Children's Hospital of Philadelphia
PolicyLab

Democratizing Our Data Amidst the Ongoing Discontinuation of Public Health Data

Health Equity

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Reliable and consistent data are the backbone of evidence-based policymaking. Without it, identifying community needs and measuring impact becomes guesswork. When key national datasets are discontinued, like we're seeing across the country, it becomes difficult to assess the effects of policy change, track outcomes over time, and measure basic indicators of child and family well-being.

This is particularly important in the face of major cuts to safety net programs enacted in H.R.1—sweeping legislation passed by Congress in summer of 2025. Additionally, the termination of the U.S. Department of Agriculture's annual food security survey eliminates a primary national source for measuring food security, limiting policymakers' and researchers' ability to evaluate trends and, in the case of H.R. 1, understand the impact of its deep cuts to federal food assistance programs.

Similarly, staffing reductions at federal agencies, including analysts at the Department of Health and Human Services who are responsible for updating federal poverty guidelines, which underpin every means-tested

program in the country, will likely constrain capacity to collect, maintain, and update critical datasets and policymaking tools.

Reductions in capacity create gaps in our statistical infrastructure, making it more difficult to implement effective policies and assess their impact. Ultimately, this undermines health and economic well-being. In response, non-governmental groups and researchers can step up to help supplement data collection, transparency and analysis.

Children's HealthWatch is one of these groups. Our newly launched Democratizing Our Data dashboard allows advocates, researchers, journalists, and other stakeholders to generate data visualizations using more than 27 years of data collected in five cities across five states. And while no one data source can replace the important role of federal data sources and collection, by providing timely insights and trends on the health and well-being of young children and their families, this dashboard can support decision making and strengthen the ability to monitor trends in program participation and material hardships.

The Data Behind the Dashboard

Children's HealthWatch is a nonpartisan network of pediatricians, public health researchers, and child health policy experts who examine how policy decisions affect the health and well-being of young children. Since 1998, we have interviewed more than 80,000 caregivers of young children seeking care in pediatric emergency departments and primary care clinics in four cities: Boston, Minneapolis, Little Rock, and Philadelphia - and, until 2021, Baltimore. We then analyze these data to determine the impact of public policies on the health and development of young children. Here in Pennsylvania, we have been interviewing families at St. Christopher's Hospital for Children in Philadelphia since 2005.

Our work, like the research published by PolicyLab, illustrates the unique challenges facing young children and their families, including gaps and inconsistencies in public insurance coverage, fear and uncertainty among immigrant families seeking health care, and the short- and long-term consequences of household food insecurity.

Together, this research also identifies evidence-based policy solutions that improve child and family health, like the Child Tax Credit, which was expanded during the COVID-19 pandemic, other direct cash transfer programs, investments in affordable housing, and robust, accessible nutrition assistance programs.

By pairing this evidence with publicly available data that track trends in economic hardship and program participation over time, researchers and advocates can strengthen one another's work, identify emerging challenges and trends related to policy changes, and equip policymakers with timely, actionable evidence to improve programs and promote family health.

Democratizing Our Data

To address growing national data gaps and improve transparency, Children's HealthWatch has launched a new interactive dashboard that provides public access to our dataset. Alongside the dashboard, we will regularly publish Children's HealthWatch Data Snapshots — short, timely analyses that pair real-time data with policy context that will help local, state, and national decision-makers better understand urgent issues facing families with young children and respond with evidence-based solutions. The first two briefs, published in May, examine food insecurity and SNAP participation among families with young children, with a focus on post-pandemic participation declines and opportunities to strengthen access.

Our goal is simple: make high-quality data accessible and actionable. Through a user-friendly and interactive interface, anyone can generate customized graphs and charts across key issue areas, including food security, housing stability and children's health care utilization.

Data in Your Hands: Using the Dashboard

Philadelphia's residents have unique needs. Alongside other organizations providing local data, including the Philadelphia Department of Health's Philly PRAMS data dashboard, the Democratizing Our Data dashboard can help city leaders visualize them. For example, a large share of the families we interviewed in Philadelphia participate in safety net programs like nutrition and utility assistance. The dashboard shows both the participation rates of these services and the rates of material hardships across multiple aspects of family life, such as food insecurity, energy insecurity and housing stability. Among Philadelphia Children's HealthWatch participants, the rate of SNAP participation is higher and the rate of food insecurity is lower than our other sites. Philadelphia's experience may indicate that robust support for families can promote stability.

The Democratizing our Data dashboard can be used in many ways, including:

- Visualizing prevalence data for hardships Philadelphians face, such as difficulty finding and affording child care, affording utility bills, and providing nutritious foods and stable housing for their families
- Comparing differences in accessing public assistance programs among Philadelphia's diverse population, including black, white, and Hispanic immigrants and U.S. citizens
- Visualizing data on the city-level to use in reporting and advocacy – such as families' participation in public assistance programs like SNAP, WIC, and LIHEAP over the last five, ten, or twenty years to demonstrate change in need and/or policy circumstances

Reliable, transparent, and robust data enable researchers, policymakers, and the public to evaluate what's working, understand what isn't, and advocate for policies that support family health and stability. When the true state of families in Philadelphia — and the effects of public policy choices on their well-being — are unclear or incomplete, everyone is affected. Children's HealthWatch and PolicyLab both rely on strong public health data to do our work and remain committed to understanding the needs of local communities and the impact of changes to public policy on children, families and communities.