes of this exemption. Any additional limits on the definition of “family caregiver” for the purposes of determining eligibility for the work requirement exemption directly violates the statute and Congress’ clear intent.

Receiving this exemption should also not depend on the individual’s specific identification as a “caregiver.” Many family caregivers meet the RAISE Act definition but, given the informal and intimate nature of caregiving, may not identify themselves “caregivers.” One study found more than a quarter of individuals identified with caregiving tasks but did not identify as a caregiver.<sup>12</sup> Rather, many caregivers perceive themselves simply as helping their loved one, though they still experience the same stress and challenges as self-identified caregivers.<sup>13</sup> If states were to rely on narrow screening questions or assume that only people who self-identify as caregivers qualify, many eligible caregivers would be missed. Therefore, federal guidance should require states to use the RAISE Act definition consistently across all exemption policies, screening tools, outreach materials, and notices. States should not be permitted to impose restrictions, such as requiring a formal disability determination, a legal or familial relationship, or a minimum number of caregiving hours, to qualify for the exemption.

Whenever possible, caregivers should first have their caregiving exemption status verified ex parte through existing data sources particularly in Medicaid and other related public benefit programs. For example, some family caregivers may be paid through the state Medicaid Home- and Community-Based Services (HCBS) program. In that case, the state has accurate data showing the individual’s caregiving status and should grant the exemption through ex parte

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<sup>11</sup> Pub. L. 119-21, § 71119(xx)(9)(A)(ii)(III).

<sup>12</sup> Harrington, E., & McInturff, B. (2021). *Working while caring: A national survey of caregiver stress in the U.S.* [Key findings]. Rosalynn Carter Institute for Caregivers. <https://rosalynncarter.org/wp-content/uploads/2021/09/210140-RCI-National-Surveys-Executive-Summary-Update-9.22.21.pdf>

<sup>13</sup> Harrington & McInturff (RCI), 2021.

review without requiring the individual to submit additional verification. Caregiver data may be available ex parte through caregiver support programs or state caregiver tax credits.<sup>14</sup>

Although ex parte review is crucial, many caregivers do not appear in existing data sources, in which case the state should accept self-attestation when ex parte review is insufficient. H.R. 1 allows states to accept self-attestation - which states already use to verify Medicaid eligibility<sup>15</sup> - to show eligibility for an exemption.<sup>16</sup> Most family caregivers do not have formal documentation, payroll data, or other information that would be easily captured in any database. Requiring caregivers to provide non-existent documentation of their caregiving duties defeats the purpose of the exemption. Federal guidance should make clear that self-attestation of caregiving is sufficient. States should not require medical records, letters from providers, or proof of caregiving hours. These requirements are inconsistent with the statute and would create barriers that Congress explicitly sought to avoid.

Advocates have expressed concern that states may attempt to deny exemptions by taking the position that someone who is working or appears able to work cannot be a family caregiver and does not qualify for the exemption. Approximately 70 percent of working-age caregivers are employed while also providing care.<sup>17</sup> They may work only a few hours, have a flexible schedule, or an otherwise accommodating employer that enables them to work while caregiving. Crucially, H.R. 1 does not condition the caregiving exemption on a caregiver's inability to work and federal guidance must explicitly prohibit states from using payroll data, employment records, or assumptions about "ability to work" to deny exemptions. If an individual meets the statutory definition of "family caregiver" or any other exemption, they qualify *regardless* of employment status. Further, states should apply exemptions whenever they are applicable, even if the individual also meets community engagement requirements, because employment does not eliminate caregiving responsibilities. Requiring exempt individuals to complete ongoing reporting would undermine the purpose of the exemption and increase the risk of wrongful coverage loss.

## **Direct Care Workers**

Reporting requirements for home care and other direct care workers must reflect the realities of their lives and the work they do.

While the majority of care for older adults and people with disabilities and other health conditions is provided by unpaid family members and friends, direct care workers play an

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<sup>14</sup> Hado, E., & Flinn, B. (2026). *States can ensure continuity of coverage for family caregivers in Medicaid community engagement requirements* [Spotlight]. AARP Public Policy Institute. <https://www.aarp.org/content/dam/aarp/ppi/topics/health/coverage-access/states-coverage-family-caregivers-medicaid-community-engagement-requirements.doi.10.26419-2fppi.00391.001.pdf>

<sup>15</sup> Centers for Medicare & Medicaid Services. (n.d.). Medicaid/CHIP eligibility verification plans. Retrieved February 11, 2026, from <https://www.medicaid.gov/medicaid/eligibility-policy/medicaid/chip-eligibility-verification-plans>

<sup>16</sup> 42 U.S.C. 1396a(xx)(3)(A).

<sup>17</sup> AARP & National Alliance for Caregiving. (2025). *Caregiving in the U.S.: Research report*. <https://www.caregivingintheus.org/app/uploads/2026/02/Final-2025-CGUS-Report-1.pdf>

extremely important role in ensuring access to care for people who need it. Direct care workers include home care workers (e.g., personal care and home health aides), residential care aides, and nursing assistants in nursing homes. Analyses of workforce data by PHI show that home care workers make up a large majority of this workforce, with approximately 3.2 million home care workers providing essential support that allows older adults and people with disabilities to remain in their homes and communities.<sup>18</sup> Other direct care workers play a critical role in ensuring the safety of people receiving care in nursing homes and other residential settings. Low wages for this workforce mean that many direct care workers rely on public benefits, including Medicaid. For instance, nearly half of home care workers rely on public health care programs, typically Medicaid.<sup>19</sup> Personal care aides make up the second largest occupation group among adults enrolled in Medicaid without children, the group targeted by community engagement requirements.<sup>20</sup>

The nature of home care and other direct care work is likely to create special challenges for compliance with work requirement rules—despite the fact that these workers spend hours providing essential care. For instance, the individualized needs of older adults and people with disabilities requires workers to be flexible, often resulting in fluctuating work hours and unpredictable schedules that could impact their ability to meet the work reporting requirements in a particular month. A worker’s client may enter the hospital or die, leading to a period of a few weeks or longer with no work hours, even though the worker intends to resume work. These variations do not reflect a lack of engagement but rather the nature of the work itself. Likewise, the prevalence of workplace injuries among direct care workers—who have among the highest occupational injury<sup>21</sup>—means that workers may need to take time off from work to recover from an injury. While the law does include special reporting rules for seasonal employees, direct care workers are unlikely to fit in that category. Thus, any reporting system that assumes stable, full-time, or predictable employment will inevitably harm direct care workers by putting this crucial workforce at risk of losing coverage.

In addition to the unstable nature of their work, direct care workers may experience other circumstances that should be taken into account when implementing these new requirements. 85 percent are women, who typically have multiple care obligations.<sup>22</sup> Indeed nearly 30 percent of home care workers have a child under 18.<sup>23</sup> The average age for home care workers is 48,<sup>24</sup>

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<sup>18</sup> PHI. (2025). *Direct care workers in the United States: Key facts 2025* [Report].

<https://www.phinational.org/resource/direct-care-workers-in-the-united-states-key-facts-2025/>

<sup>19</sup> PHI. (2025). *Direct care workers in the United States: Key facts 2025* [Report].

<https://www.phinational.org/resource/direct-care-workers-in-the-united-states-key-facts-2025/>

<sup>20</sup> Zhang, E. (2025). *Workers in a broad range of occupations at risk of having their coverage taken away* [Research note]. Center on Budget and Policy Priorities. <https://www.cbpp.org/research/health/workers-in-broad-range-of-occupations-at-risk-of-having-their-coverage-taken-away>

<sup>21</sup> Campbell, S. (2018). *Workplace injuries and the direct care workforce* [Issue brief]. PHI.

<https://www.phinational.org/wp-content/uploads/2018/04/Workplace-Injuries-and-DCW-PHI-2018.pdf>

<sup>22</sup> PHI. (2025). *Direct care workers in the United States: Key facts 2025* [Report].

<https://www.phinational.org/resource/direct-care-workers-in-the-united-states-key-facts-2025/>

<sup>23</sup> PHI, 2025.

<sup>24</sup> PHI, 2025.

meaning they belong to a "sandwich generation" caring for both minor children and aging parents.<sup>25</sup> As noted above, some paid workers may actually be providing care to a relative in a Medicaid HCBS program. These realities underscore the need for targeted policy responses to ensure this population does not lose Medicaid coverage.

All direct care workers who are eligible for a family caregiver exemption should be able to easily receive one, including through self-attestation. This exemption must be accessible to both paid family caregivers and paid caregivers who are providing care for a non-family member but have other caregiving obligations. As discussed above, employment should never be used to disqualify someone from an exemption they otherwise meet.

In the case of direct care workers who do not qualify for an exemption and must comply with reporting requirements, states should develop a robust system for implementing the law's requirements for ex parte verification of compliance as the default, and future guidance and regulations should ensure that states use the full range of data sources that are available. Medicaid is the primary payer for home care, meaning that state Medicaid programs themselves can be a source of this data. Approximately 1.5 million home care workers work as independent providers in self-directed HCBS programs<sup>26</sup> and are paid directly by the state, typically through a fiscal intermediary with which the state contracts, information states can easily tap to verify whether workers meet the law's income or work hour thresholds. Likewise, the fact that states have implemented the 21st Century Cures Act (2016) requirement for implementation of Electronic Visit Verification systems to track home care visits points to another source of data for ex parte verification.<sup>27,28</sup>

When ex parte verification is not possible, systems should be designed to facilitate reporting, without requiring frequent online reporting or complex documentation. Direct care workers often work for multiple agencies or serve multiple clients, making it difficult to gather and submit pay stubs in a given month. They may also participate in training or other continuing education programs in addition to their paid work. Workers who meet the income threshold

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<sup>25</sup> Caldera, S. (2023). A closer look at sandwich generation caregivers of Medicare beneficiaries. *Insight on the Issues*. AARP Public Policy Foundation. <https://www.aarp.org/content/dam/aarp/ppi/topics/ltss/family-caregiving/closer-look-sandwich-generation-caregivers-of-medicare-beneficiaries.doi.10.26419-2fppi.00215.001.pdf>

<sup>26</sup> PHI. (2025). *Direct care workers in the United States: Key facts 2025* [Report].

<https://www.phinational.org/resource/direct-care-workers-in-the-united-states-key-facts-2025/>

<sup>27</sup> 21st Century Cures Act, Pub. L. 114-255, 130 Stat. 1275, § 12066 (2016).

<sup>28</sup> Centers for Medicare & Medicaid Services. (n.d.). *EVV compliance status for personal care services by state or territory*. Retrieved February 11, 2026, from <https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-guidance-additional-resources/electronic-visit-verification/evv-compliance-status-for-personal-care-services-state-or-territory>

should not need to report work hours, and states should facilitate reporting of income, such as through consent-based verification.<sup>29</sup>

As discussed above, while direct care workers are unlikely to meet the definition of seasonal employees, the generally unstable nature of their work presents similar challenges. Future federal guidance must ensure reporting requirements accommodate these fluctuations rather than penalize them. States should be able to employ flexible lookback and reporting windows so that workers are not disenrolled simply because their hours temporarily fall below the threshold due to circumstances beyond their control.

### **Additional Recommendations**

As stated above, states should maximize the use of ex parte verification when possible, and if not possible, then beneficiaries must be able to report their activities with minimal burden. Individuals who qualify for exemptions should receive them regardless of employment; likewise, CMS should support states by issuing detailed guidance and providing ongoing technical assistance with the input and involvement of beneficiaries, including Medicaid Advisory Committees. States must also monitor and report how community engagement requirements affect coverage continuity, exemption requirements, and access to care for people with disabilities, older adults, family caregivers, and direct care workers. Such data should then be used to inform policy that protects coverage and service access for vulnerable groups.

### **Conclusion**

Medicaid coverage is essential for all people who live with MH conditions, SUDs, and disabilities, especially those in the 50–64 age group. Likewise, paid and unpaid caregivers are vital to the health, safety, and dignity of older adults and people with disabilities. We strongly encourage the administration to issue guidance protecting these individuals in these groups from improper and detrimental coverage loss. If you have any questions, please contact Gelila Selassie at [gselassie@justiceinaging.org](mailto:gselassie@justiceinaging.org). Thank you for your time and consideration.

Respectfully,

AFL-CIO

AFT: Education, Healthcare, Public Services

Aging Life Care Association

Alliance for Retired Americans

American Federation of State, County and Municipal Employees (AFSCME)

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<sup>29</sup> Wagner, V., Singleton, S., & Stewart, M. (2025). *A guide to reducing coverage losses through effective implementation of Medicaid's new work requirement* [Report]. Center on Budget and Policy Priorities. <https://www.cbpp.org/research/health/a-guide-to-reducing-coverage-losses-through-effective-implementation-of-medic aids>

American Geriatrics Society  
APWU Retirees Department  
B'nai B'rith International  
Center for Medicare Advocacy  
Community Catalyst  
Compassion & Choices  
Gerontological Society of America  
International Association for Indigenous Aging  
Justice in Aging  
LeadingAge  
Medicare Rights Center  
National Academy of Elder Law Attorneys (NAELA)  
National Active and Retired Federal Employees Association (NARFE)  
National Adult Day Services Association  
National Adult Protective Services Association  
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