

Public Policies to Advance the Intellectual and Developmental Disability Sector

By: Kristen Farry¹, Mike Clark¹

¹Social Innovations Partners

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Abstract

Healthcare access and fiscal sustainability represent two critical priorities for the intellectual and developmental disability (I/DD) sector. Three policy approaches offer both improved outcomes and cost savings: passage of the Healthcare Extension and Accessibility for Developmentally Disabled and Underserved Population (HEADs Up Act) to create a medically underserved population designation, a strategic response to federal Medicaid policy changes, and implementation of the PACE (Program of All-Inclusive Care for the Elderly) model for IDD populations. Demonstrated cost savings of 15-20% through integrated care models provide governments with fiscally responsible approaches to expanding access during a constrained budget environment.

Introduction

Healthcare access and fiscal sustainability represent two critical priorities for the intellectual and developmental disability (I/DD) sector. Recent federal Medicaid policy changes create both challenges and opportunities for state governments seeking cost-effective service delivery models. Three policy approaches merit attention: passage of the Healthcare Extension and Accessibility for Developmentally Disabled and Underserved Population (HEADs Up Act) to improve primary care access, strategic planning around federal Medicaid changes, and implementation of proven integrated care models that demonstrate significant cost savings while improving outcomes.

"Change is the only constant" – Heraclitus.

Nonprofits in the intellectual and developmental disability (I/DD) sector have encountered significant change following the COVID-19 public health emergency and in the years since. We must start to drive change before our fate is chosen for us. In *Forces for Good: Six Practices of High Impact Nonprofits*, Crutchfield and Grant state that effective organizations proactively work with government and advocate for policy and systems change. This article examines three specific proposals for policy and systems change relevant to both quality improvement and fiscal responsibility: healthcare access through the HEADs Up Act, understanding Medicaid policy changes, and expansion of integrated care models like PACE to serve IDD populations.

In an environment where state budgets face new pressures from federal policy changes, demonstrating cost efficiency alongside quality outcomes becomes essential. Access issues, funding sustainability, and integrated care models shape the future of our industry. Public policy serves as a strong tool at our disposal in determining what lies ahead for the I/DD sector.

Medically Underserved Population (MUP) for I/DD Population: Reducing Emergency Care Costs

The Healthcare Extension and Accessibility for Developmentally Disabled and Underserved Population, or HEADs Up Act (H.R. 3409), sponsored by Representatives Seth Moulton (D-MA), Brian Fitzpatrick (R-PA), Debbie Dingell (D-MI), and Joseph Morelle (D-NY), would designate people with intellectual and developmental disabilities (I/DD) as a "medically underserved population" or MUP. The bill was introduced on May 14, 2025, with bipartisan sponsorship and support from over 40 organizations.

MUPs have a shortage of primary care health services for a specific population subset within a geographic area. These groups may face economic, cultural, or language barriers to health care. Current MUP designations include: people experiencing homelessness, people who are low-income, people who are eligible for Medicaid, Native Americans, and migrant farm workers.

MUP designations create financial incentives that improve healthcare access while reducing government costs. The designation allows doctors to receive higher payments from Medicare and Medicaid for serving this population, offers repayment of student loans for providers who serve MUP populations, provides federal funding for Federally Qualified Health Centers to develop specialized IDD programs, enables medical school tuition aid for providers focusing on IDD care, authorizes J-1 visa waivers for international medical students serving this community, funds National Health Service Corps scholarships and loan repayment programs, supports continuing education grants for provider training, and directs research funding on topics affecting the group.

The fiscal rationale is compelling: inadequate primary care for Americans with I/DD results in expensive emergency room visits and hospital admissions that strain Medicaid budgets. Current medical education provides less than 11 minutes of IDD-focused instruction during four years of medical school, according to the 2022 Surgeon General's Task Force on Developmental Disabilities. Enhanced provider training and reimbursement can reduce reliance on costly emergency care.

The Medical Center at Woods, opened in mid-2018 in partnership with Medicaid, managed care organization Keystone First, demonstrated—through year-over-year pilot data—20% lower costs, 39% fewer hospitalizations, and 15% fewer care gaps compared to traditional care models. These results show that investing in appropriate primary care access reduces overall government healthcare expenditures by preventing costly emergency interventions.

In December 2024, Woods System of Care announced new affiliations, expanding its reach to serve 40,000 individuals with comprehensive services including crisis intervention, outpatient counseling, substance use treatment, and integrated case management. This partnership advances a population health management approach that connects prevention, wellness, behavioral health, and social services with coordinated healthcare delivery.

Federal Medicaid Policy Changes: The Imperative for Cost-Effective Models

The One Big Beautiful Bill Act (Public Law 119-21), signed into law on July 4, 2025, makes significant changes to Medicaid funding structures. According to Congressional Budget Office estimates, the legislation reduces federal Medicaid spending by \$990 billion over ten years. This creates new fiscal constraints for state governments that fund I/DD services primarily through Medicaid.

The legislation contains multiple provisions with staggered implementation timelines. Provider tax restrictions took effect immediately, prohibiting states from establishing new provider taxes or increasing existing ones. Beginning December 31, 2026, states must implement work requirements and six-month eligibility redeterminations. By fiscal year 2028, provider tax caps phase down from 6% to 3.5% in expansion states, affecting the revenue that states use to maintain reimbursement rates.

According to the Kaiser Family Foundation analysis, Medicaid funds 77% of services for people with IDD, covering 3.4 million enrollees under age 65. Home and community-based services are classified as optional under federal Medicaid law, while nursing facility services are mandatory. This classification structure creates vulnerability for community-based services during budget constraints.

In this fiscal environment, demonstrating cost efficiency becomes essential for preserving and expanding community-based services. States analyzing implementation of federal policy changes are seeking care delivery models that achieve better outcomes at lower costs. Provider organizations and state agencies have a mutual interest in identifying approaches that maintain or expand access while demonstrating fiscal responsibility.

The Commonwealth achieved a 19% reduction in its emergency waiting list during 2024, from 4,592 to 3,703 individuals, and now serves over 40,000 people with I/DD. This reflects strategic investment of \$354.8 million in combined state and federal appropriations in the FY 2024-25 budget. However, Pennsylvania projects potential federal funding changes of \$51-53 billion over 10 years, based on various implementation scenarios of the new federal policy.

National advocacy organizations have released policy recommendations emphasizing economic value alongside quality. The American Network of Community Options and Resources (ANCOR) and United Cerebral Palsy's Case for Inclusion 2025 Policy Blueprint recommend establishing a Standard Occupational Classification for Direct Support Professionals to improve workforce data, increasing HCBS funding with provider access to opportunities, and

implementing mandatory access monitoring systems to ensure reimbursement rates align with costs. These recommendations recognize that sustaining community-based services requires demonstrating their fiscal advantages.

PACE Model for IDD: Proven Cost Savings and Partnership Opportunity

In a fiscal environment requiring demonstrated cost efficiency, the Program of All-Inclusive Care for the Elderly (PACE) offers a proven model with documented savings. PACE provides comprehensive, fully integrated care through interdisciplinary teams for over 87,750 participants requiring nursing home-level care. The model demonstrates 15-17% cost savings (\$2,968/month vs. \$8,000-10,000 for nursing homes), maintains 93% of participants in community settings, and achieves high satisfaction scores. For governments facing budget constraints, PACE offers both fiscal responsibility and quality outcomes.

The PACE Innovation Act, enacted November 5, 2015, authorizes the Secretary of Health and Human Services to conduct demonstration projects expanding PACE to serve adults ages 21-54 with developmental disabilities, physical disabilities, and behavioral health needs. Research from The Commonwealth Fund (2020) found that nearly 40% of younger adults with developmental disabilities qualified as both high-need and high-cost—precisely the population where integrated care models achieve greatest cost savings.

Current PACE programs serve the traditional elderly population (age 55+). Expanding PACE to IDD populations represents an opportunity for cost savings that could help state budgets during a period of fiscal constraint. Organizations with proven integrated care infrastructure stand ready to partner with federal and state governments on demonstration projects when authorized.

Woods System of Care: Ready to Partner on PACE Demonstrations

Woods System of Care has developed the comprehensive infrastructure, interdisciplinary expertise, and documented cost performance to serve as a flagship PACE demonstration partner. With 112 years of experience providing life cycle care management to 40,000 people annually through affiliates in Pennsylvania and New Jersey, Woods stands ready to work with federal and state partners on implementing PACE-model integrated care for IDD populations.

Documented Cost Performance. Woods has demonstrated the cost savings achievable through integrated care in two distinct programs:

Medical Center at Woods (2018-present): Comprehensive primary care facility with enhanced provider reimbursement achieved 20% lower overall costs, 39% fewer hospitalizations, and 15% fewer care gaps compared to traditional care. These results meet or exceed the 15-17% savings demonstrated by traditional PACE programs.
Keystone First Partnership (150 IDD patients): Collaboration with Medicaid MCO documented 8.7% cost reduction, 39% lower inpatient costs, and 400% increase in primary care utilization. The dramatic increase in primary care visits with simultaneous

cost reduction demonstrates that appropriate front-end investment prevents expensive downstream interventions.

Integrated Care Infrastructure. Woods operates comprehensive facilities that align with PACE service requirements:

Medical Center at Woods provides centrally located healthcare services, including primary care, specialists, behavioral health, dental, occupational/physical/speech therapy, pharmacy, radiology, lab services, social work, and care coordination—the service array required by PACE regulations.

Bridgeway affiliation (December 2024) expanded Woods' behavioral health capabilities to serve 40,000 individuals with crisis intervention, outpatient counseling, substance use treatment, supportive housing, and integrated case management. Given that up to 40% of people with IDD have co-occurring mental health conditions, this integrated behavioral health capacity is essential for PACE-model comprehensive care.

Interdisciplinary team experience serving IDD populations across the lifespan, including individuals with complex medical and behavioral needs—precisely the high-need, high-cost population where PACE models achieve greatest cost savings.

Geographic and Operational Scale. Woods serves 40,000 people annually through Pennsylvania and New Jersey affiliates, providing operational scale for meaningful demonstration projects. A pilot demonstration would represent a manageable implementation while generating statistically significant outcome data.

Partnership Infrastructure. Woods has established relationships with critical partners, including Medicaid managed care organizations (Keystone First), state agencies (Pennsylvania Office of Developmental Programs), and community providers—the collaborative infrastructure necessary for PACE's community-integrated service model.

Potential Fiscal Impact for Government Partners. Pennsylvania faces approximately 14,800 people with I/DD on waiting lists to obtain waiver services or Home- and Community-Based Services (HCBS). The Commonwealth's \$2.6 billion annual I/DD spending represents a significant opportunity for efficiency gains. Woods' demonstrated 8.7-20% cost reductions suggest that a 10% efficiency gain across Pennsylvania's I/DD system could yield \$260 million annually, with the capacity to serve 1,500-2,000 additional individuals from waiting lists without increasing total expenditures. For states analyzing budget options in light of federal policy changes, these efficiency gains offer a path to expanding access while demonstrating fiscal responsibility.

Necessary Modifications for IDD Populations. Adapting PACE for IDD populations requires specific modifications while maintaining the core integrated care model:

Eligibility starting at age 22+ rather than 55+, using nursing home/state center/ICF level-of-care criteria appropriate for IDD populations.

Maintaining existing long-term services and supports (LTSS) provider relationships rather than requiring all services through PACE centers, recognizing IDD populations' established community connections.

Nurse Practitioner Coordinator serving as healthcare navigator, coordinating medical care, assessments, service planning, and crisis services with interdisciplinary teams.

Partnership Opportunities. Federal authorization of a PACE demonstration for IDD populations would enable partnerships between experienced providers and government agencies. Implementation would involve: establishing per-member-per-month medical rates with the National PACE Association and state Medicaid agencies; securing start-up budget funding; developing a federal funding strategy; and implementing quality outcome measures, including satisfaction, quality of life, emergency room utilization, and medication management. Woods' existing infrastructure and documented cost performance position the organization to serve as an effective demonstration partner when federal and state agencies are ready to proceed.

Conclusion

To develop a system of care for the I/DD population that meets both quality and fiscal responsibility requirements, three policy elements merit priority attention: healthcare access through MUP designation that reduces emergency care costs, strategic response to Medicaid policy changes emphasizing cost-effective service models, and implementation of integrated care approaches like PACE that have demonstrated 15-20% cost savings while improving outcomes.

The policy landscape in 2025 requires demonstrating value to government partners facing budget constraints. Woods Services' documented results—20% lower costs, 39% fewer hospitalizations, 8.7% overall cost reduction, and 400% increase in primary care utilization—show that appropriate investment in integrated care generates net savings for government budgets. These are measured outcomes from operational programs serving real populations.

Recent federal Medicaid policy changes create fiscal pressure on state budgets. This environment makes cost-effective service models more essential. Pennsylvania's analysis suggests that a 10% efficiency gain on its \$2.6 billion IDD spending could yield \$260 million annually, capacity to serve 1,500-2,000, and additional individuals from waiting lists without increasing total expenditures. Woods' documented performance indicates this efficiency level is achievable through integrated care models.

The PACE Innovation Act provides legislative authority for expanding PACE to IDD populations. Woods System of Care has the infrastructure, documented performance, interdisciplinary expertise, and operational scale to serve as a demonstration partner. The Medical Center at Woods operates the service array PACE requires. The Keystone First

partnership documented the cost reductions that integrated care achieves. The Bridgeway affiliation provides behavioral health integration for populations with co-occurring conditions. The 112-year organizational history and 40,000 annual service population demonstrate operational stability and scale.

A MUP designation for the I/DD population, strategic implementation of Medicaid policy changes, and federal authorization of PACE demonstrations for IDD populations represent policy approaches that serve both quality improvement and fiscal responsibility. Comprehensive IDD services generate economic returns through enabling family caregivers to work, supporting local job creation, preventing costly institutionalization, and demonstrating 15-20% cost savings through integrated care. Policy decisions in the coming years will determine how proven cost-effective innovations can expand to serve more individuals while meeting government fiscal requirements. Woods Services stands ready to partner with federal and state agencies to demonstrate that improved outcomes and reduced costs are achievable goals through properly designed integrated care models, benefiting both people with IDD and the government agencies that serve them.

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