CHCS Center for Health Care Strategies, Inc.

Data Across Sectors for Health

Advancing Health, Equity, and Well-Being through Community-State Data-Sharing Partnerships: Thought Leader Insights

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IN BRIEF

Communities throughout the nation are innovating to coordinate efforts across public health, health care, and social services sectors to address community members' needs in a more collaborative way through relationship building and information/data-sharing. These multi-sector data-sharing partnerships can also connect with state policymakers who can contribute unique tools and levers to advance local-level efforts, and potentially guide broader policy, programs, and systems change. To support communities to strengthen and leverage relationships with state agencies in support of data-sharing efforts, *Data Across Sectors for Health*, in partnership with the Center for Health Care Strategies and with support from the Robert Wood Johnson Foundation, is leading a new national initiative called *Learning and Action in Policy and Partnerships* *(LAPP)*.[†]

This report describes contributing success factors and emerging opportunities for advancing community and state-level, multi-sector data sharing partnerships to improve health, well-being and advance equity. It highlights examples of: (1) current priorities in the context of COVID-19, an economic recession, and rising calls for racial justice; (2) new and emerging opportunities in support of data-sharing efforts; and (3) key ingredients for successful multi-sector data sharing efforts to improve health and advance equity. While the report is intended to inform and encourage applications for LAPP, the lessons herein can be applied in other multi-sector community-state data-sharing partnerships across the country.

As part of its focus on strengthening alignment among public health, health care, and social services sectors, the Robert Wood Johnson Foundation is supporting Data Across Sectors for Health (DASH) in partnership with the Center for Health Care Strategies (CHCS) to lead a funding opportunity that supports communities to strengthen and leverage relationships with state agencies in support of data-sharing efforts. *Learning and Action in Policy and Partnerships* (LAPP) will enable communities to bolster state partnerships to better inform comprehensive policy and systems alignment at both the community and state level.

Increasingly, communities are testing new ways to improve health, equity, and well-being by sharing data among public health, health care, and social services systems. In addition to leading data-sharing efforts at a local level, community partners can also connect with state policymakers that have various levers to support efforts to improve health, especially within communities most at risk of inequities. These levers include:

- **Data access:** Community-level data can drive integration and inform state policy, and states may have data that is needed by communities.
- **Policy and legal clarity:** As needed, states can clarify and amend regulations that govern how and what data can be shared.
- **Shared services and systems:** States may develop or purchase systems that can be made available to communities (e.g., health information exchanges, social services referral platforms).
- **Interoperability rules:** Communities and states may play a role in developing standards or guidance to ensure data can be linked across sectors.
- **Financing:** States can change how services are paid for and what metrics need to be captured to align incentives and accountability, and can also invest in community-level infrastructure development.
- **MCO contracting:** States can integrate language into managed care organization (MCO) contracts that encourage collaboration with communities (e.g., social services referrals).

[†] The application deadline to participate in Learning and Action in Policy and Partnership is December 16, 2020. To learn more and apply, visit https://dashconnect.org/funding-opportunities/lapp/.

Sharing data across sectors and building relationships among community and state partners can inform decision-making to improve community health and well-being, strengthen systems of care, and break down silos that perpetuate disparities and create barriers to health. Events in 2020, including the COVID-19 pandemic, the economic recession, social uprisings, and the demand for racial justice, heighten the need for efforts to improve health, equity and well-being.

Community-State Data Partnerships: Opportunities for Success

To support the design and implementation of the LAPP program, DASH and CHCS undertook an exploration ("Opportunity Analysis" (OA)) of the success factors and opportunities for advancing community and state-level multi-sector data sharing partnerships to advance health, well-being, and equity. The OA sought to glean insights from thought leaders at the national, state, and local levels regarding: (1) new and emerging opportunities at the federal level to support data-sharing; (2) current priorities in the context of COVID-19, the economic recession, and rising calls for racial justice; and (3) key ingredients for successful multi-sector data-sharing efforts to improve health and advance equity.

Through interviews with more than 30 individuals, including state officials, leaders of community-based organizations, and other relevant subject matter experts, DASH and CHCS aimed to answer key questions, including:

- What are specific opportunities to leverage improved data-sharing through state-community partnerships to achieve health or equity outcomes?
- What are examples of successful community-state multi-sector data sharing efforts to improve health/advance equity? What were the contributing success factors?
- What are the potential effects and/or leverage opportunities associated with new federal resources (e.g., from the Coronavirus Aid, Relief, and Economic Security (CARES) Act; Office of the National Coordinator for Health Information Technology Data Modernization, etc.) to support data sharing and integration?
- What are current strategic priorities at the community and state-level? How could improved partnerships to support data-sharing align with or advance work toward those priority aims?

This report details lessons from the analysis, including the key themes that emerged related to fostering relationships among community and state partners to inform policy and systems change. It highlights actionable ideas for DASH and CHCS to consider incorporating into the design of the LAPP project, including a summary of the external supports that would be helpful to advance data-sharing efforts. While the learnings summarized herein are oriented toward communities and states that are interested in participating in the LAPP program, the themes are broadly relevant for multi-sector community-state data-sharing partnerships across the country.

Key Themes

Distinct themes that emerged from the stakeholder interviews with national, state, and local experts from across the country (see Acknowledgements, page 2), are organized below into three categories:

1. **Current priorities** in the face of COVID-19, the economic recession, and national calls for racial justice;
2. **Emerging opportunities** in support of data-sharing efforts; and
3. **Key success factors** for community-state data-sharing efforts to improve health, well-being and advance equity.

1. Current Priorities

The impacts of the pandemic and associated economic fallout have been widespread, but are particularly prevalent among Black Americans reflecting longstanding inequities often stemming from structural racism. COVID-19 is exacerbating inequities that have long been a priority for some in the public health, health care, and social services sectors, including disparate access to education, employment, housing, and access to quality health care. Interviewees shared their current strategic priorities at the community and state levels, and also discussed how improved partnerships to support data-sharing align with or could advance their priorities. These priorities include:

COVID-19 Response Efforts

Interviewees noted that COVID-19 pandemic response efforts remain a key priority at the community and state levels. Efforts are focused on testing and contact-tracing, which have leveraged partnerships between local and state public health agencies, health care stakeholders, and community-based organizations to conduct outreach into communities. According to interviewees, data-sharing between health and social services can be leveraged to ensure an individual who needs to isolate after testing positive for COVID-19 has the necessary social supports (such as housing and food). As a vaccine becomes available, those state-community partnerships will likely transition to focus on equitable vaccine distribution, access, and vaccine utilization tracking.

Examples

- 2-1-1 San Diego is leveraging its Community Information Exchange to engage with the community around COVID-19 testing sites and resources. Given 2-1-1 San Diego's priority focus on serving vulnerable populations, community partners have been able to use the Community Information Exchange to assess whether individuals who test positive have all of the social resources they need to socially isolate safely, and respond accordingly. At the state level, California Governor Gavin Newsome's administration is overseeing a project to gather what social needs have been related to COVID (e.g., food assistance, rental/utilities assistance, etc.) time in order to inform public health emergency planning, response, and recovery efforts.
- The Philadelphia Department of Public Health is balancing efforts to address immediate COVID-19 needs through testing, tracing, and treatment along with other health conditions that have been exacerbated by the pandemic. Like other cities, Philadelphia's Department of Public Health saw its childhood vaccination rate plummet during COVID-19 as a result of school closures and families skipping routine primary care appointments. To combat this, Pennsylvania changed state vaccination laws to allow families to purchase and receive childhood vaccines directly from local pharmacies. Philadelphia Department of Public Health is now working to ensure that pharmacy vaccination data are incorporated into children's electronic health records and the state vaccination registry.

Population Health and Prevention Efforts

COVID-19 has worsened several critical health and social issues, including homelessness rates, the prevalence of substance use disorders, and food insecurity. Interviewees underscored that pre-pandemic priorities for public health, health care, and social services collaboratives remain top-of-mind and in most cases are considered even more urgent now than before COVID-19.

Examples

- Philadelphia has experienced increasing gun violence during the pandemic, and as a result, the city is focused on designing and implementing programs that use violence interrupter models, which focus on identifying and intervening in conflicts before they intensify, alongside policy design efforts. Data-sharing partnerships among community-based organizations, police departments, health departments and state agencies to track use of guns and gun violence are helping to inform this effort. In addition, Philadelphia is pursuing legal strategies to enable greater local control of policies that can reduce gun violence.

- Vermont has had a long-standing focus at the state level to address affordable and accessible housing. COVID-19 data collection efforts provided more accurate data on individuals experiencing homelessness, giving the state an opportunity to address the issue of housing more immediately. As a short-term measure, the state placed people experiencing homelessness in hotels as a form of emergency housing during COVID-19. Housing continues to be a top priority and the state is engaged in a data-sharing project to understand the relationship between access to mental health services and housing as a stabilizing factor.

Efforts to Advance Health Equity

Rising calls for racial justice amid glaring COVID-19 health disparities and unjust police violence this year have propelled states and communities to examine efforts to improve health with a racial equity lens. This environment is also providing a concrete opportunity to standardize how diverse sectors collect, analyze, and make available race and ethnicity data. Interviewees confirmed that the current health and economic crisis is making long-standing problems related to health-related social needs and health inequities even worse with hardships like food scarcity, interpersonal safety, stress, eviction, homelessness, and challenges with access to health care.

Examples

- In Rhode Island, the Rhode Island Department of Health (RIDOH), in collaboration with the Care Transformation Collaborative of RI (CTC-RI) and Well-being (WE) and Equity in the World launched the nascent, "Diabetes Health Equity Challenge" to improve community-clinical linkages and population health. Two high-density Rhode Island communities embarked on this learning collaborative to improve the lives and community conditions for people with diabetes who are at higher risk for COVID-19. The Rhode Island Diabetes Health Equity Challenge uses funds from the Centers for Disease Control and Prevention's Innovative State and Local Public Health Strategies to Prevent and Manage Diabetes, Heart Disease and Stroke to engage learning collaborative participants, including: Health Equity Zones, Community Health Teams, Accountable Entities (Medicaid ACOs) and residents with lived experience of diabetes and social inequities. The goal of this work is to accelerate pathways to improve an equitable, rapid and sustainable response for people experiencing health and social disparities in diabetes outcomes in the context of COVID-19. The participants come together to learn best practices from the Pathways to Population Health Framework (P2PH) and apply the P2PH tools to their communities. The two Rhode Island communities participating in this initiative are the Pawtucket/Central Falls Team and the East Providence Team.
- The Oregon legislature passed a bill in 2013 requiring the Oregon Health Authority to increase and standardize collection of Race, Ethnicity, Language, and Disability (REALD) data, and to develop the standards in collaboration with community members. The Oregon Health Authority continues to work toward achieving full compliance with the REALD legislation. The department is also beginning efforts to standardize collection of sexual orientation and gender identity data.

2. Emerging Opportunities

COVID-19 presents new opportunities to support or advance data-sharing and integration. For instance, states and communities are interested in standardizing COVID-19 testing and tracing data across multiple partners' systems, with uniform guidance on what is collected and how it is shared to facilitate greater exchange.

Federal or National Resources

Several interviewees noted that while the CARES Act may have provided opportunities to support data-sharing efforts, it is challenging to coordinate across agencies in the context of time-limited resources. In addition, the pandemic has highlighted the importance of investing in public health data systems that build on existing community investments to connect individuals with the health care and social services they need. Interviewees underscored that there may be a window of opportunity to use the momentum of COVID-19 for changing the definition of success from a delivered service to a "whole-person" view.

Examples

- Well-Being In the Nation (WIN), a network of organizations and communities coming together to advance intergenerational well-being and equity (health, economy, housing, education), has developed a set of vetted common measures to improve population health and social determinants of health (SDOH) across sectors at local, state, and national levels. The Delaware Division of Substance Abuse and Mental Health applied the WIN measures amid COVID-19 to assess and address the well-being of individuals they serve. Delaware care managers reaching out to clients for general check-ins assessed individuals for COVID-19 symptoms, mental health symptoms, and used questions from the WIN measures to inquire about self-perceived overall well-being, hope for the future, financial insecurity, loneliness, peer support, housing, and legal needs.
- Funding from the CARES Act is prompting Medicaid agencies to think about what COVID-19-related projects to continue after the federal resources end, and how. The CARES Act funding provides an important opportunity to standardize how data are defined and reported. In Philadelphia, the city health department did not have the ability prior to the CARES Act to require reporting of race and ethnicity data for its COVID-19 testing efforts, resulting in incomplete datasets to inform efforts to address disparities. Federal agencies prioritizing race and ethnicity data for reporting has provided a crucial lever to capture complete data to address inequities in infections, testing, and treatment.

Leveraging Existing Efforts

Other opportunities noted include leveraging existing efforts, such as aligning community health needs assessments with state health improvement planning -- and maximizing state authority, for instance, leveraging partnerships among Medicaid and Medicaid managed care plans to require reporting of standard measures.

Examples

- Strengthening partnerships between community-based organizations and Medicaid MCOs is an emerging priority across the states, particularly given the role that MCOs often play in the delivery of Medicaid benefits. In Pennsylvania, for example, an MCO is partnering with a community-based organization to increase access to permanent supportive housing relevant to the health care of people with disabilities who could maintain their health and wellness with supportive housing. The partners are using county-level housing stability records data along with health care claims data to measure the outcomes of their efforts. This highlights an opportunity for states, MCOs, and community organizations to work jointly for state-level quality measures that address issues relevant to the health care of people with disabilities who could maintain their health and wellness with supportive housing.
- Some interviewees underscored the opportunity to align community health needs assessments with state health planning efforts. Particularly as community health improvement has been moving from local health departments to health systems/hospitals, there is a large opportunity for growth in terms of integrating data to mobilize action based on communities' specific needs and assets.
- Health Information Exchanges (HIEs) have been established in a number of states using federal funds from the Office of the National Coordinator for Health Information Technology, including $2.5 million in funding from the CARES Act to strengthen existing HIE infrastructure. Interviewees noted the potential of HIEs to serve as a trusted body to set data standards and definitions and facilitate multi-sector, regional-level data-sharing. A number of state HIEs, including Maryland, Virginia, Oregon, Washington, and Arkansas have brought in community partners. During the COVID-19 pandemic, HIEs have supported meaningful work on vulnerability analyses that characterize individuals most at risk and analyze the interactions between SDOH and COVID-19 outcomes to identify opportunities for intervention.

3. Key Factors for Success

When asked about success factors for mobilizing multi-sector data-sharing efforts among community and state partners, interviewees almost always pointed to the following competencies: (a) committed and engaged leadership across partners; (b) clear, equitable data governance competencies and infrastructure; and (c) partnership/ stakeholder engagement that supports shared understanding, trust, and accountability. This includes having clearly defined goals with established arrangements for data sharing (i.e., data-use agreements in place), decision-making, resource allocation, and project management. In addition to the critical focus on building technical capabilities and staff capacity, having explicit focus on trust building — especially among partners with historically unequal power or resource dynamics — is essential to success. This includes understanding each partners' unique priorities, levers, and constraints — and prioritizing stakeholder engagement and convening throughout the process. Additional factors include: (a) inclusion of people with lived experiences as empowered drivers of the effort; and (b) long-term vision to lay a sustainable foundation for future work.

Examples

- **Community participation and empowerment**
    - Across its work, the National Birth Equity Collaborative strives to "listen, first." They noted that the most impactful and equitable efforts require centering the family experience — and building trust with patients of color and other marginalized populations. For instance, the collaborative is involved in a collective effort in New Orleans to empower women to take charge of their health and make more informed choices to help decrease maternal mortality. Their work uses the stories of women with lived experiences and their families to inform a patient-centered reporting process and robust patient advocacy mechanisms based on trauma-informed principles.
    - Vermont's OneCare model recognized the importance of including community members with lived experience in decision-making processes. Participants were paid for their time to demonstrate the value of their contributions and expertise. The Vermont field directors emphasized the importance of trust building across the participating community organizations who had historically unequal power and resources.
    - A coalition of racial and ethnic communities in Minnesota used a multi-year stakeholder engagement process to gain buy-in to collect race and ethnicity data. The effort, initially led by the Alliance for Racial and Cultural Health Equity (ARCHe) and then Voices for Racial Justice involved collaboration with state agencies, concerted efforts at trust building among health care stakeholders, clear communication about why the data was important. These efforts ultimately resulted in legislative action in 2015 requiring the Minnesota Department of Health to stratify five quality measures by race, ethnicity, preferred language, and country of origin. Provider-collected race, ethnicity, and language data is now very strong and housed by MN Community Measurement, a nonprofit which brings together community groups, clinics, hospitals, providers, and plans.
- **Governance**
    - In Allegheny County, Pennsylvania, a collaborative governance process was key to the creation of a new data-sharing project. The health department director served as facilitator, convening multiple stakeholders and bringing health plans to the table. The groups came to agreement about what data would be shared, how long partners would be involved, which entity would serve as the broker, and what they would do with the data. This resulted in a successful collaboration and set the foundation for collaboration on future projects.
- **Leadership**
    - Multiple interviewees noted that leadership at the state is crucial to breaking down silos and fostering culture change that prioritizes equitable multi-sector data sharing. In Maine, the Department of Health and Human Services and the Governor's office demonstrated such leadership and encouraged legislative changes around data-sharing for public health and emergency response.

Implications for Program Design and Beyond

Interviewees also provided valuable insights into states' and community-based organizations' priorities and suggested unique opportunities for partnership around data-sharing. These findings have informed the development of the LAPP Request for Proposals and its program design. Based on insights gleaned from interviews, the following are potential opportunities for the LAPP project and future programs to support state-community partnerships around data-sharing:

- **Address power dynamics.** Power dynamics are often at play in cross-sector partnerships, especially among partners with historically unequal power and resources. Given this common power imbalance, opportunities to empower community-based organizations and, more broadly communities, include:
  a. Facilitating community ownership of their own data (e.g., endowing communities with the power to make decisions based on their own data, wherever feasible);
  b. Providing funding or opportunities to build communities' capacity for engaging in data-sharing efforts to improve health;
  c. Framing data and data-sharing as a mobilizer for communities to create change (e.g., viewing data as an organizing strategy for communities);
  d. Centering lived experiences and valuing individuals and communities throughout program design and implementation efforts; and
  e. Prioritizing use of equitable shared governance models for community-state partnerships.

- **Build cross-sector, data-sharing capacity.** New workflows and common standards need to be defined among partners to facilitate cross-sector data-sharing. Opportunities to create new or bolster existing data-sharing capacity among cross-sector partners include:
  a. Ensuring there is an understanding of the need for shared data and how it fits into a broader project or program plan;
  b. Taking time to appreciate the types of data each partner has access to and any existing data-sharing policies within each organization, in addition to the time and resource commitment needed for data collection and sharing efforts;
  c. Building skills for translating different data to be able to communicate the information to broader audiences; and
  d. Ensuring there are standard definitions for data variables to avoid miscommunication or inconsistent data collection.

- **Facilitate cross-sector learning and collaboration within and across participating sites**. The work that is achieved in the LAPP project can be amplified by sharing experiences and lessons across participants during and after the award period. Potential activities to foster this collaboration include:
  a. Sharing of ideas, best practices, and lessons to foster connections across common goals and efforts;
  b. Sharing and leveraging insights from peers and subject matter experts to advance project efforts; and
  c. Establishing paths for sustainability as a key project activity.

- **Increase access to relevant resources.** Many thought leaders cited access to data-sharing resources and subject-matter expertise as a crucial need for community-based organizations or multi-sector community data-sharing collaboratives. To support community organizations in cross-sector partnerships, important resources include:
  a. Standardized templates for use, and a model or toolkit of resources (e.g., data use agreements);
  b. Existing trainings on privacy and security that could be leveraged for staff;
  c. Legal supports and privacy/security subject matter expertise;
  d. Examples of data governance structures; and
  e. Guidance on technology procurement and workflow adjustments.

V. Conclusion

This national analysis provides valuable insights into current and emerging priorities that are key opportunities for meaningful state-community partnership. These partnerships should be driven by the community with a foundation of a shared governance model. Themes from this analysis can help inform efforts to ensure the sustainability of projects after the conclusion of LAPP funding. The lessons outlined here can contribute to community and state multi-sector data-sharing projects to inform policy actions or systems change that may drive meaningful improvements in health, equity, and well-being.

ABOUT THE CENTER FOR HEALTH CARE STRATEGIES

The Center for Health Care Strategies (CHCS) is a nonprofit health policy resource center committed to improving health care quality for low-income Americans. CHCS works with state and federal agencies, health plans, providers, and community-based organizations to develop innovative programs that better serve people with complex and high-cost health care needs. For more information, visit **www.chcs.org**.

ABOUT DATA ACROSS SECTORS FOR HEALTH

Data Across Sectors for Health (DASH) is a national initiative launched by the Robert Wood Johnson Foundation to improve community health, well-being and equity, by fostering greater alignment among health care, public health, and other community-based social systems to improve multi-sector collaboration and data sharing. For more information, visit **www.dashconnect.org**.