

A Community-Centered Approach to Data Sharing and Policy Change: Lessons for Advancing Health Equity

By Liz Buck and Alissa Beers, Center for Health Care Strategies, and Waldo Mikels-Carrasco, Data Across Sectors for Health

TAKEAWAYS

- Sharing data across state agencies and community-based organizations is critical for advancing health equity and addressing complex health challenges that involve multiple sectors.
- Including individuals with lived expertise in data sharing and policy development can make these efforts more responsive to the needs of community members, particularly those in historically marginalized populations. Insights from individuals with lived expertise provide valuable context to inform data-sharing efforts that is critical to improving health equity.
- This brief highlights key lessons to inform data-sharing partnerships between community-based organizations, state agencies, and individuals with lived expertise and outlines considerations for engaging community members in all aspects of data-sharing.

Longstanding structural inequities, particularly those facing Black, Indigenous, and People of Color (BIPOC) communities, require public health, health care, and social service sectors to be more accountable in supporting community members in decisions that impact their health. The COVID-19 pandemic exacerbated complex health challenges that involve different public systems and directly impact communities. This includes, for example, the mental health needs of youth during and beyond the pandemic, health inequities for people involved in the justice system, and the health care needs of people experiencing homelessness, among others. Sharing data across sectors and state agencies is a critical first step to guide effective policy responses that encompass multiple systems and address consumer needs and preferences. As more states seek to advance health equity, community members with lived expertise can help inform data and



policy strategies that impact their lives directly, such as behavioral health access, housing, homelessness, food insecurity, and criminal justice involvement.

Partnerships involving individuals with lived expertise along with state and local partners have the potential to address broader systemic policy issues more equitably and effectively at the state or local level than partnerships without community advisement. While historically states have not included community members in data-sharing efforts, feedback shared by people with lived expertise is a critical data point that can guide more equitable public policy.

Data Across Sectors for Health (DASH), together with the Center for Health Care Strategies (CHCS) and with support from the Robert Wood Johnson Foundation, is leading a national initiative, [*Learning and Action in Policies and Partnerships*](#) (LAPP), to test new ways to support community-based data-sharing efforts. The first cohort included six communities — in **Arizona, Connecticut, Rhode Island, South Carolina, Washington, D.C., and Washington State** — that sought to strengthen relationships between communities and state agencies to address health equity priorities via data-sharing efforts (see Exhibit 1). This brief shares lessons from these six pilot sites to help guide additional states and community-based organizations (CBOs) in enhancing community data-sharing capabilities and fostering relationships between state governments, CBOs, and community members with lived expertise.

KEY TERMS

- **Data Sharing:** “The practice of providing partners with access to information (in this case, administrative data) they can’t access in their own data systems. Data sharing allows stakeholders to learn from each other and collaborate on shared priorities.” - *Actionable Intelligence for Social Policy, University of Pennsylvania*
- **Data Integration:** “A more complex type of data sharing that involves record linkage, which refers to the joining or merging of data based on common data fields. These data fields include personal identifiers, such as name, birth date, social security number, or an encrypted “unique ID” that is used to link or join records at the individual level.” - *Actionable Intelligence for Social Policy, University of Pennsylvania*
- **Data Ecosystems:** “The what, the who, and the how that enables data sharing and collaboration within a community.” - *DASH*
- **Lived Expertise:** The experiences of individuals who have or currently are involved in or are affected by different systems or policies, including Medicaid, housing/homelessness, criminal justice, poverty, and individuals impacted by structural racism, which can be used to inform cross-sector data and policy efforts.

Exhibit 1: LAPP Participants’ Projects

LEAD ORGANIZATION	PROJECT FOCUS	SELECT PILOT ACTIVITIES
Arizona Housing Coalition	Improve coordination of care for people experiencing homelessness in Arizona.	<ul style="list-style-type: none"> Collaborate with people with lived expertise and providers to understand how to improve coordinated care for people experiencing homelessness. Integrate statewide Homelessness Management Information Systems data with Medicaid data.
Center for Health and Justice Transformation at The Miriam Hospital	Develop an integrated data system that includes criminal justice and Medicaid data.	<ul style="list-style-type: none"> Create a secure, accessible database of individual level, deidentified criminal justice data (which includes data from the Attorney General’s Office, Public Defender’s Office, Courts, Department of Corrections) to integrate Medicaid data. Develop a data governance process that guides researchers and community members in statewide data and research requests.
D.C. Primary Care Association	Develop a community resource inventory that facilitates coordination of care between social service agencies and health care organizations.	<ul style="list-style-type: none"> Design processes for maintenance of community resource inventory data to be shared among health and social services systems. Develop mechanisms for governance of shared resource data and associated partnerships and processes. Engage the D.C. Health Information Exchange Policy Board to adopt Community Resource Inventory stewardship and governance recommendations and model.
United Way of Central and Northeastern Connecticut	Increase awareness of multisector health improvement collaboratives and inventory the state’s existing multi-sector data, including access barriers.	<ul style="list-style-type: none"> Conduct a systems-mapping exercise to inventory the state’s existing multi-sector data, interoperability, and data access needs and barriers. Develop a prioritized list of community information needs to inform the state. Develop a “road map” for potential policy and systems changes with the goal of: (1) improved access of relevant data; and (2) improved data sharing across communities and agencies.
University of South Carolina	Use an integrated data system that focuses on the educational and health needs of children in South Carolina.	<ul style="list-style-type: none"> Inform statewide policy recommendations through community engagement sessions with educators, youth leaders, and superintendents, as well as state and local education and health data. Collaborate with youth advocates, superintendents, and teachers to understand research priorities and students’ needs during the COVID-19 pandemic.
Washington State Economic Services Administration, Department of Social & Health Services	Develop a shared vision between state agencies and community members that defines an equitable economic recovery.	<ul style="list-style-type: none"> Create a shared vision and definition for “equitable economic recovery” and “just and equitable future” in partnership with communities historically excluded from economic well-being. Ensure the expertise, stories, and experience of people and communities historically excluded from economic well-being are included in state decision-making processes. Inform and galvanize efforts to reduce poverty across the state, including the creation of a Subcabinet on Intergenerational Poverty via Governor’s Executive Order in December 2021. Passed legislation on compensation of lived expertise (SB5793) on March 7, 2022.

Key Lessons for Incorporating Community Perspectives into Data-Sharing Efforts

Following are key insights gleaned from the LAPP pilot sites that integrated community voices into data ecosystem projects to address complex health equity goals.

1. Involving communities as partners in cross-sector data sharing and policymaking often requires reconfiguring how government traditionally operates.



Resources, time, and capacity building are necessary components to ensure community-informed data sharing is sustainably embedded in government and communities. In **Washington State**, the LAPP team focused on involving people and communities historically excluded from economic well-being, namely BIPOC communities, in building accountability toward a “just and equitable future” in state decision-making. This work galvanized Washington State’s poverty reduction work and creation of a Subcabinet on Intergenerational Poverty via Governor Inslee’s [Executive Order](#) in December 2021. It also resulted in state-level, multi-agency momentum on involving community members’ perspectives in policies, programs, practices, and decision-making, including the passage of [legislation](#) to compensate individuals with lived expertise for their participation in state-level boards, committees, and other similar groups to inform policymaking.

The state’s lead community partners, [Statewide Poverty Action Network](#) and [Front and Centered](#), convened community members throughout the state to develop a community-led vision for state policy and community-defined measures for economic well-being as well as a proposed governance process for including BIPOC community members in state decision-making. This work aimed to ensure that state efforts to shift to an economy that is sustainable, equitable, and just is informed directly by communities. Partners from the Washington State team facilitated 13 listening sessions with individuals and leaders across the state representing BIPOC communities and organizations generating discussions about individuals’ experiences of the economy, community-defined purpose of the economy, and community-defined governance of the economy.



“Many agencies and organizations are bringing in community voice to co-create solutions utilizing human-centered design to get to equitable outcomes. It’s about sharing power, flipping power, diffusion of power — all of it.”

*- Lindsay Morgan Tracy, innovator-in-chief,
Washington State, Department of Social & Health Services*

These sessions led to the development of 13 core recommendations related to measures of well-being; strengthening community capacity in economic literacy and power to effectively participate in state decision-making processes; a process for co-creating with state agencies and sharing governing power; and a set of prospective 2023 legislative actions. Without investments in social and economic stability and mobility, state leaders saw that deeply rooted demographic and geographic inequalities would continue to put Washingtonians at risk of poverty and its intergenerational consequences. From state leaders' perspective, lawmakers or legislators cannot drive this work alone; it takes community, community-based organizations, agency leadership, and others to collectively drive this transformation.

KEY THEMES FROM WASHINGTON STATE'S COMMUNITY ENGAGEMENT MODEL

Through 13 listening sessions, committee meetings, and additional discussions with individuals with lived expertise, Front and Centered, in partnership with Faduma Ahmed of the [People's Economy Lab](#), gathered community feedback to develop a proposed community consultation model and foundation for improved data systems. Major themes of the [community consultation model](#) developed for Washington State include:

- **Universal understanding and measures of well-being.** Community members identify qualitative and quantitative indicators of well-being for state agencies.
- **Establishing commitment.** Agencies incorporate racial equity analysis and community input in policy, budget, and strategic plan decisions.
- **Building capacity.** Agencies consider funding and supporting a statewide network of “Community Assemblies,” led by community-based organizations, to provide leadership, direction, and co-governance oversight. Community assemblies are a participatory democratic platform that bring people together with a clear strategy to understand specific community needs and provide solutions inclusive of all stakeholders.
- **Equitable practices.** Communities develop a “community equity and accountability” framework to apply to agency practices and activities (e.g., rules, budgeting, and contracting process).
- **Sharing governing power.** Agencies create guidelines and tools on how to decentralize power within their leadership structure.

These themes were shared with the Governor and other state agency leadership, including the Department of Commerce, Employment Security Department, Department of Social and Health Services, Department of Health, Health Care Authority, Office of Financial Management (to name a few), as well as community partners, to guide poverty reduction efforts.

For the **Center for Health and Justice Transformation at The Miriam Hospital in Rhode Island**, incorporating community perspectives into how state agency data should be shared and used was a significant change in how state agencies typically operate. The team solicited community feedback using surveys and presentations at community workgroups and coalition meetings to identify the priorities of people most directly impacted by the criminal justice system. The team continues to explore opportunities to build public-facing data dashboards and visualizations to provide data transparency to community members without requiring a lengthy data-request process.



“The realization that the citizenry has a vested interest in what information is collected, how it is reported, and how it can be used to inform policy has been an eye-opening experience for all stakeholders. Ensuring involvement with community members requires a clear articulation and understanding of the utility and purpose of data and research projects.”

- Sarah Martino, project lead,
Center for Health and Justice Transformation

2. Addressing health equity goals requires confronting silos within and across agencies, sectors, and systems.



Several LAPP participants focused considerable time aligning approaches across agencies and community-based organizations that work within the same system (e.g., homeless service system partners or criminal justice agencies) to align broader health equity goals in their communities or states.

In **Arizona**, all three [Continuums of Care](#) (i.e., regional planning bodies that coordinate housing and services for individuals and families) needed to agree to share data to better understand the housing and service needs for people experiencing homelessness across the state. This was challenging since each regional Continuum of Care is independent and has its own governing bodies and different definitions for users of Homeless Management Information Systems (HMIS). Reaching consensus across each Continuum of Care was a significant step that helped build the momentum for each organization to subsequently agree to share data. Including Arizona’s Medicaid agency in this data-sharing effort encouraged all three Continuums of Care to join their data-sharing efforts and better understand the health needs of people experiencing homelessness across the state. The Continuums of Care found value in receiving Medicaid data to improve care delivery and partnerships locally. While some Continuums of Care staffers were initially hesitant regarding potential risks related to these new data-sharing efforts, the Continuums of Care highly valued the availability of Medicaid data and were incentivized to overcome these challenges.

The **Center for Health and Justice Transformation in Rhode Island** (CHJT) focused on sharing criminal justice data across multiple agencies, including justice practitioners, policymakers, researchers, and advocates, to provide insight into the experiences of justice-involved Rhode Islanders across systems and person-level outcomes at different points in the justice system. At the start of the project, the Judiciary, Department of Corrections, Attorney General’s Office, Public Defender’s Office, and state and local law enforcement came together to share data and discuss what collaborative data-sharing goals and governance might look like. Initially only two agencies had the technical capacity to share data, so the project pivoted to attempt to break down siloes between the justice agencies and the health and human services agencies. Participation in LAPP presented CHJT and partners with the opportunity to advance integration between criminal justice data and Rhode Island’s Medicaid data ecosystem, which had always been a long-term goal. Ultimately, this planned integration will allow for the exploration of criminal justice outcomes in Rhode Island as well as shed light on justice system involvement on health and other social determinant outcomes.

For the **United Way of Central and Northeastern Connecticut**, their LAPP efforts inventoried the state’s existing multi-sector and state agency-based data, interoperability, and data access needs and barriers. The United Way team used system mapping — i.e., visual depictions to clearly describe relationships and feedback loops within a complex system — to understand what data exists within and across state government agencies and divisions. The LAPP team also established consistent state data usage standards for Connecticut’s [Health Enhancement Communities](#) and other Connecticut Community Health Improvement Collaboratives, which include community members and individuals with lived expertise; health care providers; housing and transportation agencies; social services; and other organizations focused on community health and disease prevention efforts. The United Way of Central and Northeastern Connecticut’s core LAPP partner group consisted of nine Health Enhancement Communities; two additional health improvement collaboratives; the Connecticut Office of Health Strategy (an All Payor Claim Database and host of the Health Enhancement Communities); the state’s health information exchange; DataHaven (a nonprofit organization that empowers people to create thriving communities by ensuring access to data on well-being and equity); Trinity Health of New England/Saint Francis Hospital; and the Connecticut Hospital Association. Through the system mapping exercise, the Connecticut team found that to provide community members and local community-based organizations with access to data, they first had to understand what data exists across various agencies and the barriers to access that data. Further, while a centralized data repository would be helpful for local Health Enhancement Communities and other individuals and organizations, it would

necessitate increased alignment and resourcing to manipulate how data is being reported and collected so that it could be used for the purpose of health improvement. Connecticut stakeholders, including the United Way team and their Health Improvement Collaborative, the North Hartford Triple Aim Collaborative, are now focusing their efforts on broader advocacy.

3. Sharing data across systems and sectors requires a common vision and strong internal champions to advance a governance structure, policies, and legal allowances.



The LAPP experience highlights that each agency needs at least one champion to facilitate processes for data collaboration and identify mechanisms for overcoming hurdles to data sharing or data integration across sectors.

For the **Washington, D.C.** project, led by the District of Columbia Primary Care Association (DCPCA), developing a clear governance process and close coordination with the [DC Health Information Exchange \(HIE\) Policy Board](#) was key to their success. DCPCA’s LAPP efforts focused on developing a Community Resource Inventory (CRI) and adopting governance recommendations from the D.C. HIE Policy Board. Development of the CRI, which contains information about community resources and services, was guided by a subcommittee of policy and data experts, together with social service professionals and with support from the District’s Department of Health Care Finance.

DCPCA attributed the willingness of HIE Policy Board members to bring in new non-medical members through a CRI subcommittee as a critical component of their success in designing data-sharing processes among health and social services systems. The CRI subcommittee also developed proposed mechanisms for governance of shared resource data and associated partnerships and processes. In addition, the subcommittee identified important questions to guide CRI development, such as, “Who is the database meant to serve?” “What’s the purpose of the CRI?” and “What are implications for the HIE Policy Board?” The group recognized the need to develop CRI capacities that were sensitive to community needs. They worked on a governance and sustainability strategy to consider and approve recommendations that could move to the full HIE Policy Board.

In-depth involvement from HIE Policy Board leadership provided a built-in opportunity to vet the recommendations and align them across health and social data systems. Building relationships and ensuring that everyone on the committee understood how each recommendation would influence their work was also key to their success. This level of coordination enabled D.C. to [develop recommendations](#) toward making the community resource directory information publicly available.

For the **Arizona** team, which focused on the integration of HMIS and Medicaid data, the development and use of a [shared commitments document](#) was a critical tool for building momentum and guiding project direction among Continuums of Care, the state Medicaid agency, and people with lived expertise. This document articulated data-sharing commitments made to date and was approved by each organization and agency participating in the project. The document reminded participants regarding areas of consensus and progress toward shared goals, which grounded discussions when there were staffing changes or questions about past decisions.

4. Building cross-sector data integration efforts where community members are equitable partners requires a significant investment in time, resources, and capacity.



Organizations or entities that lead cross-sector data-sharing efforts need to bridge cultures and sectors. Based on feedback from community members, Washington State is hiring new positions to develop state-level capacity to partner directly with community members. For example, the state is hiring a research justice employee who will focus on how the state collects data, how the voices of community members are incorporated into data-related decisions, and how communities can benefit from the data.

Each LAPP site that partnered with individuals with lived expertise built in necessary funding and adapted standard approaches to meaningfully bring individuals with lived expertise as partners into these projects. These efforts provided critical insights to inform broader health equity goals. For example, in **Arizona**, the team expanded engagement of people with lived expertise to guide improvements in care coordination practices. The Arizona team contracted with a community engagement consultant who interviewed those most impacted by the homelessness system — including people with disabilities, youth, and BIPOC community members. Rather than having a single representative or rely on individuals who experienced homelessness but are now housed, the Arizona team expanded their approach to include insights from individuals currently experiencing homelessness. Getting insights from a broad range of individuals who are currently experiencing homelessness provided critical insight into the current systems' challenges that exist across different populations. In general, individuals experiencing homelessness expressed serious challenges in accessing integrated services within current systems, and a need for agencies to reduce the trauma of retelling stories to multiple service providers and improve coordination across homeless systems, behavioral health programs, and health care organizations. These insights are informing statewide care coordination efforts. The robust community

engagement, along with the placement of individuals with lived expertise on the governing committee, helped to integrate first-hand experiences into data solutions. For example, individuals experiencing homelessness were supportive of data sharing across agencies as a way to improve broader coordination with providers and reduce the retelling of traumatic experiences across multiple providers.

5. Involving different voices from a community can help inform solutions to address complex policy challenges.



The **University of South Carolina** research team created a robust process to understand the needs of community members and inform broader data analysis and policy recommendations. The project’s lead researcher convened a series of focus groups, including youth organizing groups, youth leaders, superintendents, teachers, and community members, to discuss child well-being. These meetings helped the researchers better understand and respond to community needs.

For example, hearing from youth leaders and community members about the growing mental health needs of students during the pandemic allowed researchers to focus more specifically on this topic area. Using themes from these community discussions, researchers were able to focus their analysis and, in analyzing the data, found a connection between mental and physical health needs of students and links to absences. This understanding is enabling state agencies and local leaders to better understand the link between student health, student absences, and drop-out rates. These community discussions and data analysis were critical to advancing broader state education policy through the [Whole Child Policy Analysis](#) effort.



“We believe engaging students and parents, as well as educators and helping professionals, to define local opportunities and gaps in community schooling will lead to deeper, more equitable learning.”

*- Matt Irvine, director, Yvonne & Schuyler Moore
Child Development Research Center*

In **Connecticut**, Data Haven, in partnership with the United Way of Central and Northeastern Connecticut, conducted 20 focus groups comprised of members and affiliates of 10 Health Enhancement Communities and other local health improvement collaboratives across the state in addition to conducting surveys of more than 140 community members. These information-gathering activities sought to: (1) better understand participants’ ability to access data, including specific data resources and general information sources; (2) identify and prioritize information needs; and (3) make suggestions for addressing identified needs, including resources, policies, and system solutions.

Through these efforts, community members identified six data access priorities:

- Ensure availability of real-time local-level data that reflects demographic groups, such as minority populations or individuals with unique health and social needs;
- Ensure availability of real-time local-level data that reflects each neighborhood, town, or community in the area;
- Pool resources to link information from existing data sources (e.g., hospitals and community agencies);
- Ensure that data sources are published more frequently (ideally in real-time);
- Create a centralized infrastructure, designate state staff, and/or finance and train local level staff to help users access relevant information from myriad sources and agencies, assess its quality, and provide analytics; and
- Collect stories and qualitative data to share alongside statistical data from agencies.

In Connecticut, the identification of community members’ priorities directly informed the creation of a roadmap for addressing those needs. The roadmap outlines key state considerations for increasing community access to enhanced local-level data; increasing data sharing across state and local systems; training community-based staff on collecting, analyzing, and using data to better inform service provision; and planning and coordination among community-based and state agencies.

6. Partnering between community members, and local and state agencies can achieve big and small policy wins.



In **Washington State**, the collaboration between community members and state agency leaders led to newly passed [legislation](#) related to the compensation of community members. This effort also attracted interest across other state agencies involved in poverty reduction work. The Washington State LAPP team developed a subcommittee across state agencies involved in poverty reduction work, including involvement from the Department of Social and Health Services’ Poverty Reduction Workgroup/Steering Committee and Equitable Recovery Committee; the Department of Health’s Environmental Justice Committee and its Health Equity Zones Committee; the Commerce Department’s Office of Homeless Youth Committee, among others. There is growing multi-agency momentum to incorporate lived expertise into Washington State’s policy and programmatic decision-making. Many agencies are working to standardize how to work with community members and value and compensate the expertise of people and communities most affected by injustice. As a result of this work, Washington State agencies are working together to

distill best practices for incorporating community perspectives into state program and policy decision-making.

In **Washington, D.C.**, one critical outcome of DCPCA's work has been buy-in from many different stakeholders. The CRI design and implementation is reflective of the priorities of many different stakeholders, and thus more likely to be effective and sustained. This includes technology providers who needed confirmation that interoperable data exchange can effectively support their operations; policymakers who understood the human and organizational demands of data collection and sharing; and community stakeholders who needed to understand why this effort would succeed when others had failed, especially those who already maintain resource directories. DCPCA's process of drafting a strategic data framework involved all stakeholder groups through each phase of their project lifecycle. As a result, DCPCA's initiative, while launched by large institutions in the health care sector, reflects the priorities of small and large institutions across the social service sector. The initiative has also led to the inclusion of key social sector stakeholders on the subcommittee of D.C.'s Health Information Exchange Policy Board, which has approved recommendations to support DCPCA's data framework.

Looking Ahead

Data-sharing partnerships among state government and community partners offer unique opportunities to advance health equity. These partnerships should be grounded in bringing individuals with lived expertise as key stakeholders in all aspects of data-sharing efforts.

The impacts of the COVID-19 pandemic, particularly on BIPOC communities, have created a renewed urgency for the public health, health care, and social services sectors to be accountable to the longstanding health needs of individuals and communities. Empowering individuals with lived expertise to contribute to decisions related to data and policy decisions is a step closer to achieving health justice and racial equity.

Cross-sector state and community partnership initiatives, like the LAPP project, illustrate how data-sharing partnerships among state government and community partners represent unique opportunities to advance health, well-being, and equity. They demonstrate that these partnerships should engage individuals with lived expertise in all aspects of data-sharing efforts. Bringing individuals with lived expertise into these initiatives requires a rethinking of how government traditionally operates and calls for new processes, funding mechanisms, and partnerships. If done well, these coordinated partnerships across sectors and involving people with

lived expertise will have the potential to more fully address the broader systemic issues that have created health inequities across communities.



ABOUT THE CENTER FOR HEALTH CARE STRATEGIES

The Center for Health Care Strategies (CHCS) is a policy design and implementation partner devoted to improving outcomes for people enrolled in Medicaid. We support partners across sectors and disciplines to make more effective, efficient, and equitable care possible for millions of people across the nation. 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.