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A Slice of Pie

Communication from the Policy Information Exchange

A Slice of Pie is an ongoing publication keeping our readers informed about important public policy issues. It is the mission of the Policy Information Exchange to **educate and inform Pennsylvanians with disabilities, their families and advocates, and the general public, regarding public policy issues and to further the exchange of policy information between the Pennsylvania Developmental Disabilities Council and federal, state and local policy makers.**

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State News

Pennsylvania Budget Delay Affects Disability Services

Pennsylvania's incomplete budget delays funding for disability services across the state, affecting early intervention, behavioral health, and support programs. Counties face late payments, risking service cuts, staff layoffs, or borrowing. Organizations report dwindling funds, with over 80% of the Pennsylvania Association of Nonprofit Organizations' members close to running out by October, already cutting staff or taking loans. RCPA warns that the situation worsens daily, and providers like Pathways Forward and Pittsburgh Community Services struggle without reimbursements. Even if the budget passes soon, funds will take weeks to arrive. Advocates call for swift action to prevent the loss of essential support for people with disabilities.

The state Treasury has stepped in with $21 million in bridge loans to help keep essential services running smoothly during the budget impasse. Treasurer Stacy Garrity has also introduced a $500 million low-interest loan program to support county governments and service providers impacted by the funding freeze. This includes organizations serving rape survivors, pre-K children, and victims of domestic violence. So far, mainly Pre-K programs have applied. Some organizations have shared concerns about the 4.5% interest

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rate, hoping lawmakers will consider waiving fees to ease their financial load.

Advancing Performance-Based Contracting for Disability Services

Pennsylvania's Democratic House members, administration leaders, and disability advocates met to discuss ways to improve services for people with intellectual and developmental disabilities. The plan is called performance-based contracting, where providers are rated based on how well they support individuals. The state aims to improve services, especially in rural areas, and to assist more people on the waiting list. They discussed care models like Life Sharing, where a person with a disability lives with a supportive family. These models are less costly and easier to maintain because they need fewer staff. The state also wants to support Direct Support Professionals (DSPs) by enhancing pay and training.

The meeting also shared encouraging news about health care improvements. More people are getting regular checkups and follow-up care after hospital stays. The state is working on better ways to connect individuals with providers who meet their specific needs. Families will soon be able to use an online tool to see how providers are rated. Leaders said they listen to feedback from families, providers, and people with disabilities to enhance the system. They plan to keep working on these changes and ensure that no one loses services during the transition.

Advocates Speak Out

Pennsylvania leaders and disability advocates gathered at the Capitol to oppose significant cuts to Medicaid. Secretary of Health Val Arkoosh and Representative Dan Miller stated these cuts will hurt people who depend on Medicaid for doctor visits, medication, therapy, and home care. Advocates shared personal stories demonstrating how Medicaid supports people living full, independent lives. They warned that these reductions could cause hospital closures, increased costs, and fewer services. Everyone agreed: Medicaid is not charity — it's justice. They called on lawmakers to protect Medicaid so individuals with disabilities and families can access the care they need.

Disability advocates and lawmakers also came together at the Capitol to endorse the Family Care Act, which would give workers paid time off to care for loved ones or themselves during illness. Speakers shared stories about how hard it is to choose between earning a paycheck and caring for family. They explained that many, especially those with disabilities, face tough decisions without paid leave. Advocates emphasized that this law would help families stay strong, healthy, and financially stable. They also pointed out that other nearby states already have similar laws. Supporters urge lawmakers to pass the bill and ensure no one is penalized for needing time to care.

Department of Health and Human Services Data Dashboard

The Pennsylvania Department of Human Services (DHS) has a webpage where you can access valuable data and reports about its services. This includes details on programs like public assistance, child welfare, disability services, and more. The site features charts, dashboards, and annual reports that illustrate how these programs operate and their improvements. It's an excellent resource for anyone interested in understanding how DHS supports residents across Pennsylvania and how real data guide decisions.

Families Face Big Gaps After High School for Adults with Disabilities

A Carlisle family recently shared how hard it is to find support for their son, Evan, who has an intellectual disability. While Evan got help at school, those services stopped after graduation. His family says it felt like "falling off a cliff." Evan was put on a long waitlist for adult programs, and he's one of over 11,000 Pennsylvanians waiting for help.

This story highlights a bigger issue many families face. When students with developmental disabilities leave school, they often lose access to services like therapy, job training, and daily support. Schools are required to help students plan for life after graduation, but once they turn 21, families must find adult services independently. These services can be hard to access, underfunded, and confusing to navigate. Advocates are calling for better funding, more precise guidance, and stronger support systems to help young adults with disabilities live full, independent lives.

Help Train Future Doctors – Get Paid!

Penn State College of Medicine is looking for children and young adults with intellectual and developmental disabilities (IDD), ages 26 and under, along with a caregiver or support person, to help train future doctors. Families will act as "standardized patients" during a medical student training session, where students practice basic skills like asking health questions and listening to the heart and lungs. This is a paid opportunity; the participant and caregiver earn $21 per hour. Training and sessions will take place in November, and families will receive support and an excused absence form for school or work.

This is an excellent chance for families who care about disability inclusion to make a real difference in medical education. Participants will work in a welcoming environment and can also join a feedback group to share their experience. Travel to Penn State College of Medicine must be arranged independently. The team is happy to answer questions or talk more about the opportunity.

Sign Up

New SNAP Work Rules in Pennsylvania

The Pennsylvania Department of Human Services (DHS) has updated its Supplemental Nutrition Assistance Program (SNAP) rules following a new federal law. Starting September 1, 2025, certain SNAP recipients—specifically adults aged 18–54 without dependent children—must work, volunteer, or participate in education or training for at least 20 hours a week (or 80 hours a month) and report these activities to DHS to continue receiving benefits. If they do not meet these requirements, they may only receive SNAP for three months within three years. The DHS website explains who is affected, how to meet the criteria, and how to apply for an exemption if eligible.

Speak Up for PCA Admission Allowance

The Pennsylvania Human Relations Commission (PHRC) wants to hear from the public about new guidance they are creating. This guidance explains when places like museums, parks, and events should provide Personal Care Assistants (PCAs) with free or reduced admission when they help someone with a disability. The goal is to make sure people with disabilities can fully take part in public life. The law does not always require free entry for PCAs, but sometimes it is necessary to provide equal access. PHRC states that if the person has a disability and the assistance is reasonable and necessary, the venue should try to accommodate it—unless it causes major issues for the business. Advocates are encouraged to share their thoughts during the public comment period. Additionally, we encourage you to review and advocate for the proposed Michael's Law legislation.

Waitlist Progress

In Pennsylvania, many with intellectual disabilities and autism have waited long for services. Gov. Josh Shapiro and DHS Sec. Val Arkoosh say progress is happening. Over a year, the emergency adult waitlist dropped 28%, and pay for Direct Support Professionals (DSPs) increased to $17.85/hour, reducing job vacancies to the lowest since 2015. These updates help more people live independently and join their communities. Families are already noticing the impact; one father shared his daughter now attends college, works, and volunteers after getting off the waitlist. While thousands still wait, the state is expanding services and jobs. Advocates warn federal budget cuts could slow progress, especially for Medicaid waivers that support people living at home instead of institutions, saving money and improving lives. Gov. Shapiro emphasizes that people with disabilities strengthen Pennsylvania, and he's committed to their success.

Webinar: Using Data to Strengthen the Direct Care Workforce

Advancing States is hosting a free online webinar on Wednesday, November 19, at 3:00 p.m. ET. The webinar is called "From Numbers to Action" and will show how states can use data to better support people who work in Home and Community-Based Services (HCBS). Speakers will discuss how to plan for future workforce needs and make smart choices to improve care. Advocates, service providers, and decision-makers are encouraged to join and learn how data can help improve services.

Register for the webinar here

AI and IEPs

Teachers are increasingly using artificial intelligence tools to help draft Individualized Education Programs (IEPs), saving time and reducing paperwork. These tools assist in creating goals, accommodations, and progress reports, often utilizing templates and student data. Some educators say AI allows them to focus more on instruction and student interaction. Special education advocates and

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experts interviewed in an Education Weekly article expressed concerns about using AI in this sensitive area. They caution that overreliance on AI could produce generic or unsuitable IEPs that do not reflect each student's unique needs. There are also worries about data privacy, bias in AI-generated content, and the potential loss of collaborative, team-based decision-making vital to the IEP process. Future actions might include establishing clear guidelines, ensuring transparency, and providing professional development to promote ethical and practical use of AI in special education.

Early Intervention and the Child Welfare System

A recent Penn State study found that involvement in Pennsylvania's child welfare system (CWS), especially foster care, may enhance early diagnosis of developmental delays in children under three. Led by Christian Connell, the research showed that children engaged with CWS were more likely to undergo developmental assessments and receive early intervention services compared to similarly at-risk children not involved with the system. This is partly because of increased access to preventive medical care and mandated evaluations under federal law for children who have experienced abuse or neglect. The study highlights both the benefits and challenges of service delivery, noting that while CWS involvement can facilitate timely diagnosis and support, barriers such as voluntary participation and missed identification still exist. These findings emphasize the importance of strengthening systems that connect vulnerable children to developmental services early, which can greatly improve long-term outcomes.

Read the study

https://www.psu.edu/news/research/story/child-welfare-system-involvement-may-improve-diagnosis-developmental-delays

Federal News

Federal Government Shutdown – What It Means for Disability Services

The U.S. government shut down on October 1, 2025, and it's already impacting services that people with developmental disabilities depend on. While Social Security, Medicare, and Medicaid benefits continue to be paid, many other services are slowing down or paused due to staff shortages. Agencies such as the Social Security Administration, Department of Health and Human Services (HHS), and Centers for Disease Control and Prevention (CDC) have furloughed thousands of workers. This delays disability research, public health updates, and program oversight. Families may experience longer wait times for help with appeals, claims, or getting replacement cards. Programs like SNAP and WIC are still operating, but future payments could be delayed if the shutdown persists.

Advocates warn that even brief shutdowns can cause confusion and harm, especially for those needing urgent care or support. Services that monitor and enhance healthcare, education, and employment for people with disabilities are being disrupted. Civil rights enforcement continues, but investigations may be delayed. The shutdown also impacts grant programs, research, and outreach efforts that promote disability inclusion. Advocates call on Congress to restore funding quickly to protect disability services and prevent families from falling through the cracks. They highlight that people with disabilities deserve stability, support, and access to the services they need to live full and independent lives.

The U.S. Department of Education laid off most staff in its special education office due to the government shutdown, including those helping schools comply with IDEA and investigating discrimination. Katy Neas of The Arc said these jobs protect students' rights and support families. Without them, families may lack resources when schools fail to provide needed services. The Arc urges Congress to protect these offices so that all children with disabilities get proper education. A federal judge temporarily halted the layoffs, citing their rushed and harmful nature, especially to disabled students. The court will decide if the layoffs are legal; jobs are now safe, but more hearings are pending.

Big Court Case Could Change How Disability Is Defined

The U.S. Supreme Court is examining a case that could alter how people are diagnosed with intellectual disability. Currently, doctors consider more than just IQ scores—they also evaluate how a person thinks, learns, and manages daily life. However, the state of Alabama wants the court to rely solely on IQ scores. Disability groups argue this is dangerous and unfair. They believe the court should continue using the full medical guidelines to protect individuals with disabilities. This decision could impact not only people facing the death penalty but also those who need support in school, healthcare, and everyday life.

The Arc of the United States filed an amicus brief in Hamm v. Smith, urging the Supreme Court to use a full clinical evaluation—not just IQ scores—to determine intellectual disability. They emphasize that relying solely on IQ scores ignores decades of science and legal precedent. The American Association on Intellectual and Developmental Disabilities (AAIDD) supports a comprehensive diagnostic framework that includes both intellectual functioning and adaptive behavior, developed through years of research and clinical practice.

For precedents, Atkins v. Virginia (2002) established that executing individuals with intellectual disabilities violates the Eighth Amendment. Hall v. Florida (2014) and Moore v. Texas (2017) also reinforced that courts must use clinical standards, not just IQ scores, when determining intellectual disability.

Cross Identity Concerns

A proposed federal change could stop collecting data on racial disparities in special education, which is used to identify unfair treatment.

The proposed change

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Department of Defense Not Meeting Disability Employment Goals

The Department of Defense Education Activity (DODEA) aims to better support employees with disabilities, but it does not meet federal targets. In 2024, about 6% of employees reported disabilities, with just over 1% reporting targeted disabilities—below the 12% and 2% goals. These figures are based on self-reporting so that the actual numbers could be higher. DODEA operates schools for military children worldwide and employs over 14,000 staff. It uses strategies like attending veteran job fairs, utilizing specialized hiring programs like Schedule A, providing accommodations, collaborating with organizations, and maintaining qualified candidate lists. While it doesn't have specific career programs for people with disabilities, it offers personalized career support. The agency recognizes that more work is needed to improve opportunities and support.

Improving Dental Care Access for People with Disabilities in Nursing Facilities

Access to dental care remains a major challenge for people with disabilities. Medicare does not cover most dental services, leaving many individuals with developmental disabilities without necessary care. Poor oral health can worsen chronic conditions such as diabetes, heart disease, and dementia. The Justice in Aging report emphasizes that adding a dental benefit to Medicare Part B would help reduce these health disparities. It would provide consistent coverage for preventive and medically necessary dental services, regardless of income or Medicaid status, and facilitate easier arrangements for care. This change could improve health outcomes and decrease emergency visits caused by untreated dental issues.

In Pennsylvania, House Bill 583 is the key legislation addressing this issue. Passed by the House in June 2025, the bill would restore Medicaid coverage for root canals, periodontal disease treatment, and emergency dental exams—services cut in 2011. These treatments are often critical for people with disabilities who face barriers to accessing care due to transportation, income, and health challenges. The bill covers routine cleanings and fillings and aims to reduce pain, prevent serious health problems, and improve overall well-being. HB 583 now awaits consideration in the Senate.

Leucovorin Approved for Treating Cerebral Folate Deficiency

The FDA approved leucovorin for cerebral folate deficiency (CFD), a condition affecting the brain and causing autism-like symptoms. Genetic or immune problems prevent folate from entering the brain despite normal folate levels. Children with CFD show early signs like speech delays, seizures, and movement issues. Leucovorin bypasses the blockage, delivering folate directly to the brain. Studies indicate that 85% of children improved, especially in speech.

The FDA is updating its label to include CFD, potentially increasing access and Medicaid coverage. The National Institutes of Health plans further research to confirm safety and effectiveness. Autism groups respond carefully: the Autism Society of America warns against labeling treatments as cures, while the Autism Research Institute calls for more research and personalized care. The Autism Community in Action supports the FDA's decision with events and resources. Experts see promise but emphasize the need for more research, respect for neurodiversity, and more straightforward diagnostic guidelines, as CFD diagnosis is complex and requires biomarkers.

New Medicare Prescription Drug Information Available

Doctors and health care providers can now see Medicare prescription drug costs and coverage right away. This means they can quickly check if a medicine is covered and how much it costs, and send requests for approval without delays. They can also share prescription information with pharmacies and insurance companies more easily. This change is part of a new rule from the Centers for Medicare & Medicaid Services to help people get the medicine they need faster and with fewer problems.

New Warnings About Tylenol Use During Pregnancy Spark Debate

In September 2025, the FDA revised warning labels on acetaminophen (Tylenol) to mention a possible link to autism and ADHD in children. This was part of the Trump administration's "Make America Healthy Again" initiative, tackling rising chronic health issues. President Trump and Health Secretary Robert F. Kennedy Jr. announced the update, advising pregnant women to avoid Tylenol unless necessary, citing studies that suggest a possible connection and noting that the evidence is inconclusive.

Medical experts responded swiftly. The American College of Obstetricians and Gynecologists (ACOG) reaffirmed that acetaminophen remains the safest pain reliever during pregnancy when used properly, warning that untreated fever and pain can be dangerous. Researchers pointed to a Swedish study of 2.5 million children that found no causal link between acetaminophen and autism, suggesting earlier studies may have been influenced by other factors.

Autism advocacy groups criticized the messaging. The Autistic Self Advocacy Network (ASAN) called the claims "dehumanizing," and the Autism Society of America described them as "dangerous" and "anti-science," emphasizing that autism is complex and influenced by many factors, not just medication avoidance.

Dr. David Mandell pointed out that the administration's approach depends more on anecdotal beliefs than science and called for research that genuinely helps autistic individuals. Educators and disability advocates worry that misinformation could lead to more stigma, bullying, and confusion, emphasizing that autism is lifelong, and policies should be compassionate and based on evidence.

At a recent cabinet meeting, the President and Secretary stated that boys who are circumcised early might have a higher likelihood of autism, possibly because they are given Tylenol for pain. In a social media post afterward, RFK Jr. doubled down, citing a 2015 study from Denmark to support his claim, but the researchers in that study said they had no data on what pain medicine was used and could not prove a link to Tylenol. Medical experts do not support these claims.

Proposals for IDEA Budget Allocation

The Trump administration's 2026 budget proposes merging IDEA funding programs into Part B for school-age children, aiming to simplify processes and keep funding at $15.5 billion. Critics worry that support for young children and specialized services might decrease. The plan introduces a $2 billion K–12 block grant, consolidating 18 programs, while IDEA Part B funding would rise slightly to $14.9 billion. Civil rights enforcement would be cut by 35%. Supporters favor Education Savings Accounts (ESAs), which allow families to use funds directly, but disability advocates fear reduced accountability. Congress responds variably: the Senate rejected most cuts, maintaining or slightly increasing IDEA funding; the House cut the Department of Education’s budget by 15%, reduced Title I by 26%, but supported some programs. Budget decisions are influenced by recent test scores showing declines since 2019, with debates on whether funding impacts educational outcomes or is influenced by political issues.

Pushback on Rule Withdrawal

Senator John Fetterman and other lawmakers are pushing to stop the practice of paying workers with disabilities less than the minimum wage. They’re asking the Department of Labor to bring back a rule that would gradually phase out special wage certificates, which allow employers to pay disabled workers below minimum wage. The senators believe that removing the rule hurts equal opportunities for people with disabilities. Over the past 10 years, 16 states have ended subminimum wages, and more are working on similar changes. According to the senators, nearly 18,000 public comments about the proposed rule were submitted, and most people supported it.

Ranking Disability-Friendly Cities

A new report reveals the best and worst cities in the U.S. for people with disabilities. It considers health care, community services, ease of living, and transportation. Minneapolis ranked as the top city. Other leading cities include St. Louis, Scottsdale (Arizona), Columbus (Ohio), and St. Paul (Minnesota). Juneau, Alaska, was ranked the lowest. Other cities struggling include South Burlington (Vermont), Gulfport (Mississippi), Pearl City (Hawaii), and Jackson (Mississippi). These cities may have fewer services, limited access to health care, or other issues that make life more difficult for people with disabilities.

Sending More Medicaid Funds to Institutions

A new bipartisan bill in Congress is raising concerns among disability advocates. The Increasing Behavioral Health Treatment Act bill would eliminate a longstanding Medicaid rule that limits funding for large mental health institutions. Supporters say this change would help people in crisis access care more quickly and improve public safety. They argue that more treatment options, including short-term hospital stays, are needed to bridge gaps in the mental health system.

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However, disability groups warn that this bill could lead to billions of dollars being spent on institutional care while cutting funding for community-based services. They say this shift could harm individuals with disabilities by reducing access to care in their own communities and increasing dependence on hospitals. Advocates emphasize that previous efforts to expand institutional funding did not improve emergency care or access, and they fear this bill might undo decades of progress toward more inclusive, community-based support.

Uber Faces Lawsuit Over Discrimination Against Riders with Disabilities

The U.S. Department of Justice (DOJ) is suing Uber again—this time for allegedly discriminating against passengers with disabilities, marking the second lawsuit in four years. The complaint states that some Uber drivers refuse riders with wheelchairs or service animals, charge unfair fees, or insult passengers. Uber emphasizes its policies, driver training, and a hotline for reporting issues. This lawsuit resembles a 2021 case settled in 2022, and raises awareness about ADA rights, hoping for improved treatment and accountability from ride-share companies.

Public Service Loan Forgiveness

The U.S. Department of Education’s final rule on the Public Service Loan Forgiveness (PSLF) program, effective July 1, 2026, aims to restore the program’s original purpose by ensuring only organizations serving the public good qualify as employers under PSLF. It defines “qualifying employer” more strictly, excluding organizations involved in illegal activities such as aiding immigration law violations, supporting terrorism, or engaging in unlawful discrimination. The rule sets a process for employer disqualification with protections for due process and reconsideration. Borrowers working for disqualified organizations won’t earn PSLF credits for payments after disqualification, but payments before still count.

For individuals with intellectual and developmental disabilities (IDD), this rule poses serious risks. Many IDD advocates and providers rely on PSLF to attract and retain staff. If an organization is found to have a “substantial illegal purpose," employees—including those supporting IDD—might lose PSLF benefits. This could discourage professionals from the disability field, reducing care quality and availability. Advocates should monitor enforcement and ensure compliance to safeguard their workforce and those they serve.

Pennsylvania Legislative Review

Legislation that supports public policy to ensure that Supported Decision-Making approaches are viable alternatives to traditional guardianship in Pennsylvania.

Legislation Enacted

House Bill 18 from Representative Olsommer passed both chambers with only a single vote against. With the Governor’s signature, it is now Act 39 of 2025. Courts are required to hold a hearing within 30 days of receipt of a petition to modify or terminate a guardianship for an incapacitated individual.

Legislation that supports medical, dental, and behavioral healthcare policies and services that meet the needs of people with developmental disabilities, particularly as those disabilities intersect with their other identities.

Legislation Introduced

House Bill 821, from Representatives Tarik Khan and Kristin Marcell, would allow Medicaid reimbursement for assisted living, offering more flexible and suitable housing options for people who need daily support but not intensive medical care.

House Bill 1848, from Representatives Borowski and Brennan, would mandate that insurance cover therapies, including physical, speech, and occupational therapy.

House Bill 1901 from Representatives Greg Scott, La’Tasha Mayes, and Andre Carroll would create a new Office of Health Equity within Pennsylvania's Department of Health and a Health Equity Advisory Committee. The Health Equity Advisory Committee would guide and oversee, ensuring marginalized communities, including those with disabilities, are represented in decision-making.

Contact PIE

Contact the PIE Team with any questions, comments, suggestions, or information to share at PIE, c/o The Arc of Pennsylvania, 1007 Mumma Road, Suite 100, Lemoyne, PA 17043, by email at pie@thearcpa.org or by phone at 800-692-7258.

- **A Slice of Pie** is available by email and contains hyperlinks for ease of accessing websites and internet documents and resources.
- PIE Alerts, PIE Information, and PIE Job Postings are available by email to keep people informed about disability issues between newsletters.
- Sign up for A Slice of Pie or PIE electronic messages by phone at 800-692-7258 or by emailing pie@thearcpa.org.
- Individuals who already get A Slice of Pie and/or PIE electronic messages can make changes at any time by clicking “Update Profile/Email Address” at the end of any PIE email message.
- A Slice of Pie is available at the Developmental Disabilities Council website ***www.paddc.org***, by clicking on “Publications” and “Slice of Pie”. Archived editions can also be found there.
- **A Slice of Pie** is available in alternate format upon request.
- The PIE office will download, copy, and mail information mentioned in A Slice of Pie upon request.

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Change of Information?

We want to be certain that you do not miss an issue of *A Slice of Pie*, so please send name or address changes either by phone 800-692-7258 or by email to pie@thearcpa.org. Thank you.