



# State-Level Data Collaborations

**Lynn A. Blewett, PhD, MA**  
**University of Minnesota, School of Public Health**  
**State Health Access Data Assistance Center (SHADAC)**

*Accelerating the Use of Findings from Patient-Centered Outcomes Research in Clinical Practice  
to Improve Health and Health Care*

National Academies of Sciences, Engineering, and Medicine

**June 17, 2022**

# State Perspective from an Equity Lens

- Promotion of equity and access from a state health policy lens requires a different approach than traditional PCORTF clinical effectiveness research
  - Different objectives
  - Different research questions
  - Different data resources
- State policy focus is on equity, access, and affordability of care
  - How better to reach and engage priority populations?
  - How to incent high quality care to low income, by race/ethnicity, via Medicaid, FQHCs?
  - What impedes access to affordable, equitable health care?
- What policy levers to states have?
  - Medicaid coverage and payment policy, MCO contract requirements
  - Private Commercial Health Insurance Market
  - State Employee Health Plan
  - State cost growth benchmarking and other cost control strategies

# Gap in the Research PCORTF Portfolio related to Health Equity

## Strategic Framework to Guide AHRQ's PCORTF Investments

<p><b>Mission:</b></p> <p>Synthesize and support the dissemination of evidence into practice and train the next generation of patient-centered outcomes researchers.</p>	<p><b>Overarching Vision:</b></p> <p>Equitable whole-person care across the lifespan.</p>	<p><b>High-level Goal:</b></p> <p>Improve health outcomes by promoting high-value, safe, evidence-based, integrated, coordinated, team-based, patient-centered care, with a focus on underserved populations.</p>
--	---	---

### High-Level Priorities and Desired Outcomes

<p><b>A. Health Equity</b></p> <p><i>Desired Outcomes</i></p> <ol style="list-style-type: none"> <li>1. Reduced health disparities for AHRQ's priority populations</li> <li>2. Engagement of underrepresented communities in training &amp; implementation initiatives</li> <li>3. Improved equity in access to needed care</li> </ol>	<p><b>B. Prevention and Improved Care of Patients With Chronic Conditions</b></p> <p><i>Desired Outcomes</i></p> <ol style="list-style-type: none"> <li>1. Increased uptake of evidence-based preventive services, early intervention, and secondary prevention</li> <li>2. Decreased fragmentation of care for patients with multiple chronic conditions (MCC)</li> <li>3. Co-design of innovations in care with patients and communities</li> </ol>	<p><b>C. Patient, Family, and Provider Experience of Care That Enhances Trust in the Healthcare System</b></p> <p><i>Desired Outcomes</i></p> <ol style="list-style-type: none"> <li>1. Improved patient/ family engagement and reported experience of care</li> <li>2. Focus on whole-person care, with attention to mental health &amp; social determinants of health (SDOH)</li> <li>3. Improved provider wellness and retention</li> </ol>	<p><b>D. High-Quality, Safe Care That is Aligned With National Health Priorities</b></p> <p><i>Desired Outcomes</i></p> <ol style="list-style-type: none"> <li>1. Transformation of healthcare organizations into learning health systems</li> <li>2. Increased uptake of evidence-based practices that strengthen healthcare quality, safety, and value</li> <li>3. Improved outcomes for targeted national priority conditions</li> </ol>	<p><b>E. Primary Care Transformation</b></p> <p><i>Desired Outcomes</i></p> <ol style="list-style-type: none"> <li>1. Uptake of new models of primary care, leveraging digital healthcare</li> <li>2. Integrated team-based behavioral health</li> <li>3. Identification and provision of needed resources for comprehensive primary care and uptake of evidence</li> </ol>
--	---	--	---	---

### Cross-cutting Strategies for Achieving Desired Outcomes

- Train and support the next generation of health service researchers with a focus on team science and advancing health equity.
- Develop and maintain the AHRQ infrastructure needed to synthesize and accelerate evidence to practice.
- Leverage and support innovation in digital health, clinical decision support, and new models of care.
- Build data, measurement, and analytic capacity to benchmark and evaluate uptake and use of evidence in learning health systems to improve outcomes that matter to patients.
- Accelerate the uptake of evidence in practice to optimize individual and population health and achieve health equity for all.
- Disseminate evidence to Federal/State/local healthcare decision makers with targeted communication strategies.
- Provide the evidence to inform policy changes needed for sustainable implementation and incorporation of evidence by healthcare systems, practices, and providers.
- Evaluate the impact of PCORTF investments on care delivery, quality, costs, health outcomes, and health disparities.

# About AHRQ's Priority Populations

- The Healthcare Research and Quality Act of 1999 (Public Law 106-129) established an Office of Priority Populations within the Agency for Healthcare Research and Quality (AHRQ) to conduct and support research and evaluation, and support demonstration projects with respect to:
- The delivery of healthcare within [inner cities and rural areas](#); and
- Healthcare for priority populations, which include:
  - [Low income populations](#)
  - [Racial/Ethnic Minorities](#)
  - [Women](#)
  - [Children/Adolescents](#)
  - [Elderly](#)
  - [Individuals with special healthcare needs](#)
- On May 18, 2021, AHRQ released an updated Policy on the Inclusion of Priority Populations in Research ([NOT-HS-21-015](#)), which expanded the definition of priority populations to include those groups identified in Section 2(a) of Executive Order 13985 as members of underserved communities: ***Black, Latino, and Indigenous and Native American persons, Asian Americans and Pacific Islanders and other persons of color; members of religious minorities; lesbian, gay, bisexual, transgender, and queer (LGBTQ+) persons; persons with disabilities; persons who live in rural areas; and persons otherwise adversely affected by persistent poverty or inequality.***

# Need for focused research and data development infrastructure at the state level to support national progress on health equity

- New projects with a focus on priority populations
- New research from an equity lens
- New data development and infrastructure for state Medicaid data and public programs
  - ✓ Measurement
  - ✓ Medicaid
  - ✓ Social Determinants of Health

## ✓ Measurement: Need for good reliable self-reported data on Race and Ethnicity

- Critical to understanding and addressing health disparities
- Challenging for providers and insurers
- Federal survey data a potential data source that collects self-reported race/ethnicity
  - *Use of Survey prompts and imputation to improve reliability and consistency of information*
- Can be powerful tool for Medicaid programs to measure social determinants of health to address health equity

Gaps in existing Medicaid claims, EHR and claims based data sources

# Race/Ethnicity Data in the American Community Survey

Variable(s)	Definition	Response Categories	Notes
<b>RACE</b>	Self-reported race	<ul style="list-style-type: none"> <li>&gt; White</li> <li>&gt; Black/African American</li> <li>&gt; American Indian or Alaska Native</li> <li>&gt; Chinese</li> <li>&gt; Japanese</li> <li>&gt; Other Asian or Pacific Islander</li> <li>&gt; Other race</li> <li>&gt; Two major races</li> <li>&gt; Three or more major races</li> </ul>	<p>Analysts frequently collapse categories and combine with ethnicity (HISPAN) to create race/ethnicity variables with fewer categories and/or categories that are mutually exclusive.</p> <p>Users can also choose to view the <b>detailed codes</b>, which include up to 252 categories depending on the year.</p>
<b>RACAMIND</b> <b>RACASIAN</b> <b>RACOTHER</b> <b>RACBLK</b> <b>RACWHT</b> <b>RACPACIS</b>	Bivariate indicator of whether person reported a specific race	<ul style="list-style-type: none"> <li>&gt; No</li> <li>&gt; Yes</li> </ul>	These variables can be used in combination with RACNUM to identify specific race combinations.
<b>RACNUM</b>	Total number of major race groups reported	<ul style="list-style-type: none"> <li>&gt; One to six</li> </ul>	<p>Major race groups include:</p> <p>American Indian, Asian, black, Native Hawaiian or other Pacific Islander, white, and some other race.</p>
<b>HISPAN</b>	Identifies persons of Hispanic/ Spanish/Latino(a) origin and classifies based on country of origin when possible	<ul style="list-style-type: none"> <li>&gt; Not Hispanic</li> <li>&gt; Mexican</li> <li>&gt; Puerto Rican</li> <li>&gt; Cuban</li> <li>&gt; Other</li> <li>&gt; Not Reported</li> </ul>	Users can also choose to view the <b>detailed codes</b> , which include up to 59 categories depending on the year.

# SHADAC Work on Measure Development

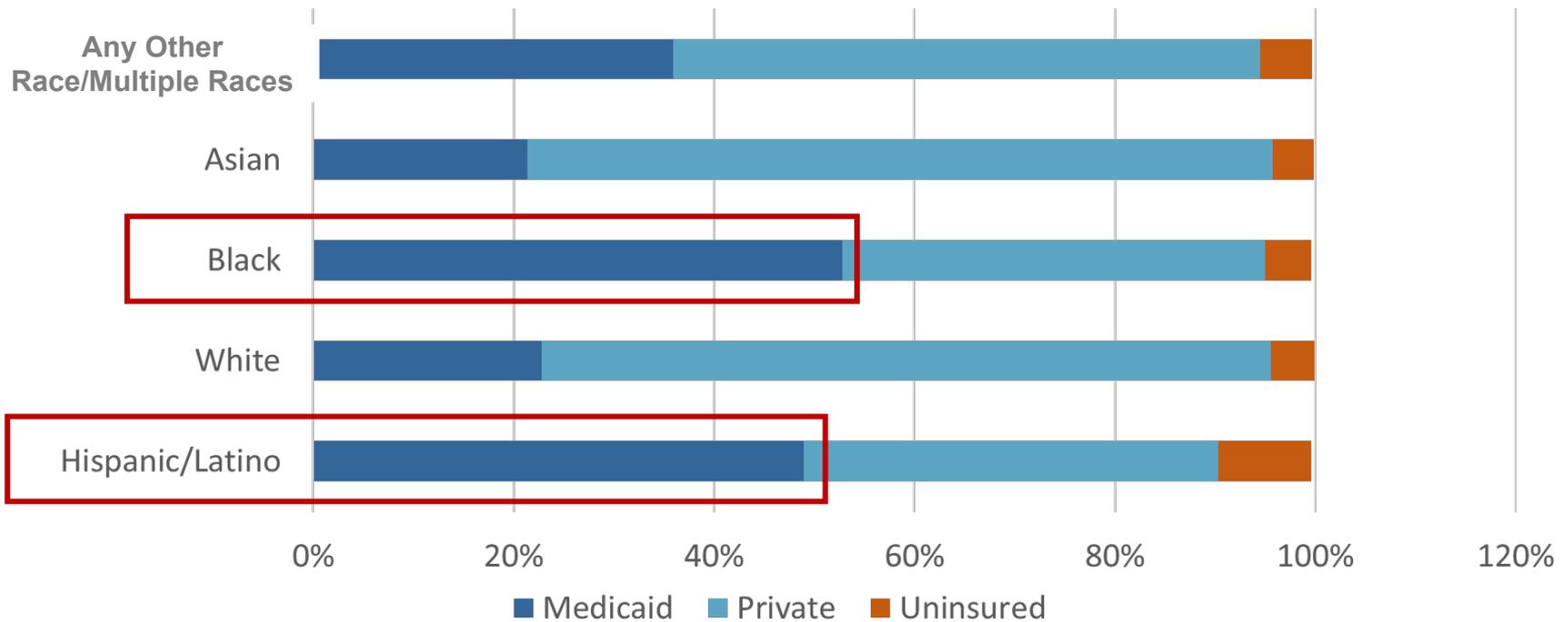
- Funded by the Robert Wood Johnson Foundation through a grant from the State Health Value and Strategies – Princeton, NJ
  - More-complete, high-quality data are needed to support reliable analyses on health equity
  - Working with state Medicaid data analysts to improve data collection and reporting on race/ethnicity, sexual orientation and gender identification (SOGI), and disability status
    - *How best to encourage Medicaid beneficiaries to share optional data on these topics*
  - Many states want to go beyond OMB standards – use this as a floor not a ceiling – but they have limited guidance on how
    - Translational work to turn evidence into best practices on data collection and policy changes
    - Efforts to operationalize policy preferences based on the available evidence and research. *If there's not some mechanism for translation, even the best research might have trouble making inroads into Medicaid policy.*
    - Analysis of state-level data to tailor improvements to their populations, policy goals

**Need for additional funding and research on best practices and translation, expanded OMB standard development and guidance on flexibility, and incentives for state engagement**

# ✓ Needed focus on the Medicaid Program: Medicaid/CHIP plays a key role for equitable access to quality care

53% of U.S. Black Children and 49% of Hispanic/Latino children are covered by Medicaid/CHIP

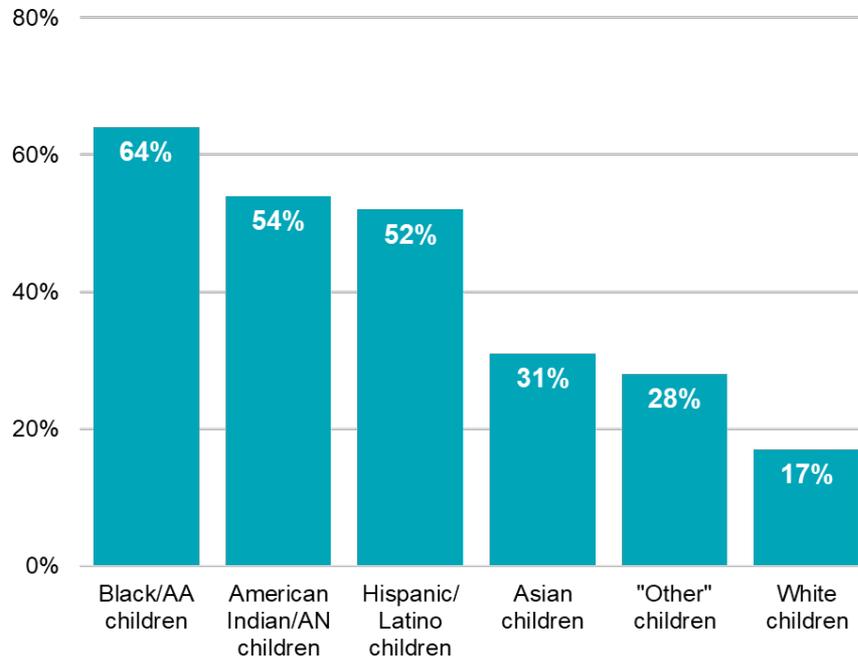
Distribution of Health Insurance Coverage by Race/Ethnicity – Ages 0-18, 2019



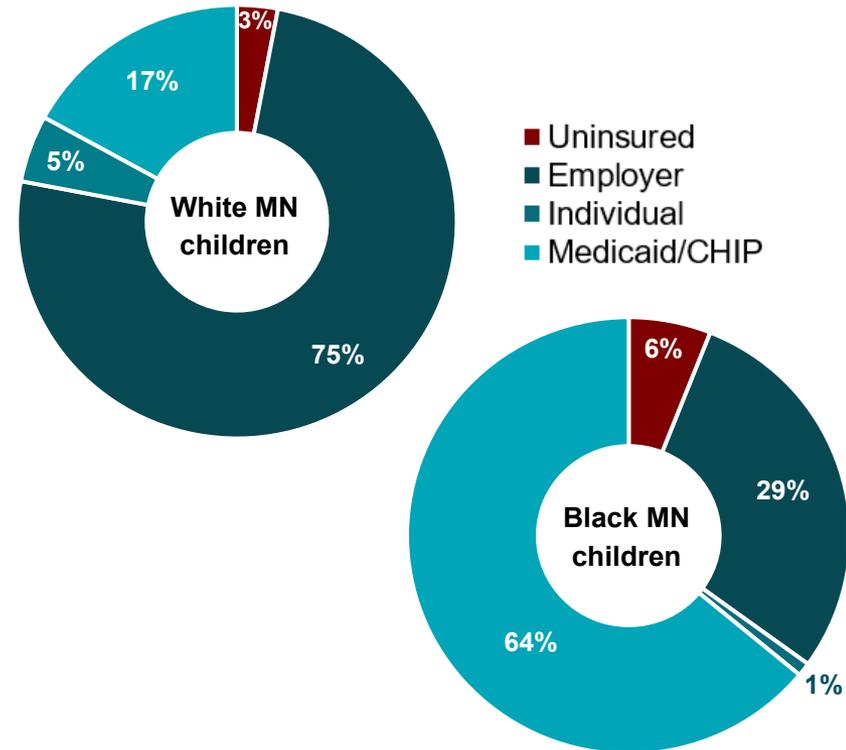
Source: SHADAC analysis of 2019, American Community Survey

# For some states, the role Medicaid plays is even greater....

**Percent of Minnesotan Children with Medicaid as Source of Coverage, by race, 2018**



**Source of Coverage for Minnesotan Children, by race, 2018**



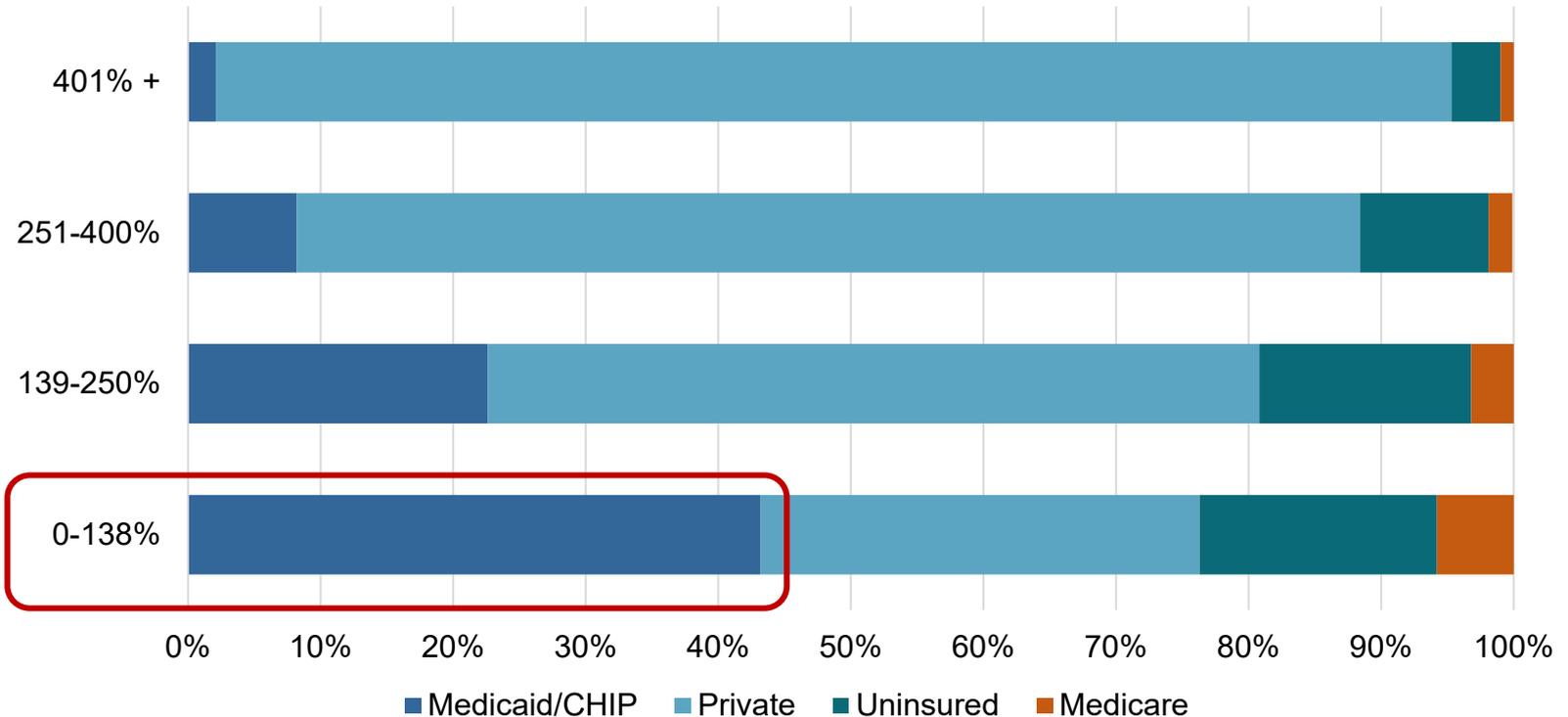
Note: \*Adjustments were made to account for low sample

Source: SHADAC analysis of the 2018 American Community Survey (ACS) Public Use Microdata Sample (PUMS) files.

# Medicaid/CHIP are critical coverage programs for low-income populations, 2019

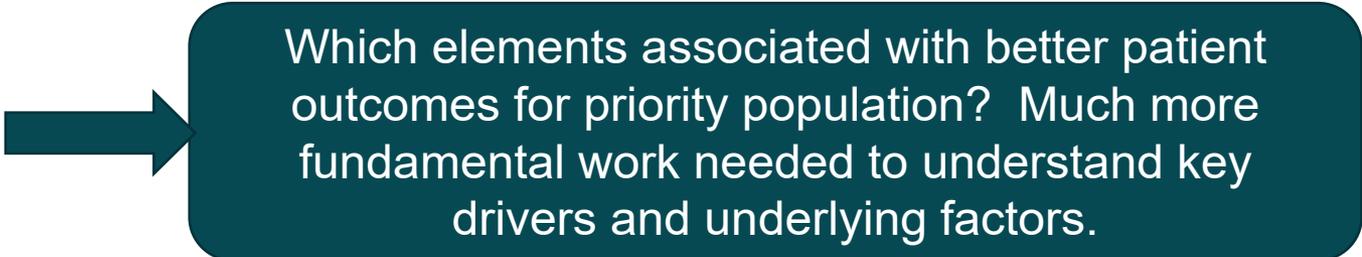
43% of people ages 0-64 under 138% of FPG are covered by Medicaid

Distribution of Health insurance Coverage by Income, Age 0-64, 2019



# How to leverage Medicaid to promote equity in access to quality care to improve health outcomes?

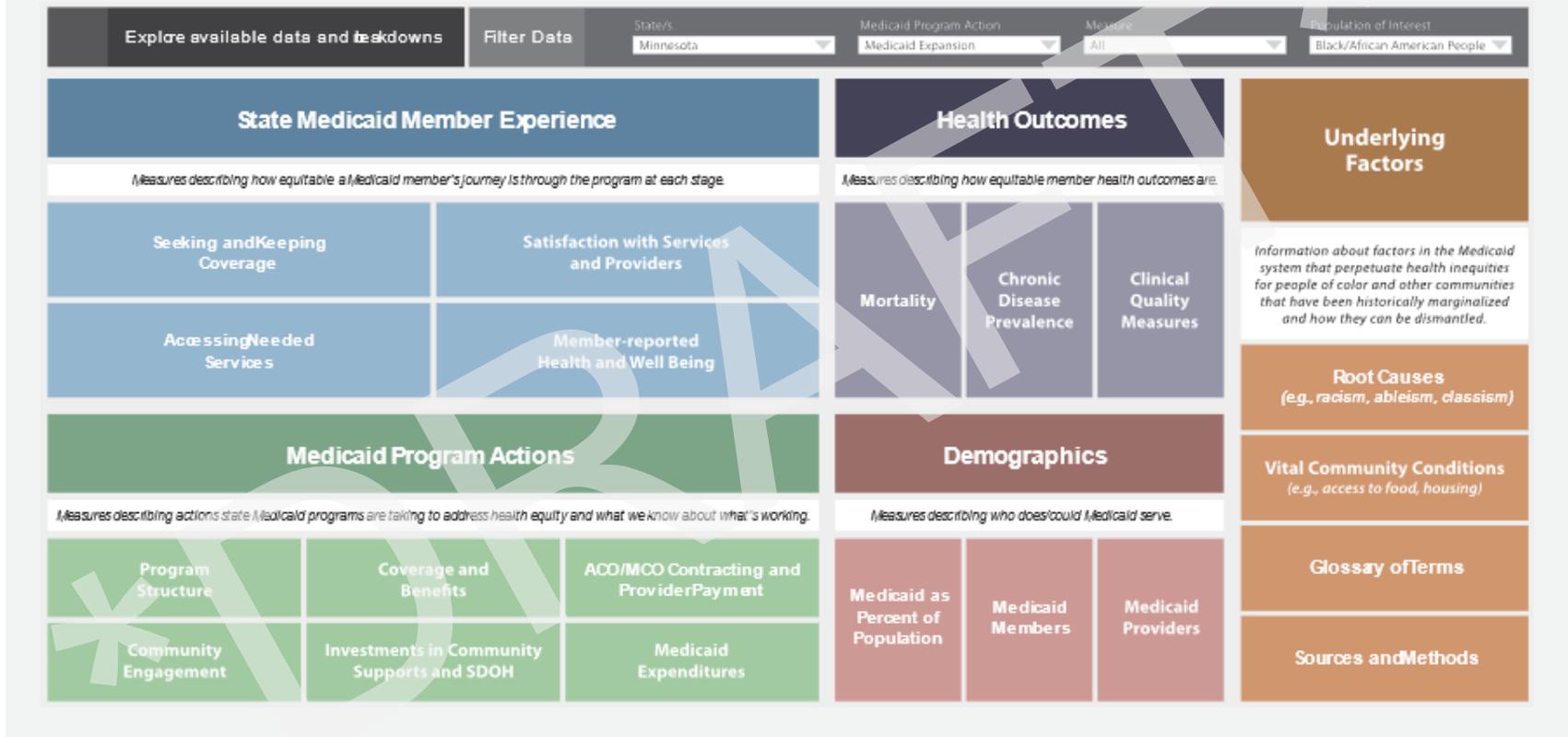
- Developing data infrastructure
- Use targeted state-level research and focus to demonstrate role of key social, medical and other factors driving poor health outcomes and high health care costs
- Develop framework for understanding underlying factors and root causes and vital community conditions that can drive health and health care
  - Use this knowledge to change the trajectory of health disparities and inequitable access to needed care



Which elements associated with better patient outcomes for priority population? Much more fundamental work needed to understand key drivers and underlying factors.

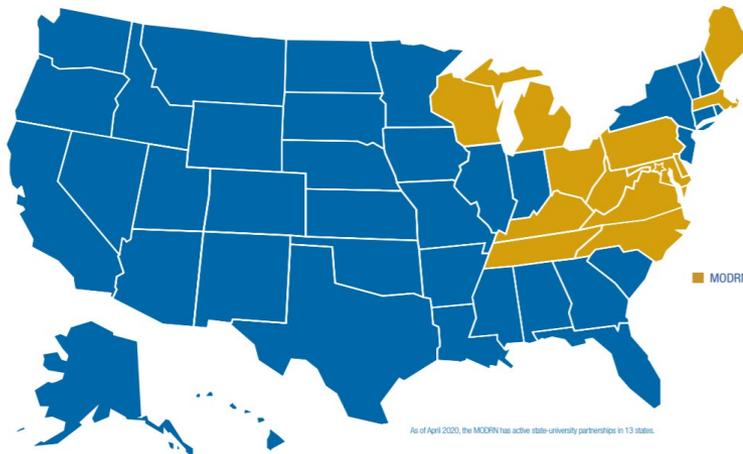
# Example #1 State Collaboration: Potential State Data Infrastructure - RWJF-Planning Funds for a Data Equity Monitoring Tool (SHADAC 2022)

Exhibit 5. Medicaid Equity Monitoring Tool “Wireframe”



# Example #2: Medicaid Outcomes Distributed Research Network (MODRN)

- Conducts multi-state Medicaid data analyses to facilitate learning among Medicaid agencies
- Builds on AcademyHealth's State-University Partnership Learning Network (SUPLN) and Medicaid Medical Director Network
- Data distributed network allows states to retain their own data while facilitating comparisons to other state outcomes.
  - Common data definitions, statistical code, outcome measures
- 13 university-state partnerships now participate



First project focused on opioid use disorder (OUD), but analytic infrastructure can be applied to any Medicaid-related topic

# MODRN - Informing behavioral health performance measurement in Medicaid



Addiction / Accepted Articles

RESEARCH REPORT

Duration of Medication Treatment for Opioid-Use Disorder and Risk of Overdose among Medicaid Enrollees in Eleven States: A Retrospective Cohort Study

Marguerite Burns , Lu Tang, Chung-Chou H. Chang, Joo Yeon Kim, Katherine Ahrens, Lindsay Allen, Peter Cunningham, Adam J. Gordon, Marian P. Jarlenski ... [See all authors](#) ▾

## Results

- Rates of outpatient follow up after emergency dept visit for OUD were low
- Follow-up not protective against overdose in all states
- Only 2 states drove the small average risk reduction across 11 states
- Reveals the value of multi-state analyses
- Potential revisions to NCQA measure needed

## Results

- Longer treatment durations convey large reduction in overdose risk
- Findings consistent across states
- Suggest performance measurement and incentives for providers/ MCOs should focus on longer treatment durations than 180 days

# What about Transformed Medicaid Statistical Information System (T-MSIS)?

In 2019, CMS released the first T-MSIS (Transformed-MSIS) Analytic Files (TAF), the latest generation of federal Medicaid claims data that replaced the now retired Medicaid Analytic eXtract (MAX).

- CMS Medicaid data files are welcome and improving
- Concern about completeness in some critical areas
  - 30 states did not submit acceptable data for inpatient managed care encounters (GAO 2021)
  - 22 states with high concern or unusable for race/ethnicity (SHADAC 2022)
- Cost for access and high bar for skill in access and use
- Continued need to support state capacity and incentives for better data quality

# Race and Ethnicity Data Quality Assessment, 2019 T-MSIS Analytic File (TAF)

Data quality assessment	Percent of beneficiaries with missing race/ethnicity values	Number of race/ethnicity categories where TAF differs from ACS by more than 10%	Number of states	States
Low Concern	≤10%	0	15	AK, CA, DE, MI, NE, NV, NM, NC, ND, OH, OK, PA, SD, VA, WA
Medium Concern	≤10%	1 or 2	2	ID, IL
	10-20	0 or 1	12	FL, GA, IN, KY, ME, MN, MS, NH, NJ, TX, VT, WI
High Concern	≤10%	3 or more	0	-
	10-20%	2 or more	1	OR
	20-50%	Any value	16	AZ, AR, CO, CT, DC, HI, IA, LA, MD, MO, MT, NY, SC, UT, WV, WY
Unusable	≥50%	Any value	5	AL, KS, MA, RI, TN

**Notes:** Though the T-MSIS includes all 50 states, the District of Columbia (D.C.), and the U.S. territories of Puerto Rico and the Virgin Islands, the latter two territories are excluded from the 2019 TAF (Data Version: Release 1) because they do not have 2019 Data Quality (DQ) Assessments or other associated information in the DQ Atlas and are therefore considered “unclassified.”

**Source:** Medicaid.gov. (n.d.). *DQ Atlas: Race and Ethnicity [2019 data set]*. Available from <https://www.medicaid.gov/dq-atlas/landing/topics/single/map?topic=g3m16>. Accessed December 17, 2021.

# Example #3: State Collaboration: AcademyHealth's Medicaid Data Learning Network (MDLN)

- **Partners:** Boston University, Cornell University, Oregon Health & Science University and the University of Pittsburgh
- **Funders:** The Commonwealth Fund and the Robert Wood Johnson Foundation
- **Objective:** To provide a forum for teams of academic researchers using T-MSIS analytic files (TAF) to share learnings, address limitations and identify best practices with the dataset for application with the broader health services research community. To share learnings with CMS, as well as state Medicaid agencies, on steps to improve the quality of the Analytic Files over time.
- **Current MDLN Research Teams:**
  - *Boston University*
  - *Brown University*
  - *Cornell University*
  - *Dartmouth University*
  - *Drexel University*
  - *Harvard University*
  - *Oregon Health & Science University*
  - *Rutgers University*
  - *University of North Carolina*
  - *University of Southern Maine*
  - *Yale University*



# Social Determinants of Health

*Data not typically found in Electronic Health Records or in Medical Claims Data*

Figure 1: Social Determinants of Health – Five Domains

Economic Stability	Education	Health and Health Care	Neighborhood and Built Environment	Social and Community Context
<ul style="list-style-type: none"><li>• Poverty</li><li>• Employment</li><li>• Food Security</li><li>• Housing Stability</li></ul>	<ul style="list-style-type: none"><li>• High school graduation</li><li>• Language and literacy</li><li>• Early childhood education</li></ul>	<ul style="list-style-type: none"><li>• Access to health care</li><li>• Access to primary care</li><li>• Health literacy</li></ul>	<ul style="list-style-type: none"><li>• Access to healthy food</li><li>• Quality of housing</li><li>• Crime and violence</li><li>• Environmental conditions</li></ul>	<ul style="list-style-type: none"><li>• Social cohesion</li><li>• Civic participation</li><li>• Incarceration</li><li>• Discrimination</li></ul>

Patients who are socially isolated, experience housing instability or food insecurity, and have limited transportation options have been consistently shown to have worse health outcomes than other patients, even when appropriate health care interventions are prescribed or recommended (NEJM 2020)

# ACS Content Relevant to SDOH and Health Equity

Demographic	Social	Economic	Housing
<p><b>Race/Ethnicity</b></p> <p><b>Age</b></p> <p><b>Citizenship</b></p> <ul style="list-style-type: none"> <li>› Place of Birth</li> <li>› Ancestry</li> <li>› Year of Entry</li> </ul> <p><b>Language</b></p> <ul style="list-style-type: none"> <li>› Spoken at home</li> <li>› English proficiency</li> <li>› Linguistic isolation</li> </ul> <p><b>Migration</b></p> <ul style="list-style-type: none"> <li>› Moved within same state, from another state, or abroad in past year</li> </ul> <p><b>Household makeup</b></p> <ul style="list-style-type: none"> <li>› Single-parent families</li> <li>› Multifamily households</li> </ul>	<p><b>Disability</b></p> <ul style="list-style-type: none"> <li>› VA-related</li> <li>› Type (cognitive, vision, hearing, other physical self-care)</li> </ul> <p><b>Educational Attainment</b></p> <p><b>Health Insurance</b></p>	<p><b>Income/Poverty Status</b></p> <ul style="list-style-type: none"> <li>› Family level</li> <li>› Health insurance unit (to determine eligibility for Medicaid and subsidies)</li> </ul> <p><b>Employment</b></p> <ul style="list-style-type: none"> <li>› Status</li> <li>› Labor force participation</li> </ul> <p><b>Other public programs</b></p> <ul style="list-style-type: none"> <li>› Income support</li> <li>› Supplemental Nutrition Assistance Program (SNAP)</li> </ul> <p><b>Transportation</b></p> <ul style="list-style-type: none"> <li>› Vehicles available</li> <li>› Commuting to work</li> </ul>	<p><b>Type and occupancy</b></p> <ul style="list-style-type: none"> <li>› Type (multi-unit, mobile home, group quarters)</li> <li>› Owner/renter</li> <li>› Time at address</li> </ul> <p><b>Housing Costs</b></p> <ul style="list-style-type: none"> <li>› Monthly rent</li> <li>› Monthly ownership costs</li> <li>› Annual heating costs</li> <li>› Annual water costs</li> </ul> <p><b>Technology/Communication</b></p> <ul style="list-style-type: none"> <li>› Phone</li> <li>› Computers/other devices</li> <li>› Internet connectivity</li> </ul> <p><b>Housing conditions</b></p> <ul style="list-style-type: none"> <li>› Kitchen facilities</li> <li>› Refrigerator</li> <li>› Plumbing facilities</li> <li>› Bathtub or shower</li> <li>› Piped water</li> <li>› Rooms per person (crowding)</li> </ul>

# Substate Geographic Areas Available in ACS One-Year and Five-Year Summary Tables

Geography	Total	One-year	Five-year
Congressional Districts	435	All	All
Metro & Micro Statistical Areas	929	56%	All
Counties	3,220	26%	All
School Districts	13,642	7%	All
Zip Code Tabulation Areas	33,120	None	All
Census Tracts	74,001	None	All
Block Groups	220,333	None	All

Source: U.S. Census Bureau. (2018). *Understanding and Using American Community Survey Data: What All Data Users Need to Know*. Retrieved on November 1, 2019 from [https://www.census.gov/content/dam/Census/library/publications/2018/acs/acs\\_general\\_handbook\\_2018.pdf](https://www.census.gov/content/dam/Census/library/publications/2018/acs/acs_general_handbook_2018.pdf).

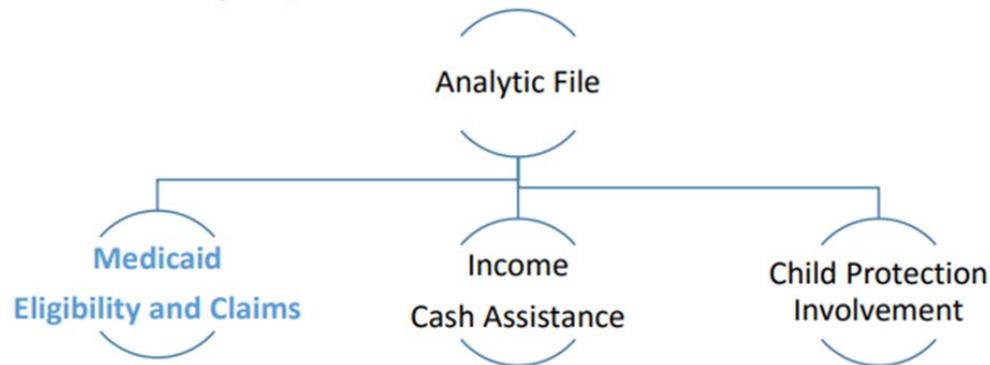
## Example #4: Use of SDOH Analysis in Medicaid Payment Policy

- State Medicaid payment policy focus on improving value
  - Efficient care delivery and improved patient outcomes
- Acknowledging the fact that patients with medical as well as **social risk factors** are more likely to have worse health outcomes and higher costs
- Risk-adjusting health care payments and/or quality measures based on social factors that place patients at higher risks
- Examples:
  - Accountable Care Organizations (Minnesota)
  - Managed Care Organizations Capitation (Massachusetts)

**A key challenge to incorporating social risk factors into risk-adjustment methodologies is filling data gaps, since health care historically hasn't systematically collected data on issues such as food insecurity, transportation access, and housing stability.**

# Minnesota Integrated Health Partnerships – Medicaid Accountable Care Organization (ACO)

- Base rate for the population-based payments will vary by the risk and social complexity of each IHP’s attributed population, with additional payments to account for the complexity and difficulty of managing care for those experiencing the identified ***social risk factors***.



- Demographics (age, gender, race geography)
- Enrollment (length, disability status)
- Medical & behavioral health (diagnoses)
- Social risk factors (child/adult)
  - Language
  - Several parental risk factors
- Outcomes:
  - Mortality
  - Morbidity
  - Disability
  - Health care use
  - Health care access
  - Health care quality, HEDIS
  - Health costs

- Social risk factors:
- Income & poverty levels

- Social risk factors:
- Children with involvement from child protection

*The data set includes more than 100 variables, both independent and dependent variables.*

Disability as a population group should be further examined.

# Minnesota's Approach to Social Risk Factor Adjustment

## All obtained from administrative data and/or claims

### Adults

- Diagnosis of substance use disorder (SUD), serious mental illness (SMI) or sever and persistent mental illness (SPMI)
- Deep poverty (income below 50%) FPL
- Homelessness: Self-reported or address determined to be a homeless shelter or nonresidential address
- Past incarceration

### Children

- *Parent with* diagnosis of substance use disorder (SUD), serious mental illness (SMI) or sever and persistent mental illness (SPMI)
- *Parent in* Deep poverty (income below 50%) FPL
- *Parent with* homelessness: Self-reported or address determined to be a homeless shelter or nonresidential address
- *Parent with* past incarceration
- *Involvement with child protective services*

# Massachusetts use of Social Risk Factor Adjustment in Medicaid Managed Care Payments

- Risk adjusting payments to Medicaid Managed Care Organizations (MCOs) since 2016 and Accountable Care Organizations (ACOs) since 2018
- Massachusetts has developed a hybrid approach using both ***administrative and survey data (American Community Survey)***.
- Goal was to “*mitigate the incentive [they] might otherwise have to limit care or avoid members with greater health care needs,*” recognizing that individuals with social risk factors may face additional needs and greater challenges to optimal health outcomes.



Early evaluations of the Massachusetts model have found that adding social determinants and related variables to risk scores strengthens the predictive power of risk adjustment and yields more accurate payments to MCOs.

# Massachusetts Hybrid Approach

- Developed an index using variables from the ACS as a proxy for individuals' own social risk factors
- Used enrollees' addresses on file to develop **census block** indicators
- Developed a “Neighborhood Stress Score”
  - % of families with incomes < 100% FPL
  - % of families with incomes < 200% of FPL
  - % of adults who are unemployed
  - % of households receiving public assistance
  - % of households with no car
  - % of household with children and a single parent
  - % of people age 25+ with no high school degree

## Plus - Housing Instability Measure

- ICD10 – Z code for Homelessness
- Three or more addresses on file in single calendar year
- Interaction of housing with medical risk scores including whether an individual had an SMI and/or SUD

**States may be able to encourage the use of Z codes by requiring MCOs to enter into value-based care arrangements with providers, and by clarifying the rules governing providers' collection and use of social needs data.**

# The Z-code dilemma

- Z-codes offer potential for systematically recording individual-level SDOH -*But providers don't widely use them because they have little incentive*
- **Massachusetts' rationale:** If we give providers a financial incentive to use Z-codes (housing) by using them to adjust payments, then providers may become more systematic in their use

## Z code

### Categories

**Z55** - Problems related to education and literacy

**Z56** - Problems related to employment and unemployment

**Z57** - Occupational exposure to risk factors

**Z59** - Problems related to housing and economic circumstances

**Z60** - Problems related to social environment

**Z62** - Problems related to upbringing

**Z63** - Other problems related to primary support group, including family circumstances

**Z64** - Problems related to certain psychosocial circumstances

**Z65** - Problems related to other psychosocial circumstances

Tying certain Z-codes to payment or quality measure performance, for instance—a state's Medicaid program could drive greater use of these codes by providers.

# Massachusetts' Approach to Social Risk Adjustment

## Administrative/ Claims Data

- Disability determined by status as client of state Departments of Mental Health or Developmental Services, Or Medicaid Eligibility due to disability
- Behavioral health diagnosis of SMI, SUD, or Opioid Use Disorder (OUD)
- Housing problems of homelessness or housing instability determined by z-code or at least three addresses on file in a single year
- Rural area, based on classification of beneficiary address

## Survey Data – American Community Survey

Neighborhood Stress Score Index – Census Block

- Families with incomes less than 100% FPL
- Families with incomes less than 200% of FPL
- Adults who are unemployed
- Household receiving public assistance
- Households with no car
- Households with children and a single parent
- People aged 25 or older without a high school diploma

# Gaps in PCORTF Research Portfolio

- Incomplete data on race/ethnicity, SOGI, disability in PCOR-funded research
  - If they aren't measured, they don't exist
  - Foundational research on getting people to respond, the right categories, how to build trust and educate on use of information
  - Community engagement
- Lack of understanding and research on the role of community context, poverty, structural racism and social determinants of health in health outcomes
- Limited understanding of the complex network of safety net providers that are not often represented in clinical trials or comparative-effectiveness research but serve vulnerable and other priority populations and provide unique access to needed care
- Limited understanding of the role of Medicaid strategies in increasing access to quality care for its enrolled populations – a key payer of health care services to priority populations

# Recommendations

- Fund research to accumulating evidence to support the role that social risk factors overlap with clinical indicators in patient outcome research acknowledging that, to promote a better understanding of the ways in which social context affects disease burden.
- Fund and prioritize proposals that promote partnership with state/local data organizations with local researchers to answer relevant policy questions and build data infrastructure
  - Use of Medicaid data and research on role of social determinants
  - Building and promoting use of regional social need indices
  - Building partnerships with state agencies and University-based researchers
    - State University Partnership Learning Network (SUPLN) - AcademyHealth
    - Medicaid Outcomes Distributed Research Network (MODRN) – University of Pittsburgh
  - Support state health data organizations linked to Policy
    - State All Payers Claim Data Bases
    - Minnesota Community Measurement
- Fund convening of state policy organizations that work with communities and policy makers on their information and research needs to develop research priorities and opportunities for policy-related research – linking researchers with policy makers and facilitating the translation of policy priorities into action
- Support research that includes the development of measures and mechanisms to capture valid and reliable self-report of race/ethnicity, SOGI and Disability status
  - Using CBO guidelines as a floor for data collection, not the ceiling
  - Build state and local capacity for community engagement

# References

- Risk Adjustment Based on Social Factors: State Approaches to Filling Data Gaps Prepared by State Health Access Data Assistance Center at the University of Minnesota for State Health and Value Strategies. August 2020. [https://www.shadac.org/sites/default/files/FINAL\\_SHVS-Risk-Adjustment-Brief.pdf](https://www.shadac.org/sites/default/files/FINAL_SHVS-Risk-Adjustment-Brief.pdf)
- State Strategies: Using Social Determinants of Health Data in Medicaid Managed Care. Presentation. State Health and Value Strategies. June 21, 2017. <https://www.shvs.org/wp-content/uploads/2017/05/SHVS-SDOH-Webinar-Slide-Set-2017-6-19-final-6-21-17.pdf>
- Agrawal, Shantanu K and William H. Shrank. Clinical and Social Risk Adjustment – Reconsidering Distinctions. The New England Journal of Medicine. Perspective. April 23, 2020. <https://bookcafe.yuntsg.com/ueditor/jsp/upload/file/20200520/1589939685826004455.pdf>
- Seifert, R.W., & Love, K.A. (2018). What to know about ACOs: An introduction to MassHealth Accountable Care Organizations. Retrieved from [https://www.bluecrossmafoundation.org/sites/default/files/download/publication/ACO\\_Primer\\_July2018\\_Final.pdf](https://www.bluecrossmafoundation.org/sites/default/files/download/publication/ACO_Primer_July2018_Final.pdf).
- Massachusetts' revised risk adjustment methodology also includes some measures that are not necessarily social risk factors, such as interaction measures specific to children—ages 0-14 and 15-20—between age and medical risk scores, to account for the particular health care costs for children with complex medical situations compared to healthy children
- Jones, Jim and Siam Muller. Social determinants of health and Medicaid payments: Steps states can take to factor social determinants of health into Medicaid payment policies. Deloitte Insights. November 8, 2018. <https://www2.deloitte.com/us/en/insights/industry/public-sector/medicaid-social-determinants-of-health.html>
- General Accounting Office. Data Completeness and Accuracy Have Improved, Though Not All Standards Have Been Met. January 2021. GAO-21-196 <https://www.gao.gov/assets/gao-21-196.pdf>

# About the State Health Data Assistant Center SHADAC

[www.shadac.org](http://www.shadac.org)

SHADAC is a multidisciplinary health policy research center with a focus on state policy. For 20 years, SHADAC has produced rigorous, policy-driven analyses, translating complex research findings into actionable information that is accessible to a broad audience. SHADAC faculty and staff are nationally recognized experts on collecting and applying health policy data to inform or evaluate policy decisions, with expertise in both federal and state survey data sources. We provide unbiased technical assistance and in-depth analysis to states and other organizations and collaborate with a wide range of partners including foundations, state and federal agencies, academic institutions, other research organizations, and nonprofits.

# Thank you!

## Lynn A. Blewett, PhD

Director, State Health Access Data Assistance Center  
University of Minnesota, School of Public Health

Check out our website at [www.shadac.org](http://www.shadac.org) and  
follow us on Twitter: [@shadac](https://twitter.com/shadac) [@lynnblewett](https://twitter.com/lynnblewett)

