

ADDRESSING FRAUD, WASTE, AND ABUSE IN MEDICAID'S HCBS

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Preserving the Integrity of President Reagan's Home- and Community-Based Services (HCBS) System by Addressing Fraud, Waste & Abuse

Background & Policy Recommendations

SUMMARY

Medicaid was created in 1965 as a joint federal-state program to ensure that Americans who were poor, elderly, or disabled had access to health care. It was designed as a health safety net so that vulnerable Americans would not be left without medical support.

For Americans with disabilities, however, Medicaid's early design came with a serious limitation. The program was built around an institutional model of care. This meant long-term services and care support were provided in institutional settings rather than in a person's own home or community. People with disabilities usually had to leave behind family, work, independence, and the rhythms of ordinary life in order to receive the care they needed. That robbed people of true dignity.

The **Medicaid Home- and Community-Based Services (HCBS)** program was created to correct that imbalance. Congress added the section 1915(c) HCBS waiver authority in 1981, and Medicaid's HCBS pathway became available in 1983, giving states the option to provide long-term services in home and community settings as an alternative to institutional care. The animating idea was both practical and humane: People with disabilities and older Americans should be able to receive needed care in the places where life actually happens, not be forced into institutions simply because that is how the funding system was structured.

Today, with recent high-profile fraud cases across the social safety programs, the **Centers for Medicare and Medicaid Services (CMS)** is scrutinizing states with spending outlays dramatically out of sync with other states. In 2026, CMS initiated investigations into Medicaid fraud in Minnesota,¹ Maine,² California,³ and New York.⁴ CMS initiated an accelerated process to withhold federal funds from Minnesota because the "Minnesota Medicaid agency fails to adequately identify, prevent, and address fraud, waste, and abuse (FWA) in its Medicaid program."⁵ In March 2026, the state of Minnesota sued CMS for deferring \$243 million in federal matching funds.⁶

Fraud, waste, and abuse are unacceptable in Medicaid, the health insurance for our most vulnerable populations. It's vital to protect the Americans who often bear the harms of fraudulent activity in Medicaid: those with significant support needs.

Waste, Fraud, and Abuse Aren't Just Budget Problems — They're Human Ones.

KEY TAKEAWAYS

- The Medicaid Home- and Community-Based Services (HCBS) program was created by President Ronald Reagan to allow people to receive needed caregiving services in the places where life actually happens, not be forced into institutions.
- Fraud, waste, and abuse are unacceptable in Medicaid HCBS for our most vulnerable populations. This paper provides 6 areas to address to make the program more successful and less susceptible to exploitation.
- Families and people with disabilities should not become collateral damage in the crackdown on fraudsters.

IN THIS REPORT

- ✓ Why Individuals With Disabilities Need Home- and Community-Based Services (HCBS)
- ✓ Why Medicaid's HCBS is Vulnerable to Fraud, Waste, and Abuse
- ✓ How to Prevent Fraud While Protecting and Improving Vital HCBS Services for America's Most Vulnerable



Continued on page 2



President Ronald Reagan embraces young Katie Beckett as he greets her parents. (Photo courtesy of the Ronald Reagan Library)

Presidential Intervention and a Supreme Court Decision

To understand why home- and community-based care matters to individuals with high needs, you should know about Katie Beckett.

Katie contracted viral encephalitis, an inflammation of the brain, when she was four months old. It partially paralyzed her and meant that she required a ventilator to breathe.⁷ Because she was born in 1978, Medicaid rules dictated that she would have to live apart from her family. Katie's case made national news because she was living in an Iowa hospital — not because there were no other viable care options — but because Medicaid would only pay for her care in an institution, not at home.

In 1981, President Reagan publicly intervened after learning about Katie's situation and directed federal agencies to find a better solution. That same year, Congress enacted the Omnibus Budget Reconciliation Act of 1981 (OBRA 1981) that allowed states to apply for waivers to use Medicaid dollars for HCBS.

This waiver option, in addition to the landmark 1999 Supreme Court civil rights decision in *Olmstead v. L.C.*, which found that unjustified institutionalization of individuals with disabilities constitutes illegal discrimination, marked a turning point in how Medicaid cared for individuals with disabilities. The Supreme Court's decision established that unnecessary institutionalization of individuals with disabilities constitutes discrimination under the Americans with Disabilities Act (ADA).

The Court held that individuals with disabilities have the right to receive services in the most integrated setting appropriate to their needs — meaning in their homes and communities whenever possible, rather than in institutions.

Over time, federal regulators have translated the *Olmstead* mandate into operational requirements for Medicaid HCBS programs. The HCBS Final Settings Rule (2014) established clear standards for what qualifies as a "community-based" setting. It requires that HCBS services:

- ✓ Are delivered in settings integrated into the broader community
- ✓ Support individual choice and autonomy
- ✓ Ensure access to employment, community life, and personal decision-making
- ✓ Avoid institutional characteristics, even in non-institutional settings

Continued from page 1

The recent CMS investigations highlight state spending on home-based personal care services and behavioral-based intervention care. Many of these services fall under the category of Home- and Community-Based Services (HCBS), the largest source of care for individuals with disabilities.

There is typically great inefficiency in state HCBS program administration, which has layers of vendors or consultants on contracts with states to manage eligibility, financial reimbursements, and care.

This has led to a lack of state oversight of HCBS intermediaries and providers. In addition to the lack of oversight, individuals with disabilities and their families must navigate this maze of contractors, compliance, and eligibility redeterminations year after year.

This paper explains what HCBS is and why it matters for individuals with disabilities. It also examines, with clear examples, how fraud, waste, and abuse have taken root. Finally, it proposes six clear reforms policymakers should implement to rein in fraud, waste, and abuse in this vital program that makes life for millions of Americans more humane and dignified.

The six recommended reforms for policymakers:

- 1) **Create Transparency to Prevent Fraud, Waste, and Abuse**
- 2) **Increase CMS Oversight of State Waste**
- 3) **Establish Consistent Fraud Detection Systems**
- 4) **Empower Recipients to Direct Their Own Care**
- 5) **Measure and Report Outcomes**
- 6) **Ensure Integrity of Third-Party Providers**

How HCBS Is Covered Under Medicaid

One-third of all Medicaid spending is dedicated to long-term supports and services (LTSS), long-term help with functioning and daily living, whether that help is delivered in an institution or in the community.

Institutional nursing care is “mandatorily” covered under state Medicaid programs. States also must mandatorily cover nursing and home health benefits, like home aides.

Home- and community-based services (HCBS) are optional services under Medicaid. The main pathway by which states request federal permission to provide in-home services is through the 1915(c) waiver. It provides federal reimbursement for states to provide a targeted set of services for individuals who would otherwise require institutional care. It must be cost-neutral to the federal government. Nearly half of all HCBS expenditures are through 1915(c) waivers.⁸

All states have an HCBS program because it costs the federal government less than institutional care and people with disabilities prefer it.

Under these state HCBS programs, states — through specific waivers like Intellectual & Developmental Disabilities (IDD), Physical Disability (PD), and Brain Injury, to name a few — provide and pay for services to support people with disabilities. These services are normally not available through private, commercially available health insurance. They can include:

- ✓ **Personal care / attendant services**
Help with activities of daily living (bathing, dressing, meals, household tasks)
- ✓ **Residential supports**
Group homes, supported living, host homes, and staff support tied to housing
- ✓ **Day and employment services**
Day programs, supported employment, and job coaching
- ✓ **Respite care**
Short-term relief for family and unpaid caregivers
- ✓ **Behavioral and clinical supports**
Therapy, behavior supports, and crisis intervention
- ✓ **Case management / service coordination**
Assessment, planning, and coordination of services
- ✓ **Home and vehicle modifications**
Ramps, accessible bathrooms, vehicle adaptations

✓ **Assistive technology**

Communication devices, adaptive equipment, and supportive tech systems

States can also deliver HCBS services through their Medicaid state plans for additional populations beyond those who qualify for institutional care:

✓ **1115 Waiver**

States can opt to provide HCBS services through their 1115 waivers, which also must be cost-neutral. Historically, they have not always been so, but as of 2027, CMS will be required to ensure every 1115 approval or reapproval is strictly cost-neutral.⁹

✓ **“State Plan” 1905(a)(24)**

The state plan includes personal care benefits.

✓ **“State Plan HCBS” 1915(i)**

States can submit a waiver to provide HCBS services for individuals who would not qualify for institutional care.

✓ **“Self-Directed Services” 1915(j)**

Covered individuals are able to hire and self-direct their personal care services, including family members and spouses.

✓ **“Community First Choice” 1915(k)**

An enhanced federal match is provided for personal attendant services.

Why Individuals With Disabilities Need Home- and Community-Based Services (HCBS)

Many Americans with disabilities require assistance to participate in daily life: an older adult with Parkinson’s who needs assistance to dress or prepare meals, a young adult with a developmental disability who needs assistance with bathing and dressing, or a child like Katie Beckett with complex medical needs requiring 24/7 nursing support to remain with her family.

People with disabilities, when given access to the supports they choose, live independently, build full lives with their families and friends, contribute through work, and fully participate in their communities.

Private or employer-sponsored health insurance does not cover this level of care, so families are reliant upon both Medicaid and an HCBS waiver for combined health care and daily support.

Family Caregiving Options

The role family caregiving plays in the lives of individuals with disabilities is important, particularly for individuals with intellectual disabilities. The average family member spends between 20-27 hours per week caring for their loved ones.¹⁰

In rural areas, a family caregiver may be the only option. All forms of caregiving should be options as the population ages and the caregiving workforce constricts.

All 50 states have some form of an HCBS waiver that allows for paid family caregiving at various levels of allowable paid hours and rates. Due to high demand and relatively scarce resources for caregiving, states' lowering of eligibility for paid family caregiving can sometimes create a direct financial incentive to claim and deliver those services.

If eligibility is lax, it can substantially increase enrollment, utilization, and program costs, while making oversight more difficult because care occurs inside the home and is often harder to verify independently.

Waiver Waitlists

Because HCBS operates as a state option, states can utilize waitlists to ration high-cost services. States have complete autonomy on how they operationalize a "waitlist." Some states operate it as a "first-come, first-serve" list with no priority given to severity of need, and other states tier their waitlists by level of need and prioritize crisis situations.

Some states screen for the level of care needed before putting individuals on the waitlist, while others conduct no screening. Many states provide no publicly available information about where an individual is on the waitlist, leaving families in the dark about how

long they will be waiting. Since 2016, the number of individuals on state waitlists has flexed around 700,000, with an average wait of 40 months.¹¹ State waitlists are primarily made up of individuals with intellectual or developmental disabilities.¹²

Because states choose the services and populations served through their HCBS waivers, the waitlists are not always comparing apples to apples. For instance, more than half of current waitlists are states that do not screen for eligibility before adding individuals to waitlists.¹³

Other states may not have waitlists, but also do not have providers available for the services covered under their HCBS waiver, creating a hidden waitlist. In 2024, CMS issued a final rule requiring states to more transparently report their waitlists by 2027.¹⁴

The Taxpayer Cost Savings of HCBS vs. Institutional Care

For most of the 8.4 million HCBS participants, the alternative to their HCBS care is institutional care, care received in a nursing home or hospital.¹⁵

HCBS is less than one-third the cost of institutional care. Institutional care is inherently more expensive, requiring round-the-clock care, usually by health professionals in an advanced clinical role. Thus, individuals who require institutional care may be inherently more expensive than HCBS users with fewer needs.

HCBS is less than one-third the cost of institutional care.

For the 8.4 million individuals using HCBS care, 2023 expenditures were \$145.9 billion.¹⁶ There were about 1.5 million institutional service users in 2023 at a

National HCBS Waitlist (Refined Categories)

TOTAL WAITING: Approximately 710,000 people

Category	% of total	Estimated # waiting	Notes
IDD (Intellectual/ Developmental Disabilities)	~73%	~518,000	Largest group, longest waits
Physical Disabilities (PD)	~15-18%	~110,000 - 128,000	Often combined with aging in reporting
Frail Elderly (FE)	~6-9%	~43,000 - 64,000	Pulled out from PD/Aged grouping
Medically Fragile (MF)	~1-2%	~7,000 - 14,000	Includes tech-dependent individuals
TBI (Traumatic Brain Injury)	~1-2%	~7,000 - 14,000	Small but high-cost population
Other (MH, HIV, etc.)	<1%	~<7,000	Often inconsistently reported

cost of \$82.7 billion.¹⁷ This works out to about \$17,369 per HCBS recipient compared to about \$55,133 per institutional recipient. This is one of the reasons states have moved their Long-Term Services and Supports (LTSS) populations from institutional care to HCBS care: About 86% of recipients are now in HCBS care and only 14% of recipients are in institutional care.

Dramatic Spending Increases with No Outcome Measurements

HCBS care has many economic and humane benefits for individuals with disabilities; however, there are reasonable concerns about the increase in expenditures.

While users of HCBS services increased between 2019 to 2023 from 7.44 to 8.4 million, HCBS expenditures during the same period increased from \$97.1 billion¹⁸ to \$145.9 billion.¹⁹ In other words, roughly 12.9 percent growth in participants over four

years led to an increase of 50.3 percent in spending. Part of this increase may be a result of additional funds from the American Rescue Plan Act (ARPA) of 2021. ARPA Section 9817 granted states a temporary ten-percentage-point increase in Federal Medical Assistance Percentage (FMAP) — the rate at which the federal government matches state Medicaid expenditures — to strengthen Medicaid HCBS. States received the higher match between April 1, 2021 and March 31, 2022, costing \$37 billion.²⁰

States dedicated the vast majority of this spending, \$24.6 billion, towards recruitment and training of personal care workers.²¹ Only \$2.6 billion was dedicated to eliminating waitlists.²²

While this spending category was an ARPA allowable category, ARPA did not require states to measure whether any of this considerable increase in federal spending led to any specific outcomes for individuals with disabilities.

HCBS Fraud, Waste, and Abuse

“Fraud, waste, and abuse” are terms that are often lumped together, but they have very different meanings and, therefore, widely different solutions. The vast majority of FWA is enabled by federal financing models and perpetrated by either state governments not providing oversight or corrupt providers — not the individuals with disabilities and their families.

FRAUD

This is an intentional misrepresentation or deception, purposefully diverting funds intended to serve vulnerable citizens to bad actors instead.²³ States often have weak incentives to invest in fraud investigations. Fraud investigations appear fiscally costly to state budgets and look politically painful because of the lobbying power of provider networks. The following are some recent examples of fraud:

Millions in Fraud Schemes

In New York, two adult day care providers pled guilty to defrauding the government of \$68 million by billing for services that were not provided.²⁴ In another case, 10 defendants were charged with fraudulently billing Medicaid for undelivered personal-care services.²⁵ In a Minnesota-based case, two thieves set up 230 fraudulent Medicaid accounts to siphon \$3.5 million from the vulnerable.²⁶

Fraudsters Swindle While People with Disabilities are Injured

Perpetrators of fraud directly harm individuals with disabilities, such as Janelle “Sky” Hansen, a

young woman with autism. She lived in an apartment through a Medicaid-funded program called Integrated Community Supports (ICS), which is meant to help adults with disabilities live independently with daily, one-on-one assistance.

Sky’s provider, American Home Health Care, LLC, was paid Medicaid dollars intended to support her housing and services. Yet the company stopped paying her rent, even though it still collected the Medicaid funds from the state. The company

committed fraud. According to local news station KARE 11’s investigation, Sky’s records reflected a daily billing rate of roughly \$421 for about 12 hours of services per day — services Sky rarely received. State Medicaid billing data showed the provider has been paid more than \$2.2 million in public funds since 2022.²⁷ Sky, who did nothing wrong, was evicted because her provider failed her. She’s spent months homeless in Minnesota.



Janelle “Sky” Hansen, a young autistic woman, was evicted from her home because the Medicaid funds intended to pay her rent were stolen by her health care provider. (Photo courtesy KARE 11 TV)

WASTE

This is safety-net spending that's technically legal, but misuses taxpayer funds instead of directing them toward the individuals with disabilities requiring the most care.

States are rewarded financially for broadening personal care services because federal Medicaid funding helps cover costs that would otherwise be borne outside the program. When eligibility is set too broadly, states can end up serving a broader population with less acute needs, which spreads dollars, workers, and oversight capacity across too many people.

Tightening the threshold requires states to concentrate services on individuals with the most severe functional limitations, reduce waitlist pressure for the highest-need cases, and preserve the program's fiscal sustainability.

One the follow page are some examples of provider-based waste payments:

Provider-Based Determination of Eligibility

There should be additional oversight of providers who conduct the assessment of recipient needs in the state plan HCBS waiver options 1115, 1915(i), (k), and (j), where the individual's eligibility for services is not automatically defined by whether they would otherwise require institutional care.

The people in these categories often need additional assistance with activities of daily living (ADLs) to

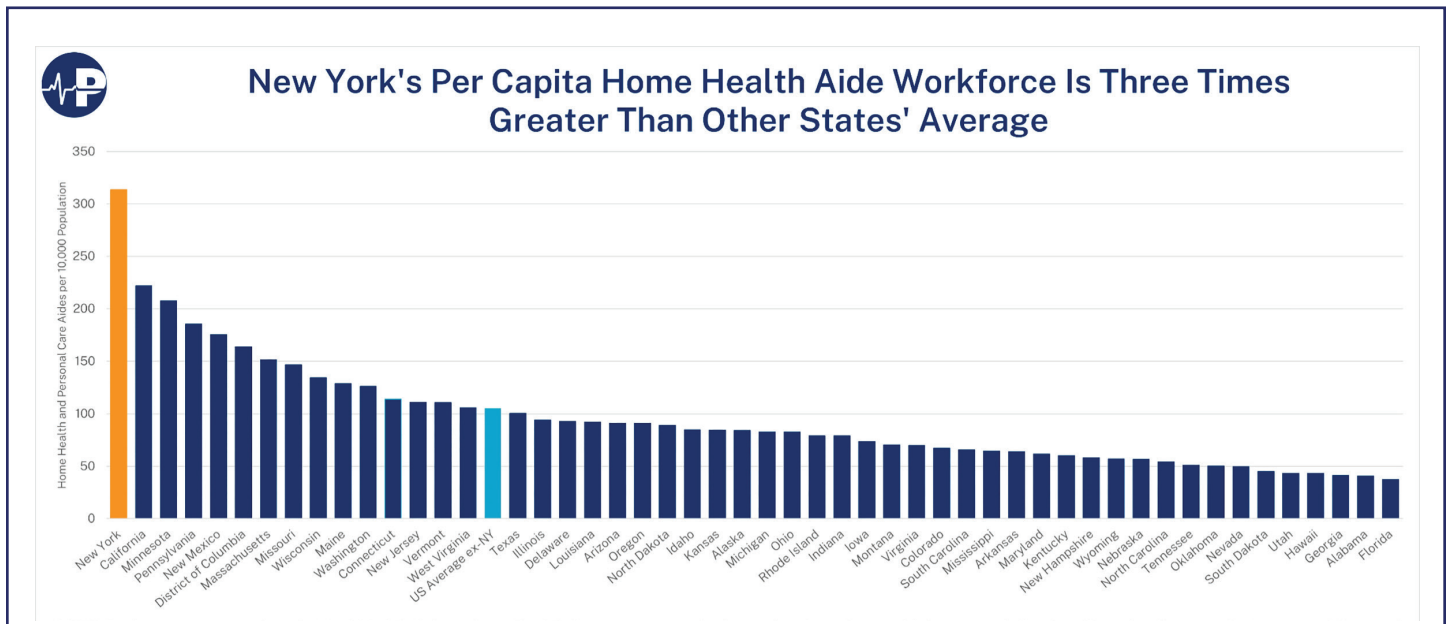
maintain their current standard of health to avoid further deterioration that would put them in danger of institutionalization, but the provider's assessment requires additional federal oversight.

For an individual to be eligible, they must meet their state's criteria involving age, disability, or health condition. They must also need help with ADLs such as bathing, dressing, or eating, and instrumental activities of daily living (IADLs) such as cooking, cleaning, and shopping. There are also requirements for the caregiver that vary across states such as passing a background check and meeting training requirements. For family caregivers there are criteria such as living arrangements and type of relation to the person. Typically, states outsource these often complex and sensitive determinations to third-party providers and do not provide adequate, ongoing oversight of the process.

New York's Exorbitant Spending

An example of a state with lax eligibility guardrails and oversight is New York. In a letter the Centers for Medicare & Medicaid Services (CMS) wrote to New York, it emphasized that the state was spending 36% more than the national average, highlighting personal care services provided through the New York Consumer Directed Personal Assistance Program (CDPAP), a State Plan personal care benefit.

In 2016, Governor Cuomo added the eligibility of parents of adult children with disabilities as paid caregivers.²⁸ At the same time, the legislature increased



SOURCE: Medrano, Chris, and Brian Blase. "Beyond Minnesota: Four Medicaid Services Vulnerable to Fraud and the Case for Stronger CMS Enforcement." Paragon Health Institute, February 17, 2026.

NOTES: Employment counts are from the May 2024 OEWS data release. The OEWS captures wage and salary workers in nonfarm establishments, excluding the self-employed owners of unincorporated firms and household workers. SOURCE: Census Bureau; Bureau of Labor Statistics, Occupational and Occupational Employment and Wage Statistics (OEWS), 2024. Accessible at <https://www.bls.gov/oes/>

the mandatory minimum wage.²⁹ Compounding this, New York had a very low eligibility threshold: Until 2025, the CDPAP only required recipients to document needing assistance with one ADL.

Although the CDPAP program has been in place since 1995, it ballooned by more than 250% from 2018 to 2024, as expenditures increased from \$3.1 billion to \$11.2 billion, with more than 290,000 consumers receiving services across CDPAP and Personal Care Services, employing 230,000 unique personal assistants.³⁰

In 2024, the program also moved to a sole source contractor as the state fiscal intermediary, causing concern about political connection and fair process for such a significant government contract.³¹

ABUSE

This constitutes unsound fiscal or medical provider practices, resulting in unnecessary cost to the program without delivering any corresponding care for individuals in need.

States do not always invest in advanced oversight technology because Medicaid's financing and political incentives reward provider payment volume and access more reliably than prevention. States often avoid preventing abuse because it's hard to avert and most of the burden falls on the federal taxpayer.

Below are some ongoing areas of concern regarding this kind of abuse:

Funding Diverted From People in Need to Union Dues and Program Administrators

A concerning avenue of abuse is forced unionization and the collection of union dues. This has expanded in nine states to include paid family caregivers.

Beginning in California in the early 1990s, labor unions like the Service Employees International Union (SEIU) and the American Federation of State, County and Municipal Employees (AFSCME) sought to revitalize their declining memberships by organizing the growing ranks of home care workers.³²

Bill Hammond with the Empire Center in New York has documented a campaign to enroll and collect dues from personal care workers in New York.³³

According to the Freedom Foundation, states diverted an estimated \$1.4 billion in caregivers' Medicaid funds to unions between 2000-2017.

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Funding Diverted From People in Need to the Politically Connected and Cycled Back to Politicians

Bill Hammond with the Empire Center has also documented how Somos Community Care, whose leaders and affiliated physicians donated to New York Governor Hochul and other state leaders, received \$29 million in Medicaid-related funding through New York's Vital Access Provider Assurance Program in 2022.³⁴

Separately, KFF Health News reported in 2022 that Centene, its subsidiaries, executives, and spouses had contributed more than \$26 million to state political campaigns since 2015, even as the company — whose business was heavily reliant on Medicaid contracts — faced Medicaid pharmacy-billing investigations in more than 20 states.³⁵

Housing for Mental Health and Substance Abuse

Over the past decade, housing intervention for those struggling with mental health and/or substance abuse disorder has expanded through CMS guidance. While these increases have been in response to real needs for individuals with serious disabilities, federal and state oversight bodies have identified vulnerabilities with recurring exploitation — for instance, when providers bill for case management or supportive services that are not actually delivered.³⁶

Among the Minnesota programs under investigation by the state, nearly half of programs cited as high risk focused on individuals with mental health and substance abuse disorder needs: "Peer Recovery Services, Adult Rehabilitative Mental Health Services, Recuperative Care,... Assertive Community Treatment, Intensive Residential Treatment Services, and Housing Stabilization Services."³⁷

Without both transparency and clear outcome measurements, states can vastly increase their spending without commensurate results for their intended beneficiaries.

Provider-Set Payment Reimbursements for New Therapies

In the absence of strong state oversight, providers offering new therapies can take advantage of vague or undefined billing categories. Improper payments can multiply when reimbursement rates are driven by providers rather than subject to clear state standards and review. Expansion of Medicaid coverage and reimbursement rates for autism services and the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) requirement led to a dramatic increase in the diagnosis of autism amongst children.³⁸ This likewise occurs within the adult autistic population, often served by HCBS programs.

Over the past decade and particularly within the past five years, Medicaid reimbursement for autism therapy, especially applied behavior analysis (ABA), has skyrocketed. With new therapies available for individuals with disabilities, providers took advantage of an obscure and undefined field.

A 2024 HHS Office of Inspector General (OIG) report found that Indiana made \$56 million in improper ABA

In the absence of strong state oversight, providers offering new therapies can take advantage of vague or undefined billing categories.

payments. In 2026, the *Wall Street Journal* reported that “[t]he number of companies offering such therapy — individualized treatments meant to help patients manage behavior and develop daily living and social skills — almost doubled between 2019 and 2023.

Direct payments from state Medicaid programs to autism therapy providers grew to \$2.2 billion in 2023, from \$660 million just four years earlier, according to the data... That made applied behavior analysis, or ABA, as the therapy is called, the fastest-growing service in Medicaid.”³⁹

How Medicaid Fraud, Waste, and Abuse are Discovered

Improper Payments

The most comprehensive Medicaid methodology for uncovering waste is CMS’s Payment Error Rate Measurement (PERM), a three-year rotating state analysis of improper payment rates.⁴⁰ That measurement, while underreported due to federal rules, consistently assesses improper payments.

CMS defines an improper payment as any payment — under or over — that a state makes in error. This is not generally a measurement of fraud, but it does capture some abuse. Enrollment errors often occur because the state has not properly assessed the applicant’s income or household makeup or has accepted the applicant’s self-attestation rather than independent verification.

In Medicaid, states have had an incentive to underinvest or avoid income and household checks in the able-bodied expansion because of the 90 percent expansion federal match for non-disabled adults. Individuals with disabilities receive the traditional state match, on average around 60 percent.

Substantial progress was made toward reducing improper payments in 2025 when Congress passed a bill that will require states to start carrying the risk of their errors.

Starting in FY2030, states with high improper payment rates will start being responsible for improper benefits over three percent. Even undercounted, Medicaid improper payments reached \$31.1 billion in FY 2024.⁴¹

While PERM was built to police the eligibility of individuals and families, a different set of tools is required to combat fraud, waste, and abuse (FWA). To rebalance trust, policymakers must extend oversight upstream to hold state leaders accountable for the management of the program. FWA is not consistently

measured because it costs the state to prevent and investigate fraud.

Medicaid FWA is investigated by state Medicaid Fraud and Control Units required to operate in every state.⁴² In FY2024, there were 1,151 convictions and \$1.4 billion recovered by the state Medicaid Fraud and Control Units.⁴³

While the federal-state share is 75%-25%, paid by the HHS OIG, the state still pays 25% of every fraud investigation. Personal care service providers were by far the most prominent source of fraud.⁴⁴

It’s vital to note that these convictions are a byproduct of investigations deployed. In 2025, the total number of state investigations was 15,921,⁴⁵ but there is an enormous fluctuation in the funding and capacity of these investigations. For instance, Ohio launched 1,058 investigations, outpacing California’s 1,052 investigations, even though California Medicaid expenditures were \$150 billion to Ohio’s \$34 billion.⁴⁶

State Medicaid programs supplement the work of their fraud units by conducting post-payment audits to identify suspicious patterns — for instance, deficient documentation or improper billing.

Some states also contract with Recovery Audit Contractors (RACs) to identify and recover overpayments to providers. Since the Patient Protection and Affordable Care Act allowed CMS to issue state exemptions, the majority of states no longer use RACs. As of 2021, only 16 states participated in the Medicaid RAC program.⁴⁷

State investigations are supplemented by CMS through the Medicaid Integrity Program,⁴⁸ which reviews state financial management, Office of the Inspector General audits, Department of Justice investigations and prosecutions, and Governmental Accountability Office reports and audits.

SOLUTIONS

How to Prevent Fraud & Improve Vital HCBS Services for People With Disabilities

Directing taxpayer funds for the benefit of people with physical, developmental, and intellectual disabilities requires laws and regulations that have clearly articulated goals, transparent implementation, and clear measurement of outcomes.

The key to identifying and restraining fraud is transparency. Congress must create a clear and consistent framework for CMS to assist states in identifying fraudulent actors. In order for taxpayers to trust the safety net and for vulnerable Americans to rely on it, reforms must be implemented that address improper payments, uncover waste and fraud, and create faster avenues to firstly prevent fraud from happening and secondarily recoup those funds for the vulnerable and punish criminals quickly. These reforms will protect the very people these programs exist to serve.

Fraud must be rooted out. Families and people with disabilities should not be uprooted with it. The integrity of the HCBS system depends on aligning oversight with areas of risk — while preserving trust in individuals with disabilities and their families. With flexible waiver eligibility and service categories inherent in waivers, transparency and oversight become more important to provide accountability.

Recently the Medicaid Access Rule, which has not yet been implemented, proposed to build on this foundation by focusing on whether services are actually accessible in practice, not just on paper. It would introduce requirements around:

- ✓ **Transparency in waitlists and service availability**
- ✓ **Accountability for timely access to care**
- ✓ **Increased oversight of provider networks and payment adequacy**
- ✓ **Stronger reporting and data requirements to measure access**

Recommendations

The following six recommendations are designed to strengthen transparency, improve provider accountability, and ensure that Medicaid dollars are used appropriately, without adding unnecessary burdens to those receiving services.

1) Create Transparency to Prevent Fraud, Waste, and Abuse

Recipients, their caregivers, and taxpayers often have very little insight into which providers are available in their communities, what services they offer and at what level, and what price point they charge to the state. States already know all of this data because they must submit it for their federal match through the Medicaid and CHIP Financial System (MACFin) and the Medicaid Budget and Expenditure System/CHIP Budget and Expenditure System (MBES/CBES).

If this data is made public, recipients and their caregivers will be better served by the system because they will finally know what services are available to them in their local area. Beyond that, they and the public will be able to hold providers accountable for what they bill the state for their services.

- For 1915 waiver approval or reapproval, require states to publish a transparent, publicly accessible dashboard detailing HCBS waiver waitlists, waiver eligibility criteria, total individuals served, and per-person waiver expenditures.
- Require state agencies to publish a comprehensive, publicly accessible directory of credentialed HCBS providers by waiver service type, including associated service rates.
- Create a cap on CMS response times to fraud reports submitted by state attorneys general and Medicaid Fraud Control Units.
- Establish a standardized, accessible whistleblower reporting mechanism across all state HCBS programs and require the CMS Center for Program Integrity and its state counterparts to respond within a certain time period.
- Require CMS to publish any waivers under federal corrective action plans to ensure visibility into state compliance issues.

2) Increase CMS Oversight of State Waste

States have a strong incentive to expand personal care services because the open-ended Medicaid benefit allows them to draw down federal matching funds for services that might otherwise fall to families, counties, or state general revenue. It's important to note here that states can extend personal care services to expansion adults.

As of 2021, nationally, 4.7% of HCBS users were in the new adult (VIII) category, 50.1% in the blind/disabled category,

and 40.1% in the aged category.⁴⁹ This new adult group receives a higher federal match, at 90 percent. However, caregivers are not an unlimited resource, and as states expand services to populations with less acute needs, attention and capacity are diverted away from individuals with the most severe disabilities.

- Create a base standard for eligibility group definitions tied to waiver access, particularly for 1915 (a),(i),(j), and (k) waivers (e.g., require a minimum of three ADLs, create a tier structure based on state expenditures, limit to the SSI population).
- Require CMS to define standards for new service categories. These guidelines should set best-practice standards for assessing need, create standardized service definitions, clarify lower-cost services, and establish clear provider qualification standards, including scopes of practice.
- Implement a rule requiring states to audit any service or device priced at 150 percent above the norm.

3) Establish Consistent Fraud Detection Systems

PERM, while flawed, is a consistent measurement of improper payments made by states. There is no comparable measurement of active fraud. Fraud is investigated by Medicaid Fraud and Control Units, which are underfunded and not required to investigate every allegation.

- Use Transformed Medicaid Statistical Information System (T-MSIS) data for predictive modeling and nationwide fraud detection.
 - Require states to contract with third-party auditors, updating the Medicaid RACs, to analyze all state claims.
 - Require states to use data analytics (billing spikes, outliers, duplicate claims) to identify high-risk providers.
 - Require CMS's Center for Program Integrity (CPI) to evaluate states' routine, annual, independent RAC evaluations of HCBS payments, duplicating each state's evaluation of high-risk providers.
 - Require Medicaid Fraud and Control Units to investigate every high-risk provider identified by states' RACs and CMS's CPI.
- Require states to submit Electronic Visit Verification (EVV) data to CMS in an accessible format. As required by the 2016 21st Century Cures Act, CMS has implemented electronic verification of services, which assesses personal care services according to type of service, individual receiving service, date, location, provider, and start/end time. CMS has tracked

states' compliance through the completion of a CMS survey — which seven states still have not finalized. Current regulations at 42 CFR § 431.17 and 45 CFR § 75.361 require the state Medicaid agency to maintain the EVV records.

4) Empower Recipients to Direct Their Own Care

Too often recipients and caregivers feel at the mercy of the Medicaid system. They are assigned to the provider available, without the opportunity to make decisions for themselves within a healthcare marketplace. When their assigned providers are unavailable, fail to show up, or even harm instead of care, recipients can feel as though they have no recourse.

- Require that all HCBS recipients have the opportunity to access their EVV data via a portal, in order to monitor and correct provider logs.⁵⁰ In implementing EVV, CMS did not require that beneficiaries have access to review their own visit data. That omission is out of step with the broader health care system, where HIPAA and related record-access standards generally favor patient access to information about their care.
- Modernize self-directed waiver options with cash-and-counseling programs, including alignment with tools such as ABLE accounts, to ensure appropriate use while preserving autonomy and choice. This would also reduce administrative spending.

5) Measure and Report Outcomes

Public welfare programs should have clear and measurable goals and hold themselves accountable to those goals. For instance, lawmakers instituting 2021's ARPA should have included expected outcomes and assessment methods before \$37 billion was expended over two years. Absent a clear standard, states are naturally incentivized to expand access to the least costly populations while maximizing federal matching dollars.

- Evaluate whether recipients actually receive authorized services using Electronic Visit Verification records as reviewed by CMS.
- Collect and report on key metrics surrounding 1915(c) waivers in all states. These should be reported immediately — not with a two-year delay.
- Establish a measure of whether individuals with disabilities have prioritized access to HCBS, using a tiered waitlist based on level of need, and hold states accountable for providing access to those with the greatest needs.
- Assess states based on whether their most vulnerable populations are better off at initial HCBS enrollment, relative to their condition.

6) Ensure Integrity of Third-Party Providers

Taxpayer funds intended to help the most vulnerable should never be used to lobby politicians or collect excessive profits. Personal care workers and family caregivers should not have their wages forcibly reduced to fund unions.

- Ban forced unionization and mandatory withholding of union dues for Medicaid HCBS personal care caregivers whose wages are financed with public funds.
- As a condition of Medicaid participation, require unified reporting by HCBS providers, including disclosure of all parents, subsidiaries, affiliates, management companies, lessors, contractors, and other related parties under common ownership or control, similar to reporting standards applied to publicly traded companies.
- Prohibit the use of Medicaid funds by HCBS providers for lobbying at the federal, state, or local level.

CONCLUSION

If taxpayers are to trust the safety net, and vulnerable Americans are to depend on it, reform must be twofold:

- 1) Root out improper payments, waste, and fraud; and**
- 2) Strengthen the government's ability to prevent abuse, recover misspent funds, and hold bad actors accountable.**

However, it's important that these efforts are targeted. Families and people with disabilities should not become collateral damage in the name of program integrity. The integrity of the HCBS system depends on focusing oversight where the real risks lie while preserving trust in individuals with disabilities and their families.

Because waiver programs are inherently flexible in both eligibility and service design, strong transparency and accountability measures are essential.

The recommendations in this report are intended to improve oversight, strengthen provider accountability, and ensure that Medicaid dollars are spent appropriately without imposing unnecessary burdens on the people these programs are meant to serve.

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Able Americans is a nonprofit, nonpartisan think tank project dedicated to advancing innovative, free-market solutions that empower Americans with intellectual, developmental, and physical disabilities.

Learn more at
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