

## Resource Guide

### **All In Webinars: A three part series on Racial Equity Throughout Data Integration. With Network for Public Health Law & the Actionable Intelligence for Social Policy**

*Part 3: October 14, 2020: Successfully engaging stakeholders to center racial equity across the data life cycle*

Cross-sector data sharing and integration enable the transformation of individual-level information into actionable intelligence that can be used to understand community needs, improve services, and build stronger communities. While most data sharing and integration occurs within a legal and governance framework, an emphasis on racial equity, transparency, and community engagement is often peripheral. This is especially troubling because government policies and programs that produce administrative data have often played a direct role in creating, enabling, and sustaining institutional and structural racism. This webinar will include “Work in Action” sites featured in the Toolkit for Centering Racial Equity Throughout Data Integration, developed by Actionable Intelligence for Social Policy (AISP), as places where agencies are proactively centering racial equity during administrative data reuse.

#### **WE STRONGLY ENCOURAGE:**

- Inclusive participatory governance around data access and use
- Social license for data access and use
- A developmental approach to data sharing and integration—start small and grow

#### **WE DISCOURAGE:**

- Broad access to individual-level linked data
- Data use for enforcement or investigation actions against residents
- Use of predictive algorithms without determining responsibility, explainability, accuracy, auditability, and fairness\*
- Use of linked data across institutions that have patterns of institutional racism, specifically, law enforcement, which has demonstrated significant racialized harm without sufficient safeguards in place

A Toolkit for Centering Racial Equity  
Throughout Data Integration



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\*<https://www.fatml.org/resources/principles-for-accountable-algorithms>

## **Presenter Bios**

### Actionable Intelligence for Social Policy

**Amy Hawn Nelson** is Research Faculty and the Director of Training and Technical Assistance for Actionable Intelligence for Social Policy (AISP), an initiative of the University of Pennsylvania that helps state and local governments collaborate and responsibly use data to improve lives. Prior to joining AISP in 2017, Dr. Hawn Nelson was the Director of Social Research for the UNC Charlotte Urban Institute and Director of the Institute for Social Capital, an integrated data system (IDS) charged with supporting university research and data-informed decision-making in the Charlotte region. She is the lead author of [A Toolkit for Centering Racial Equity Throughout Data Integration](#) (2020) and co-editor of [Yesterday, Today, and Tomorrow: School Desegregation and Resegregation in Charlotte](#) (Feb. 2015, Harvard Education Press). Prior to entering the world of IDS' in 2012, Hawn Nelson served as a teacher and school leader for 11 years. She is a community engaged researcher and has presented and written extensively on data integration and intersectional topics related to educational equity. She lives in Charlotte with her husband, two feisty daughters, and a naughty but loveable labradoodle.

### Children's Services Council (CSC) of Broward County

**Sue Gallagher**, Chief Innovation Officer, Children's Services Council (CSC) of Broward County, has been with the CSC for over 13 years providing opportunities for all children "to realize their full potential, their hopes and their dreams, supported by a nurturing family and community." She leads efforts to support community partners to collaborate on improving programs, service systems and communities, including the advancement of racial equity, so young people and their families can thrive. She worked in non-profits serving people with developmental disabilities prior to coming to CSC. Dr. Gallagher is also an adjunct professor at Florida International University where she teaches organizational and community strategic planning.

### Data Justice Program at Detroit Community Technology Project

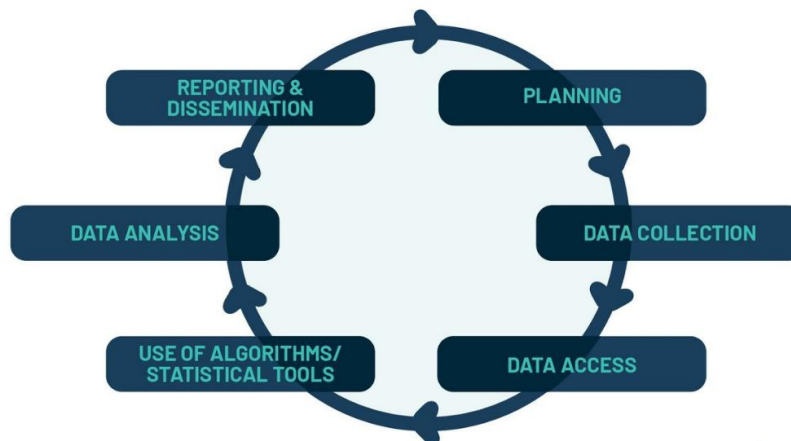
**Tawana Petty** is a mother, social justice organizer, youth advocate, poet and author. She is intricately involved in water rights advocacy, data and digital privacy rights education and racial justice and equity work. She is director of the Data Justice Program at [Detroit Community Technology Project](#), co-leads [Our Data Bodies](#), is a convening member of the [Detroit Digital Justice Coalition](#), an anti-racism facilitator with [Detroit Equity Action Lab](#), and a [Digital Civil Society Lab](#) fellow at Stanford PACS.

### Network for Public Health Law

**Sallie Milam, JD, CIPP/US/G**, is a Deputy Director with the Network for Public Health Law Mid-States region, which promotes and supports the use of law to protect the public's health by providing free direct technical assistance; developing and providing training, materials, and practical tools; and, connecting individuals with one other to build a public health law community. Her focus is navigating law to share data within and across sectors to address health inequities. Sallie has practiced law for over 30 years primarily in the health, HIPAA and general privacy areas. She is a Certified Information Privacy Professional, with US and government privacy certifications. Sallie has extensive experience in working with state agencies around data. From 2003 to 2018, Sallie served as West Virginia's Chief Privacy Officer and led the Executive Branch's Privacy Program. Previously, Sallie facilitated data sharing through her service as the West Virginia Health Care Authority's Privacy Officer and as HIPAA Senior Legal Counsel, where she led HIPAA privacy implementation across the West Virginia Executive Branch. Additionally, she was the first Executive Director of the West Virginia Health Information Network, which is West Virginia's statewide health information exchange, and was West Virginia's Project Director for its Nationwide Health Information Network contract.

### Centering Racial Equity Throughout the Data Life Cycle

"Centering racial equity throughout data integration is not a single, discrete step, but rather an ongoing process at each stage of the data life cycle—planning, data collection, data access, use of algorithms and statistical tools, data analysis, and reporting and dissemination. Each stage presents new opportunities to bring a racial equity frame to data integration, as well as new challenges and considerations."



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## **Resources, Websites & Ideas**

[Introduction to Data Sharing and Integration](#) (The Introduction to Data Sharing & Integration was created by Actionable Intelligence for Social Policy (AISP) as a primer on the basics of using, sharing, and integrating administrative data.)

[Centering Racial Equity throughout Data Integration Tool Kit](#) (This body of work seeks to encourage shifts of awareness and practice, by centering racial equity and community voice within the context of data integration and use.)

[Data Across Sectors for Health and Network for Public Health Law. Legal Bibliography](#)  
Co-developed by the Network for Public Health Law and Data Across Sectors for Health (DASH), the Bibliography is a growing resource for lawyers and community data practitioners, intended to support local collaboratives in their efforts to share data across sectors.

[COVID Health Data Sharing and Privacy](#) The Network's real-time resources, guidance, and information are available to assist the public health community in this challenging time, and law and policy experts are available to provide direct assistance.

[National Neighborhood Indicators Partnership](#) is a learning network, coordinated by the Urban Institute, that connects independent partner organizations in more than [30 cities](#).

[What We Have Learned From the First Wave of COVID-19](#) Early on during the COVID outbreak in the US, All In saw its role as providing support to the frontlines of community-based data sharing. Participants described their efforts to leverage the multi-sector relationships to move quickly together in their communities and building new data-sharing tools on top of systems they had built for other purposes.

[IZ Gateway Project Legal Agreements: Facilitating Secure Data Sharing for Jurisdictions' Immunization Information Systems](#). The IZ Gateway aims to rapidly onboard Immunization Information Systems (IIS) to support readiness for COVID-19 vaccine response through data exchange, both among IIS and between IIS and federal providers/mass vaccination reporting and consumer access tools.

[Practical Playbook II](#) (Chapter 20: All In: How and Why Communities Are Using Data to Drive Community Health Improvement)

[Baltimore's Promise, Data Scorecard](#) Our data scorecard takes a look at how Baltimore City has been doing across the five Cradle-to-Career outcomes that we are focused on improving. We have collected data since 2012 and continue to use these measures to guide where we focus our efforts to ensure that every child in Baltimore has a chance to succeed.

[Baltimore Youth Data Hub](#) Practitioners' and policymakers' efforts to tackle challenges in education, health, public safety, and economic opportunity are often limited by data silos which create a fragmented picture of services and risks shaping the lives of children and families.

[Welfare Money Is Paying for a Lot of Things Besides Welfare](#) Instead of giving cash assistance to poor families, states are widening the racial divide.

[Racism in Public Benefit Programs: Where Do We Go from Here?](#) Many scholars have written at length about racism and the history of public benefit programs and welfare reform in America. [CLASP](#) is a national, nonpartisan, anti-poverty nonprofit advancing policy solutions for low-income people.

[Algorithmic bias detection and mitigation: Best practices and policies to reduce consumer harms.](#) AI is also having an impact on democracy and governance as computerized systems are being deployed to improve accuracy and drive objectivity in government functions.

[Insights into better integrated eligibility systems](#) Implementing integrated eligibility systems can be fraught with challenges, making it difficult for states to claim success. However, there are five observations they can use to ensure triumphant future execution.

[Automating Inequality](#) by Virginia Eubanks. A powerful investigative look at data-based discrimination—and how technology affects civil and human rights and economic equity

[Digital Civil Society Lab](#) The Stanford Digital Civil Society Lab seeks to understand, inform, protect and promote civil society in a digitally dependent world

[Detroit Equity Action Lab](#) We are an innovative hub for community-driven research, programming, and media, working to dismantle structural racism in Detroit.

[Detroit Digital Justice Coalition](#) The Detroit Digital Justice Coalition (DDJC) is comprised of people and organizations in Detroit who believe that communication is a fundamental human right.

[Our Data Our Bodies](#) We are a five-person team concerned about the ways our communities' digital information is collected, stored, and shared by government and corporations.

[Growing an Equitable Community for our Children and Families](#) Sample training on the Local History of Racism/Resistance and research on implicit bias

[Florida State University Florida Institute for Child Welfare](#) Research Brief highlighting CPAR

[Public Science Project](#) Participatory Action Research (PAR) provides a critical framework for making science – systematic inquiry and analysis – a public enterprise

[Research Brief](#) Community Participatory Action Research: Co-Researching Disparities with Broward's Child Welfare Participants and System Partners

[Why Am I Always Being Researched?](#) A Guidebook for Community Organizations, Researchers, and Funders to help us get from the Insufficient Understanding to More Authentic Truth

[Children's Services Council of Broward Community Participatory Action Research](#) (CPAR) In 2018, CSC piloted CPAR with youth and system professionals in the Broward Juvenile Justice, Child Welfare and Behavioral Health Systems along with researchers from Nova Southeastern University.

### **Relevant References from CSC CPAR Abstract**

Anyon, Y, Bender, K., & Kennedy, H. (2018). [A systematic review of youth participatory action research \(YPAR\) in the United States: Methodologies, youth outcomes, and future directions.](#) Health Education & Behavior, 45(6), 865–878.

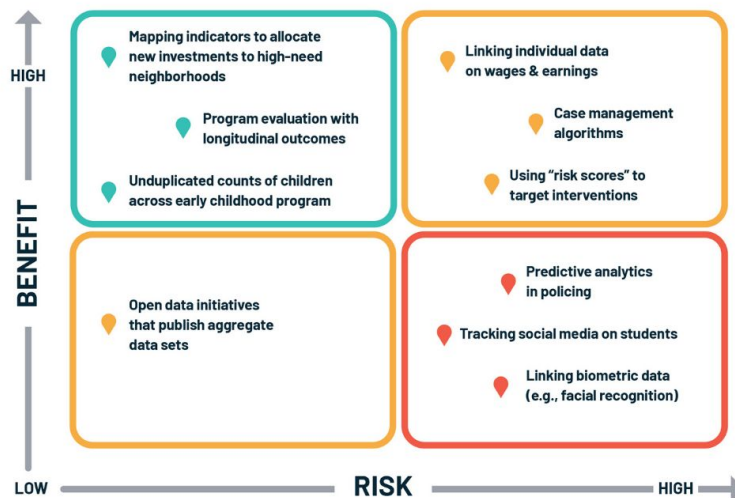
Burke, K. J., Greene, S., & McKenna, M. K. (2017). Youth voice, civic engagement and failure in participatory action research. The Urban Review, 49(4), 585–601. <https://doi.org/10.1007/s11256-017-0410-4>. Cammarota, J. (2014).

Cook, A. L, & Krueger-Henney, P. (2017) [Group work that examines systems of power with young people: Youth participatory action research.](#) The Journal for Specialists in Group Work, 42:2, 176-193, DOI Fine, M. & Torre, M.E. (2019) [Critical participatory action research: A feminist project for validity and solidarity.](#) Psychology of Women Quarterly, 43:4, 433-444

Loizou, E. (2013). Empowering parents through an action research parenting program. *Action Research*, 11(1), 73–91. <https://doi.org/10.1177/1476750313476311> DOI: 10.1080/01933922.2020.1740848

### Data Sharing Risk vs. Benefit Matrix

We have identified broad categories of use to help guide thinking about and talking through intended and unintended consequences of civic data use with a variety of voices and perspectives. Projects that are low benefit and high risk should be considered with the utmost caution, and in some instances, data sharing should not proceed.



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### Host Organizations

[Network for Public Health Law](#) (Learn more)

- Receive NPHL’s biweekly [Network Report and Judicial Trends e-newsletters](#) for insights and commentary on law and policy in public health, and updates on Network events.

[Actionable Intelligence for Social Policy](#) (Learn more)

- [Sign up for AISP’s monthly newsletters](#) (Subscribe)

[Detroit Community Technology Project](#) (Learn more)

[Baltimore's Promise](#) (Learn more)

- [Funding opportunities](#) (Learn more)
- [Initiatives](#) (Learn More)

[Data Across Sectors for Health](#) (Learn More)

[All In: Data for Community Health](#) (Learn more)

- [Subscribe to the All In Newsletter](#) (Subscribe)
- [Join the All In national learning community](#) (Join & set up your profile)
- [Sign up for an All In Affinity Group](#) (Join)
  - Health and Housing
  - Law and Data Sharing (Data Governance)
  - Community multi-sector indicator platforms/dashboards
  - Substance Use Disorder Data Sharing, Integration, Implementation

### **Upcoming All In Webinars & Partner Events**

***All In for a Shared Racial Equity Vision on Oct. 22, 2:00 - 3:00 p.m. EST [RSVP here](#)***

What does the [All In](#) community mean when we talk about racial equity? How does racial equity and inclusion show up in multi-sector community collaboration and data sharing work? As the country demands racial justice, many organizations are grappling with their place and the purpose.

**Workshop Series: Addressing Health Equity through Data Disaggregation [More info here](#)**

The National Network of Health Surveys, part of the UCLA Center for Health Policy Research, is offering a series of workshops designed to improve the disaggregation of race and ethnicity measures in health data sources. Our goal is to boost the number of subpopulation categories made available to key constituencies working to improve health equity. This is especially important for representing communities that are often “hidden” in large health data sets.

**All In National *Virtual Meeting*. Dec. 8 - 10, 2020 [RSVP here](#)**

Join All In: Data for Community Health on December 8-10, 2020 for the 4th Annual National Meeting (and 1st Virtual Meeting!). This year's themes include: examining work through the lens of racial justice and health equity; incorporating community voice and leadership; and unpacking the nuts and bolts of data sharing.



Save the Date!



**4th Annual National Meeting**  
**December 8-10, 2020 | VIRTUAL**