

## Allies for Independence Washington Insights

**Week of July 10, 2023**

### CAPITOL HILL UPDATE

Congress is back in session for the balance of this month with several items to move forward before the August recess. Many of these issues have deadlines at the end of September while some reflect rare bipartisan areas of interest.

The Senate Finance Committee is preparing to advance several pharmacy benefit manager (PBM) related bills, which could ultimately be packaged with other Senate PBM bills or a select number of House bills to rein in PBMs. Stakeholders are anxiously awaiting more details from the Senate HELP committee on a health workforce package, but the first major action on this may be a markup in the House Energy & Commerce Committee. Several health workforce programs expire at the end of September and Congress is aiming to reauthorize those programs, with targeted funding for new initiatives to improve recruitment and retention.

In the House, key health care committees are working to advance several reauthorizations, including the Pandemic and All Hazards Preparedness Act (PAHPA) and the Substance Use-Disorder Prevention that Promotes Opioid Recovery and Treatment (SUPPORT) for Patients and Communities Reauthorization Act. There is also important work that must be done on the Farm Bill and the National Defense Authorization Act (NDAA).

Completing FY24 appropriations will be the biggest test for Congress given the different approaches to FY24 spending by House Republicans and Senate Democrats. Given the lack of progress and time crunch, we are almost certainly heading for a continuing resolution to the end of the calendar year, to provide time for lawmakers to work through these differences and pass a bipartisan package. The House is seeking to make roughly \$120B in cuts to FY24 spending.

This all forecasts a difficult road ahead for stakeholders, especially those who depend on appropriations-related spending. With the 2024 election on the horizon, the balance of this year could be the best shot of advancing issues until after the election. We are closely monitoring these issues and encourage you to reach out with questions.

## **ON THE RADAR**

### **Medicaid Access Rule Comment Period Ends**

The comment period for the highly anticipated “Ensuring Access to Medicaid Services” rule closed last week. There are several proposals that will be widely supported by stakeholders if they are finalized. However, one such provision requires that at least 80% of Medicaid payments for personal care, homemaker, and home health aide services must be spent on compensation for direct care workers. CMS cites the need to increase the overall direct care workforce as its goal of the proposal.

This proposed “80/20” rule has received mixed support from stakeholders submitting comments. Proponents of the proposal say it is necessary to address workforce shortages and improve the quality of care. Other stakeholders, who strongly support increased pay for direct care workers, expressed concern that having a fixed 80% threshold could lead to many providers going out of business. Other stakeholders suggested there could be exceptions to the 80% threshold based on a variety of factors, such as size, rural/urban status, risk of closure, and other factors.

We will continue to monitor the status of this proposal and the larger rule, which could be finalized later this year.

### **FDA Grants Full Approval to Alzheimer’s Drug Leqembi**

The Food and Drug Administration (FDA) recent granted full approval for Leqembi, an Alzheimer’s drug that modestly slows cognitive decline for patients in the early stages of Alzheimer’s. The approval came with a “black box warning” that in rare cases the drug can cause serious and life-threatening events which could be fatal.

Medicare is expected to cover 80 percent of the \$26,500 cost of Leqembi if enrollees are diagnosed with mild cognitive impairment or mild Alzheimer’s dementia, with evidence of beta amyloid plaque on the brain and have a provider who participates in a CMS registry, a qualifying alternative registry, or a clinical study. Some experts say that this coverage will still lead to unaffordability for some because the 20 percent remaining is still over \$6,500 annually and other costs, such as brain scans and other related medical visits, could run the cost of treatment to around \$90,000 a year.

CMS stated that Leqembi will be covered but CMS is still going to continue to gather data to help gain more understanding on how the drug works. Reception of this registry requirement has been mixed due to the lack of clarity and arguments that access will be limited. That said, the collection of data and access to this new drug could help aging Americans and caregivers confront the challenges of Alzheimer’s when few other therapies exist.

### **Senate Veterans Affairs Considers Long-Term Care Pilot for Veterans**

The Senate Committee on Veterans Affairs is considering legislation this week that would test models for delivery of long-term care services for eligible veterans. The legislation, Expanding Veterans’ Options for Long Term Care Act, would create a pilot program for eligible veterans to receive assisted living care paid for by the VA. Currently, the VA is restricted from paying room and board fees at assisted living facilities.

The pilot program would be conducted at six Veterans Integrated Services Networks (VISNs) nationwide, including at least two program sites located in rural or highly rural areas and two State Veterans Homes. If passed, it would be a notable advancement of long-term care issues, even if the proposal is modest in its scope.

### **Nursing Homes Urge CMS to Increase Nursing Home Reimbursements**

CMS is working to finalize the annual nursing home payment rule and nursing homes advocates are urging CMS to increase reimbursement rates.

Skilled nursing facilities (SNFs) are projected to see an overall increase of \$1.2 billion under the proposed rule but advocates worry that staffing minimums will cost up to \$10B. Commissioners on the Medicare Payment Advisory Committee (MedPAC) also worry about funding as they stated in September that the nursing home sector would need additional funding to handle the federal staffing minimums in addition to guidance on how to best use current funds. The concern is that if there is inadequate reimbursement it will be harder for nursing homes to attract and retain workers which could negatively impact residents or be a barrier to accessing services.

### **ICYMI! The Independent Life Presents “Self-Directed Home Care with Mark Altieri”**

Self-Direction. Participant-Direction. Consumer-Direction. Regardless of what it is called in your state, these phrases represent a long term-care option for Medicaid eligible individuals and their families that puts them in control. If you or a loved one is an individual with disabilities, chronically ill, or simply aging, self-directed home care is your alternative for supporting you in performing everyday activities.

Mark Altieri works passionately to empower people who have chosen to remain independent in their homes and active within their communities. He talks about the services that his organization Public Partnerships offers, ranging from helping people navigate through complex systems of eligibility, enrolling people into the services they need, providing homecare services, and helping people to live an independent life.

This podcast, hosted by Tony Delisle, can be found where you listen to podcasts. If you use Apple, please [click here](#). For Spotify, [click here](#)!

### **ISSUE OF THE WEEK: Washington State Republicans Push Back on Long-Term Initiative**

A growing number of Washington State Republicans oppose the state’s long-term care program: The WA Cares Fund. In 2019, the Washington legislature created the program which will allow people to access up to \$36,500 to pay for help with basic needs like food, mobility, such as wheelchairs or scooters, home modifications, and hygiene as they age. The program is funded through premiums paid by employees through a 0.58% payroll tax.

Recently, Senior Republicans in the legislature believe any resident should be able to opt out of the tax. Currently, those with private long-term insurance plans do not have to pay the tax. However, proponents of the program argue that allowing the tax to be option would harm the program long-term.

Stakeholders are closely watching this program and whether efforts to make the tax optional succeed. Benefits will begin for eligible employees on January 1, 2025.

## **ON THE HORIZON**

### **HUD is Seeking to Update Section 504 Disability Rules**

The US Department of Housing and Urban Development is seeking comments on potential changes to its regulations implementing Section 504 of the Rehabilitation Act of 1973. Section 504 prohibits discrimination based on disability by federally administered or financed programs. The Advanced Notice of Proposed Rulemaking (ANPRM) is linked [here](#).

Comments are due July 24 and can be submitted by [clicking here](#).

### **HCBS Webinar: Getting the Services You Need from the Waiver – Safeguards**

On July 13, the Administration for Community Living (ACL) is hosting a webinar titled, “Strengthening Advocacy in the Home and Community-Based Services (HCBS) Settings Rule.” The webinar will review Appendix G – Safeguards in the HCBS Waiver application and the protections this appendix provides for participants. The presentation will cover the part of the waiver application where the state outlines its process for responding to critical incidents, safeguards it has in place around the use of restraints and seclusion, and its protocols for medication management, if applicable. The webinar will also cover how stakeholders can have an impact on the application and why the protections outlined in Appendix G are important.

A video replay and transcript will be made available following the event on ACL's [HCBS Settings Rule webpage](#).

### **Funding Opportunity on Employment for People with Disabilities**

The Social Security Administration (SSA) announced a new funding opportunity for conducting interventional research to support its programs. They are seeking applications to be conducted across five priority areas:

- Eliminating the structural barriers for people with disabilities in the labor market, particularly for people of color and other underserved communities, that increase the likelihood of people receiving or applying for Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI).
- Increasing employment and self-sufficiency of individuals with disabilities, including people of color and underserved communities (whether beneficiaries, applicants, or potential applicants of the SSDI or SSI programs).
- Coordinating planning between private and public human services agencies to improve the administration and effectiveness of the SSDI, SSI, and related programs.
- Assisting claimants in underserved communities to apply for or appeal decisions on claims for SSDI and SSI benefits.
- Conducting outreach to people with disabilities who are potentially eligible to receive SSI.

Applications for this funding opportunity are due by July 31. For more information, please [click here](#).

## **RECOMMENDED READS**

- *Roll Call* – [Biden’s long-term care agenda faces headwinds](#)
  - *Siouxland Proud* – [Difficulties of finding long-term care facilities in Iowa](#)
  - *The New York Times* - [As Cases Soar, ‘Dementia Villages’ Look Like the Future of Home Care](#)
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