Participatory Governance

Long-Form Work in Action

AISP

These case studies are an expansion of work written for AISP's Toolkit for Centering Racial Equity Throughout Data Integration Version 2.0. The original Toolkit, released in 2020, catalyzed the formation of the Equity in Practice Learning Community (EiPLC), a cohort-based technical assistance initiative to put the Toolkit into practice in ten sites. The updated Toolkit is the result of a year-long Participatory Action Research (PAR) Project, and learnings from EiPLC cohorts.

The following briefs are examples of Work in Action, a term we use, rather than exemplar, to feature site-based work that is ongoing and rooted in learning and humility. They describe the work of seven data integration efforts; five are local, based at the city or county level, and two are statewide. Each of these sites started small and expanded with purpose and intention over many years of sustained effort. Four of these sites were members of the first cohort of the EiPLC. While these examples are impressive, what they are doing is not magic, but rather proof of hard and committed work. We acknowledge that work at the intersection of data infrastructure and racial equity is complicated and contextual, and not necessarily replicable; however, we hope these examples both inspire your efforts and provide proof that these hard things are doable–even in politically complex environments.

Work in Action Case Studies

The following section includes site-based examples of Work in Action, expanding upon the summaries included within Foundations for Community Involvement.

CONTENTS

Baltimore City Youth Data Hub
Bridget Blount & James Sadler

The Baltimore Youth Data Hub is a collaborative cross-sector effort which aims to help agencies and policymakers make informed decisions on the complex needs facing youth and families across the city.

Who: Baltimore's Promise
Where: Baltimore, Maryland
Management Model: Community-Based Organization
Domains: Education, Community-based organizations, Health, Housing

The Baltimore City Youth Data Hub integrates individual-level data across Baltimore's Promise (a collective impact non-profit), Baltimore City Public Schools, and the City of Baltimore. Authorized through legislation in 2022, the Youth Data Hub has a community governance model where Baltimore City residents have many ways to get involved and direct data and policy priorities.

Although the Baltimore City Youth Data Hub was officially established by State of Maryland legislation in 2022, conversations on establishing an integrated data system in the city started in 2015 and much groundwork was laid in those early years. At the time, the legal landscape in Maryland did not allow for the sharing of individual-level data between public institutions and nonprofit organizations without cumbersome ad hoc legal agreements that could not facilitate the type of on-going data sharing that partners envisioned. The Baltimore community acknowledged that in order to understand how best to serve its youth residents–from topics covering kindergarten readiness, summer programming, postsecondary pathways, and more– the city needed an integrated data system that would allow data to be shared, linked, and analyzed seamlessly.

In 2017, work on the Youth Data Hub advanced when Baltimore's Promise joined the AISP Equity in Practice Learning Community (EiPLC) to share with and learn from other integrated data systems around the country. Soon after this experience, the Baltimore's Promise team convened two working groups. First, they developed a project team that included representatives from the City, City Schools, and nonprofit organizations to think through vision, governance, shared data priorities, community engagement, and equity. Second, they formed a city-wide data workgroup to help inform the data agenda and to discuss centering equity. Through these two groups, they developed a race and equity framework as well as the following guiding principles for the Baltimore City Data Hub:

Baltimore City Youth Data Hub

1. Quality data analysis can only be achieved with an understanding of historical context and competence.
2. Transparency and community trust building are key priorities of data governance, sharing, and use.
3. The Data Hub will focus on improving system-level program efficiencies and service coordination, not on individual participants.
4. Data will be used to highlight and eliminate racial disparaties and inequities.
5. Data use will be ethical, and transparent, and enforce high standards of privacy.

In 2020 and 2021, Baltimore's Promise focused on developing the foundational legal agreements needed to create the Youth Data Hub. Originally, with the support of AISP, legal consultants, and their partners' legal teams, the plan was to establish the Youth Data Hub with a series of MOUs and data-sharing agreements providing legal authority. Soon, they discovered that this solution would not work within the context of Maryland law, so the group pivoted to draft legislation authorizing an exception to sharing certain types of data restricted by the Maryland Public Information Act. After the legislation was drafted, team representatives, including Baltimore City Mayor Brandon M. Scott, testified in Annapolis on behalf of the Data Hub. On April 11, 2022, state legislation authorizing the Baltimore City Youth Data Hub passed, and the law went into effect on June 1, 2022.

The Youth Data Hub adheres to a community governance model, with oversight from three core committees.

The **Executive Committee** includes the Mayor of Baltimore City and the CEO of Baltimore City Public Schools (or their designees), and is charged with overseeing the work of the Youth Data Hub. With a commitment to transparency and accountability, quarterly meetings of the Executive committee are open to the public and widely advertised.

The **Data Oversight Committee (DOC)**, made up of data and programming staff of institutions that provide data to the Youth Data Hub, meets monthly to oversee the development and implementation of policies and procedures governing how data are accessed and used.

The **Community Research and Action Committee (C-RAC)** is an intergenerational group of 14 Baltimore Residents, half of whom are age 26 or younger, that helps drive the vision and purpose of the Youth Data Hub. Members of the C-RAC ensure that lived experiences are central to data products, that data is digestible and accessible to multiple different audiences, and that the questions and projects of the Youth Data Hub serve the wider Baltimore City Community.

Baltimore City Youth Data Hub

The Youth Data Hub's first use case, the Summer Engagement Ecosystem, was conducted in 2024 and answers questions about the landscape of summer programming opportunities in Baltimore City. Next, the Youth Data Hub will work on other projects related to kindergarten readiness, postsecondary pathways, and other questions the Baltimore City community seeks to answer.

Both national and local philanthropic foundations fund the Baltimore City Youth Data Hub. They are particularly grateful for the support of local foundations such as the Annie E. Casey Foundation and the Harry and Jeanette Weinberg Foundation. Additionally, they have received funding through the AISP Equity in Practice Learning Cohort grant and the MADE for Health Justice grant, both initiatives of the Robert Wood Johnson Foundation.

Learn more about the Baltimore Youth Data Hub on their site and on their AISP Network page.

Charlotte Regional Data Trust

The Data Trust uses integrated administrative data to increase the community's capacity for data-informed decision-making and foster university research that supports the community and deepens understanding of complex community issues.

Who: Charlotte Regional Data Trust
Where: Charlotte-Mecklenburg County, NC
Management Model: Non-profit
Domains: Health, Child Welfare and Adult Protection, Early Childhood, Education, Legal Systems and Law Enforcement, Economic Security and Jobs, Homelessness and Housing, Other State and Local Data, Community-Based Organization

The Charlotte Regional Data Trust (the Data Trust) uses integrated administrative data to increase the community's capacity for data-informed decision-making. By linking data across agencies, sectors, and programs, their integrated data system allows a variety of constituencies to understand challenges and opportunities beyond typical service silos. The Data Trust is governed by a board of directors, the Data and Research Oversight Committee (DAROC), and the newly formed Community Data Advisory Committee (CDAC). These oversight committees allow data to be governed by those who collect, own, or are represented in the data.

Since the Data Trust was founded, DAROC has served as the foundation of its governance process, and is composed of both long-standing and newly added data partners, including dedicated organizations (such as Charlotte-Mecklenburg Schools, Mecklenburg County Department of Social Services, and Community Support Services), individuals from the community, and proud data nerds in and outside of agencies. DAROC members are also building participatory data governance practices in their organizations (for example, the Charlotte-Mecklenburg Homeless Youth Action Board). These partnerships help the Data Trust inform and strengthen existing governance processes, including collaboration with CDAC.

In 2021, the Data Trust made the formal decision to create a governance structure that centers community voice. Since that time, the Data Trust has been planning the vision and structure for CDAC with a small team: two CDAC co-chairs, two Data Trust staff, and a facilitator. This design process has been informed by their two decades of governance experience and lessons learned from data sharing over time.

The Data Trust believes that it should be governed by those who own the data and those who are in the data because solutions come from those who are closest to the issue. By increasing community voice, the Data Trust aims to further trust, develop better research questions, and inform more meaningful change.

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Through building, operating, and expanding their participatory governance model, the Data Trust relies on the expertise of three core groups:

1. the co-chairs of the CDAC planning group: a faculty member from a local University, and a community neighborhood association leader;
2. DAROC members, who have provided key insights on data governance efforts since the Data Trust was founded
3. the Mecklenburg County Equity in Practice Learning Community (EiPLC) team, who came together around a local violence prevention effort. The EiPLC team is made up of members from the Data Trust, Mecklenburg County Criminal Justice Services, and the City of Charlotte. This group helped inform power sharing within Data Trust structures, including the application process and pay structure for CDAC.

Given the collaborative nature of this work, it is critical not to attempt to do it alone, but to partner with and rely upon many different communities for support and guidance.

Data Collaborative Serving Children & Youth

Through equitable collective action, diverse research strategies, and the use of high-quality data, we generate actionable intelligence that improves quality-of-life outcomes and community conditions.

Who: County integrated data effort
Where: A large county in Southeastern U.S.
Management Model: Agency
Domains: Child Welfare, Health, Early Childhood, Education, Legal System and Law Enforcement, Community Based Organizations

In a large county in the southeastern U.S., a local backbone organization has brought together seven local and state organizations serving children and youth to collaborate through data sharing. The initial intent of the collaborative was to create an integrated data system to improve child and family outcomes. To date, the collaborative has not established routine data integration, which requires a complex set of legal agreements, and instead relies primarily on bilateral data sharing agreements with limited scope.

From inception, the collaborative partners' valued the expertise of community members and system participants to identify opportunities to improve systems and outcomes. By building the capacity of system participants and system professionals to nurture trusting relationships, develop co-researching skills, and co-create solutions, the hope and goal has been to share decision making power and center the expertise and creativity of people whose data are collected due to their contact with government systems.

Since 2018, the collaborative has completed three community participatory action research (CPAR) projects with youth, parents, and system professionals in child welfare, juvenile justice, and behavioral health. These CPAR projects have resulted in policy, system, and narrative change by centering the expertise of system participants and by building relationships that nurture trust and share power across different interest-holding groups.

The first CPAR, which took place in 2018 with partial funding from a federal grant, included system participants (older youth) and system professionals with experience in the juvenile justice, child welfare, and behavioral health systems. It resulted in changes in the juvenile justice and child welfare systems and an educational video in the behavioral health system.

Data Collaborative

In 2019, the collaborative received a state grant to complete a second CPAR with 3 core groups: youth transitioning out of foster care, parents who participated in the child welfare system, and child welfare system professionals. As a direct result of this process, the collaborative created both a parent leader group and a youth system organizers structure to support youth transitioning out of care to work with child welfare system professionals on continuing research.

In 2023, a third CPAR project was commissioned to explore the youth mental health system. This resulted in an educational video, alternative transportation pilot, and an interactive cultural arts exhibit. Youth and parents for each of the three CPAR projects were identified and selected in conjunction with partners from collaborative-funded prevention programs, child welfare, behavioral health, and the juvenile justice system. Across all projects, clear explanations of the process, desired outcomes, and time commitments were provided to both partners and potential youth and parent CPAR co-researchers. Further, all youth and parent co-researchers were provided with a stipend of $25/hour. Collaborative staff noted that youth and parents who had strong existing relationships with program staff had less attrition and greater confidence in their participation. These existing relationships were leveraged in the co-researching process.

Each CPAR project requires significant investment, costing between $60,000-$70,000 to complete, not accounting for staff time. Facilitation was skillfully provided by Dr. Maria Elena Torre, Director and co-Founder of CUNY's Public Science Project, and Dr. Sarah Zeller-Berkman, Academic Director of Youth Studies Programs at the CUNY School of Professional Studies. Collaborative staff reflected that trained facilitators are essential to centering the lived experience of youth and parents, navigating difficult conversations arising from different perspectives, and building trust and shared power.

State of Connecticut
Scott Gaul & Katie Breslin & Pauline Zaldonis

Integrating data across government agencies to decrease racial disparities in public health

Who: Connecticut Office of Policy and Management, Department of Social Services, and Office of Health Strategy
Where: Connecticut
Management Model: Government Agency
Domains: Health, Child Welfare & Adult Protection, Early Childhood, Education, Economic Security & Jobs, Homelessness & Housing, Other State and Local Data Sources, Community-Based Organizations

The State of Connecticut's Office of Policy and Management (OPM), the Department of Social Services (DSS), and Office of Health Strategy (OHS) have been working together as part of the AISP Equity in Practice Learning Community to responsibly and securely share administrative data and develop procedures and tools for incorporating resident perspectives in the process. The EiPLC team has integrated data across 15 government agencies in the P20 WIN system, as well as healthcare data in the All Payer Claim Database (APCD), and created a bundle of resources to standardize and contextualize available information. Through these actions, the team aims to increase accountability and transparency in and around state integrated data systems, providing residents and data users with information that allows them to use data effectively and equitably. This cross department effort is currently in the process of building a resident advisory board, composed of current and former state service recipients, who will provide feedback on data requests that involve overrepresented populations. Beyond including residents, the team has created a variety of resources and standards to make it easier to center equity in data use.

The P20 WIN integrated data system and the APCD are shared data infrastructure maintained by the state to inform decision-making. To ensure these resources are used intentionally the team has developed a set of equity oriented resources. The Office of Health Strategy led collaborative work to design and implement race, ethnicity, language, and disability (REL-D) data collection standards. The High-Value Data Inventory catalogs data collected and maintained by the state to use these resources more effectively. Another resource, the annotated bibliography of the history of race in Connecticut, provides users with an understanding of how racism has impacted both data collection and what data are currently available. These resources provide context around data, ensuring transparency and encouraging data users to frame research in an equitable way.

The team has developed resources to help determine who can access these integrated data systems and how to report and disseminate findings in an equitable way. The Data Protection, Privacy + Equity Impact Assessment (DPPEIA) is a set of guiding concepts to consider when data requests are reviewed. This framework includes both equity and privacy considerations that should be taken into account when determining data access. There are also guidelines for equity awareness in data reporting and creating accessible visualizations. These documents provide guidance to ensure projects are inclusive and accessible to those represented in the data.

Read our 2-pager for more information and links to the resources mentioned here.

Data You Can Use
Victor Amaya

Helping people access data and make it useful in improving community conditions

Who: Data You Can Use

Where: Milwaukee, WI

Management Model: Community-Based Organization

Domain: Secondary sources across housing, health, education, economic security

Data You Can Use (DYCU) was created in 2016 by a diverse group of local professionals to use data alongside community expertise to improve community conditions in Milwaukee. DYCU holds regular convening designed to build bridges between research, practice, and impact. Staff behind each of these activities are focused on ensuring DYCU's work is conducted respectfully and is in the best interest of Milwaukee residents. Through hiring directly from the Milwaukee community, DYCU ensures their organization reflects community demographics and furthers the organization's commitment to building local capacity for data use and impact. They also participate in initiatives that help younger generations become skilled data users to build out the pipeline of locally-rooted practitioners, both as leaders and as host sites for long-standing workforce programs.

DYCU hosts a range of activities to get community members involved in ways that center their agency and are meaningful for them. Milwaukee's Annual Data Day, now over 10 years old, provides an opportunity for leaders from neighborhoods, nonprofits, universities, and the public sector to better understand what data are available and the implications of data on community revitalization. Data Chats can now be hosted by anyone using their free guide, designed in partnership with the Urban Institute's National Neighborhood Indicators Project. Data Dreams connects DYCU staff with analytic skills to community partners to help specific projects come to life. Many nonprofits that work directly in the Milwaukee community don't have the capacity to have a data analyst as part of their staff, and DYCU, funded using philanthropic dollars, is able to help fill that gap.

New youth initiatives include summer workshops with Milwaukee Public Schools' Black and Latino Male Achievement cohort and involvement with i.c. Stars—a technology workforce training and placement program for young adults. Student interns from UW-Milwaukee and Marquette University, including Trinity Fellows and Public Allies through AmeriCorps, also participate in DYCU programming and initiatives. A student from the UWM School of Public Health is now a full-time employee with DYCU, demonstrating the fidelity of the programs and the relationships they nurture.

DYCU's work is funded through a combination of local and national grants, contracts with nonprofits, and support from partners such as the Zilber Family Foundation, Northwestern Mutual Foundation, Greater Milwaukee Foundation, and the United Way Racial Equity Fund.

DYCU is committed to expanding their reach by increasing the number of neighborhood portraits, enhancing program services, and further integrating resident expertise into data initiatives. The path forward involves securing sustainable funding, continuing to diversify the board of directors, including the addition of a youth representative seat, and hiring additional staff to support organizational growth. Learn more in their 2023 Impact Report.

The Hartford Data Collaborative
Kate Eikel & Michelle Riordan-Nold

Facilitating data sharing among community-based organizations and government agencies to improve programs serving Hartford youth.

Who: The Hartford Data Collaborative (HDC)
Where: Hartford, CT
Management Model: Community-Based Organization
Domains: Early Childhood, Education, Legal Systems & Law Enforcement, Economic Security & Jobs, Homelessness & Housing, Other State and Local Data Sources

The Hartford Data Collaborative was founded in 2019 to share and integrate data between various government agencies and community-based organizations that serve Hartford's youth. The first few years were spent developing technical, legal, and governance structures to allow for ethical and permissible data sharing that would ultimately help inform policy and program change. Once HDC established policies and procedures for data sharing and integration, they started the Hartford Youth Data Fellowship to include the input of youth represented in the data.

HDC's Hartford Youth Data Fellowship program has now hosted three cohorts of youth fellows, and developed a framework that is beneficial for both the HDC and its fellows. Through weekly meetings and workshops, fellows help drive HDC's research agenda and learn data skills to prepare for the culminating fellowship event, the HDC Data Walk, where fellows present their projects to community members to share what they have learned. As Nate Gardener, an alum of the fellowship, said: "[the program] has given me a new understanding on a multitude of topics, opened up new career opportunities, helped me gain valuable connections, and understand the importance of how everybody's story matters."

HDC has also developed a multifaceted evaluation rubric to assess the success of the fellowship. This rubric includes the experience of the fellows, the community's opinion of final projects, online engagement with the projects, the utility of projects' findings to HDC partners, and the outcomes for fellowship alumni. HDC surveys fellows before and after the fellowship to track their change in data knowledge and confidence, as well as their college and career aspirations, which are included in their biographies during the Data Walk event. HDC also surveys Data Walk attendees to understand the impact of the fellows' projects, and posts each project on the CTData website where engagement is tracked over time.

The Hartford Data Collaborative

HDC stays connected with alumni to follow and support their future successes. For example, when Alex Edwards was struggling to find employment in the computer science field, he joined the Youth Data Fellowship and completed a project on the impact of evictions on well-being in Hartford. The data snapshot he created helped him land an internship at a local manufacturing firm.

Going forward, HDC is launching a new project designed to provide youth fellows with more hands-on experience with integrated data. Often, fellows have moved on to other opportunities before the data can actually be shared and integrated for the projects that they conceptualized. However, HDC's new initiative aims to provide access to information earlier in their experience so that fellows can provide their insights from growing up in Hartford and participating in youth development programs during the data analysis phase.

Metriarch
Jacqueline Blocker

Metriarch is shifting narratives by normalizing and broadening women's health conversations through mixed-methods data analysis, tracking synthesis, policy evaluation, and outreach events.

Who: Metriarch®
Where: Oklahoma
Management Model: Community-Based Organization
Domain: Data Intermediary

Metriarch* is an Oklahoma women's public health think tank that aims to normalize and broaden women's health conversations through data storytelling, policy evaluation, and interactive outreach events. Through a web of statewide contacts, Metriarch provides access to data sources that are critical to improving health outcomes for Oklahomans. These relationships with organizations and decision makers uniquely position Metriarch to bring together a diverse group of policymakers to ensure effectiveness, efficiency, and an overall positive impact on women's health policy. Metriarch's model focuses on both bodily and social drivers of health, and provides all of its services at no cost, thanks to the support of local philanthropists. This distinct approach is celebrated by providers, lawmakers, and decision makers statewide.

Metriarch began with the goal of democratizing publicly available resources. They publish a weekly newsletter, Fierce Facts, that highlights news impacting women's health, partner updates, and helpful terms and concepts. The *Policy in Pink* podcast that features community leaders who have dedicated their lives to improving public health outcomes in Oklahoma. The website also has a variety of resources such as a legislative tracker, a judicial guide, and a data "lookbook." Currently, Metriarch hosts a weekly statewide meeting during the legislative session to help community partners and decision makers understand the bills that might impact their work. Metriarch also shares information across all social media platforms (@metriarchok).

Their website also features Data Stories, narrative-based policy briefs that take a candid look at women's health policy in Oklahoma and the responses of local organizations. Our Stories compiles qualitative narratives centered around women's public health, including narratives about food sovereignty, mental health, domestic violence, and maternal health. In 2024, Metriarch published the first issue of their academic health journal, Metrilineal, which features op-eds, issue briefs, media reviews, and policy briefs focused on women's health in Oklahoma.

Metriarch also provides both quantitative and qualitative research and data analysis upon request for decision makers statewide. For example, when a local health department asked them to research the intersection of substance use disorder (SUD) and pregnancy, Metriarch developed an informative report with quantitative and qualitative data and policy recommendations. Their research led to an interim study and proposed bills, a partnership with a national organization defending pregnant women in Oklahoma courts, and a legal practicum in partnership with law schools at the University of Tulsa and Georgetown University.

*Metriarch is a pilot program incubated within, and serves as the Data and Policy arm of Take Control Initiative.

By working with state decision makers, Metriarch has become a trusted statewide facilitator and collaborator for women's health policy. Oklahoma ranks 48th for women's health, 4th in maternal mortality, and 4th for criminalization of pregnancy. Oklahoma has 77 counties—all of which are maternal healthcare deserts, and was one of the states to be under an almost total abortion ban over a month before the fall of Roe vs. Wade in 2022. Additionally, during each legislative session, there are policies proposed that would negatively impact women's health. In the face of this challenging political and social environment, Metriarch models how to effectively use accurate data and resources to enact and implement policy to improve health outcomes for women in Oklahoma.

Recently, Metriarch has partnered with various government agencies across the state to research and design policies to better women's health outcomes. During the 2023 legislative session, the Economic Development and Health Coalition (EDHC) was formed to investigate the negative economic impact restrictive public health policy is having on corporate recruitment, retention, and development in Oklahoma City. In two short years, the EDHC has effectively stopped a plethora of legislation that would broaden health inequity and reduce access to adequate care for girls and women statewide.

Metriarch has also worked with the Oklahoma Healthcare Authority to design the pregnancy Medicaid expansion package. The expansion package increased pregnancy coverage by 67%, moving Oklahoma out of the bottom four states for pregnancy coverage under Medicaid. Furthermore, Oklahoma is one of the first states to implement medicaid covered postpartum care and doula reimbursements for up to 12 months. Metriarch continues to work in partnership with the Oklahoma Healthcare Authority to help improve maternal health outcomes by hosting a monthly "pregnancy stakeholder" meeting with the state agencies and organizations focused on maternal health.

Visit metriarchok.org for more information.

Metriarch®
OKLAHOMA WOMEN'S PUBLIC HEALTH THINK TANK

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