

# Help Protect RISP and Projects of National Significance



## What are Projects of National Significance?

Projects of National Significance (PNS) allow a rapid response to the most pressing issues affecting people with disabilities and their families. They create and enhance opportunities for people with intellectual and developmental disabilities (IDD) to contribute to and participate in all facets of community life.

### A Lifeline Is Being Cut — We Need Your Voice

For 48 years, the Residential Information Systems Project (RISP) —recognized as a Project of National Significance—has been a vital resource, tracking and analyzing longitudinal data on Medicaid-funded long-term supports and services for people with IDD. Policymakers, advocates, families, and individuals have relied on this trusted data to drive real change.

Now, it's on the chopping block.

The President's budget proposes eliminating funding for this program and others that people with IDD count on every day. This isn't just about data—it's about dismantling decades of progress.

### What's at Risk

- Proven research that drives inclusive policy change
- Leadership training in IDD data and accessibility
- Community supports that help people with IDD live, work, and thrive
- Why It Matters: Every person deserves to live with dignity. Cutting this program says otherwise.



Call, visit, or write your members of Congress. Urge them to restore funding for PNS programs. This is about more than dollars—it's about our values and ensuring everyone has the chance to live a full life.

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## Current Ongoing PNS Projects



### **Bridging the Aging and Disabilities Networks**

Supports people with I/DD and their families to improve planning and address their own needs, goals, and preferences



### **Empowering Youth with I/DD to Manage Their Healthcare Transitions**

Empowers youth with I/DD to direct their own healthcare transitions from pediatric to adult models of care



### **Self-Advocacy Resource and Technical Assistance Center (SAR-TAC)**

Provides support to organizations to make their information accessible to people with I/DD



### **Community Collaborations for Employment**

Supports people with I/DD in gaining Competitive Integrated Employment and community living



### **Alternatives to Guardianship Youth Resource Center**

Supports youth with I/DD in moving away from guardianship to Supported Decision-Making (SDM)



### **Strengthening the Healthcare Workforce and Addressing Health Disparities among People with I/DD**

Advocates for embedding disability-related content into the health education



### **Living Well**

Develops and tests new approaches for Home and Community-Based Services (HCBS) for people with I/DD

## Ongoing Longitudinal Data Collection Projects of National Significance

These projects provide unique data that cannot be found anywhere else from the 50 states, the District of Columbia, and the U.S. Territories.



### **State of the States**

In Intellectual and Developmental Disabilities

KU | CENTER ON DEVELOPMENTAL DISABILITIES

### **The State of the States in Intellectual and Developmental Disabilities**

This project investigates federal, state, and local spending and program trends in I/DD services and supports.

Visit [stateofthestates.ku.edu](http://stateofthestates.ku.edu) to learn more.



ThinkWork!

**State Data**

INSTITUTE FOR COMMUNITY INCLUSION, UMASS BOSTON



### **StateData: The National Report on Employment Services and Outcomes**

This project investigates day and employment services for people with disabilities.

Visit [thinkwork.org/statedata](http://thinkwork.org/statedata) to learn more.



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### **The National Residential Information System Project (RISP)**

This project investigates data on Medicaid-funded residential and in-home supports for people with I/DD.

Visit [risp.umn.edu](http://risp.umn.edu) to learn more.