



SHADE: Access Unmuted – Healthcare Justice Watchlist

This national movement fights for justice in healthcare. Below are key policy issues we are watching, explained in simple terms. Each matters deeply for patients, families, and caregivers across the country.

Note: Policy landscapes shift quickly, so we update our priorities regularly to reflect the most urgent threats and opportunities in healthcare.

We believe healthcare is a human right—not a partisan issue. SHADE supports fiscally responsible solutions that protect the sick and vulnerable without raising taxes. We want to preserve and strengthen Medicaid and NIH funding—not expand them—because these lifelines uphold the dignity of our communities. Continuing research and innovation is not just smart policy—it’s how America leads the world and brings hope to those who suffer. We also recognize that there is waste in the system—but taking away from the most vulnerable is not the solution. Let’s fix inefficiencies, not punish patients.

1. 2025 Fiscal Debate & Health Program Funding

- **Definition:** The 2017 Tax Cuts and Jobs Act is set to expire in 2025.
- **Issue:** Congress will face tough decisions on whether to extend tax cuts and how to pay for them.
- **Why It Matters:** Without careful balance, safety-net programs like Medicaid and SNAP could face deep cuts.
- **Without It:** Up to 7.6 million Americans could lose coverage; food insecurity would rise.

2. Medicaid Cuts & Work Requirements

- **Definition:** Medicaid is public insurance for low-income people and those with disabilities.
- **Issue:** \$800+ billion in proposed cuts; new work requirements.
- **Why It Matters:** Medicaid covers over 80 million Americans, including 1 in 3 children and nearly 1 in 5 adults. Many families depend on Medicaid for life-saving care and home supports.
- **Without It:** Millions will lose care access, especially those with complex medical needs. In states where work requirements have been implemented, over 100,000 people have lost coverage.

3. Disbanding the RUSP Committee

- **Definition:** The committee that recommends conditions for newborn screening (RUSP).
- **Issue:** HHS is consolidating agencies, eliminating this committee.
- **Why It Matters:** Newborn screening currently saves over 12,000 babies annually from severe disabilities or death. Early diagnosis through RUSP screenings reduces lifelong medical costs by up to 80% per patient.
- **Without It:** No new diseases added. MLD and DMD may be the last.

4. Rare Pediatric Priority Review Voucher (PRV)

- **Definition:** Incentive for rare pediatric disease drug development, expired in 2024.
- **Issue:** Needs reauthorization through the Creating Hope Act.
- **Why It Matters:** Small pharmaceutical companies can spend 80% of their budgets on research and development, risking failure up to 14 times per drug—costing billions each time. They need incentives. The PRV shortens FDA review time, helping kids get treatments faster.
- **Without It:** Fewer incentives = fewer cures. Children lose access to innovation.

5. Accelerating Kids' Access to Care Act (S.752 / H.R.1509)

- **Definition:** Bill to help doctors provide care across state lines for Medicaid patients.
- **Issue:** Cross-state care is currently a paperwork nightmare.
- **Why It Matters:** Nearly 40% of Medicaid children live in states where cross-state care is limited or difficult. Specialist wait times for Medicaid patients can be up to 3 times longer than for privately insured children. Children often need out-of-state specialists.
- **Without It:** Delays, denials, and avoidable harm to children.

6. Cuts to NIH Research Funding

- **Definition:** The National Institutes of Health (NIH) funds medical research that leads to cures and innovation.
- **Issue:** Proposed budget cuts would significantly reduce NIH funding.
- **Why It Matters:** NIH funding has led to over 2,500 FDA-approved drugs and vaccines in the last 50 years. Every \$1 invested in NIH research generates about \$8 in economic growth. Research funded by NIH drives breakthroughs in cancer, rare disease, Alzheimer's, and more.
- **Without It:** Innovation stalls. Hope fades. America loses its edge as a global leader in science.

7. Animal Research Misconceptions

- **Definition:** Scientific use of animal models to develop human treatments.

- **Issue:** Misinformation campaigns label this as cruelty to sway public support.
 - **Why It Matters:** Animal research contributed to 70% of Nobel Prize-winning medical discoveries in the past 20 years. Over 90% of new drug candidates fail in clinical trials without prior animal testing. Ethical, regulated animal studies lead to cures.
 - **Without It:** Research halts. Cures delayed. Lives lost.
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Let's rally. Let's educate. Let's act.

This isn't politics. It's people. **SHADE: Access Unmuted**