



# FOURTH IN A SIX-PART SERIES

# Centering Racial Equity Across the Data Life Cycle

By Sharon Zanti, Matthew Katz, and Amy Hawn Nelson

P olicymakers strive to make data-driven decisions that support the common good, and as a result, sharing and integrating administrative data are now commonplace across local, state, and federal agencies. Cross-sector data sharing and integration enable the transformation of individual-level information into actionable intelligence that can be used to understand urgent and long-term community needs; improve services, systems, and practices; develop innovative policies and interventions; and, ultimately, build stronger communities.<sup>1</sup> Yet, the way that cross-sector data are used can also reinforce legacies of racist policies and produce inequitable resource allocation, access, and outcomes.<sup>2,3</sup>



# About This Series on Advancing Race Equity

Last year, APHSA incorporated a race equity lens into our **Strategic Playbook**—a five-year plan that guides our work and shows our commitment to advancing the potential and well-being of all people.

Applying a race equity lens means at the core of our work we are actively seeking to illuminate disparate outcomes and paying disciplined attention to race and ethnicity while analyzing problems, looking for solutions, and defining success. This involves actively working to understand the environmental and structural root causes preventing social and economic mobility and health and well-being for all people. Within our national context and point in history, APHSA is committed to be an accountable actor and supportive ally in systematically eliminating racial inequity.

As part of our commitment, we will include a feature article in every issue of *Policy & Practice* this year showcasing communities working to apply a race equity lens to health and human services. If you have an inspiring story to tell, we would love to hear from you. Please contact Jessica Garon at *jgaron@aphsa.org.* 

Check out the APHSA website for our full *Call to Action for Human Services,* which includes resources we will continue to add to throughout the year (*https://aphsa* .org/About/call\_to\_action.aspx).

Black, Indigenous, and people of color (BIPoC) and/or people living in poverty are often over-represented within government agency data systems, and disparate representation can cause disparate impact.4 Laws, policies, business rules, and narratives are affected by structural racism, which is the root cause of the racial disparities evident in system outcomes.5 Such disparities demonstrate the consequences of structural racism: that, as a group, BIPoC in the United States have worse outcomes in many human services system measures regardless of socioeconomic status.6



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Since its inception in 2008, Actionable Intelligence for Social Policy (AISP) has developed extensive knowledge and best practices for shared data infrastructure to support reuse of administrative data for research, evaluation, and policy analysis. However, when sites sought guidance in using integrated data systems for equity, justice, and centering community voice, there were few resources to offer, nor exemplars to replicate. Since January 2019, AISP has led a diverse workgroup of civic data stakeholders with the overarching goal of better understanding and documenting best practices for administrative data reuse that centers on racial equity. The workgroup represented diverse perspectives across race, gender, and geography, and included community organizers, government administrators, and nonprofit staff from across the country and all levels of government. Over the course of 18 months, the workgroup developed research questions and a research framework, collected data, and, ultimately, co-created a toolkit for centering racial equity throughout human services data use and integration.

#### 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

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

The Toolkit for Centering Racial Equity Throughout Data Integration presents this framework of best practices, strategies, and suggested activities to center racial equity throughout the administrative data reuse life cycle. Additionally, the toolkit includes detailed examples of positive and problematic practice and site-based examples of current "Work in Action."7 This process is ongoing as the toolkit is an evolving resource. The following sections highlight key recommendations and examples for centering racial equity at each stage of the data life cycle, including careful considerations of risk versus benefit.



# Racial Equity Across the Data Life Cycle

#### **Racial Equity in Planning**

Centering racial equity requires you to develop an understanding of the local racial, social, and historical context in which your effort is taking place. As part of that learning process, we recommend engaging diverse stakeholders early on in conversations about data-sharing goals, risks and benefits, and project plans.

#### **Table 1: Positive and Problematic Practices, Planning**

Positive Practices	Problematic Practices
Including diverse perspectives (e.g., community members with lived experiences and agency staff who understand the data) on planning committees	Using only token "representation" in agenda- setting, question creation, governance, or institutional review board
Building capacity for researchers, administrators, and community participants to work together on setting agenda	Using deadlines or grant deliverables as an excuse to rush or avoid authentic community engagement
Researching, understanding, and disseminating history of local policies, systems, and structures involved, including past harms and future opportunities	Using only historical administrative data to describe the problem, without a clear understanding of harmful policies and co-created plan of action to improve outcomes
Lifting up research needs of the community to funders; helping shape funding strategy with funders to support community-driven research	Accepting grant/philanthropic funding for a project that is not a community priority or need

**Work in Action:** Broward County, FL demonstrates how using Participatory Action Research in planning can infuse racial equity throughout the data life cycle. Broward County's data collaborative intentionally involves system participants in governance, research, evaluation, and solution creation to address racial, economic, and social/spatial gaps between predominantly White researchers and policymakers, and those using public services. In planning, Broward County is creating an integrated data system that supports sharing strengths-based stories about the community and using data to co-create system and policy improvements.

See Racial Equity on page 32

#### **RACIAL EQUITY** continued from page 17

Racial Equity
in Data Collection
Administrative data are
typically collected for opera-
tional purposes, rather than
for research or evaluation.
Because of this, there are
potential risks for reusing
administrative data for
research, evaluation, and
policy analysis. These data
are vulnerable to biases,
inaccuracies, and incom-
plete or missing data, and
often include individuals
living in communities that
are over-surveilled by gov-
ernment. An equity lens
considers these inherent
vulnerabilities in data col-
lection and how they can be
reduced or contextualized
appropriately.

#### Table 2: Positive and Problematic Practices, Data Collection

Positive Practices		<b>Problematic Practices</b>	
Adhering to data management l secure data as they are collecte with carefully considered, role-b	d—specifically,	Assuming that program data have training in da data security.	-
Including agency staff and community stakeholders in defining which data should be collected or reused		Inviting only researcher	s to identify data needs
Collecting only what is necessary to your context		Failing to consider whic elevated risk of causing when determining whic your context (e.g., a ho collects resident HIV st	harm if redisclosed ch data to collect in using program that
Strong efforts to support metadata		Failure to clearly identif	y, explain, and
documentation, including key dimensions of		document data integrity	y issues, including data
metadata such as:		that are:	
description	provenance	inaccurate	undocumented
technical specifications	rights	unavailable	incomplete
preservation	citation	inconsistent	
Including qualitative stories to quantitative data	contextualize	Allowing quantitative da without context or disc	

**Work in Action:** The Allegheny County, PA initiative to collect sexual orientation, gender identity, and gender expression (SOGIE) data in child welfare validates an intersectional approach to centering equity in data collection. For this effort, the Department of Human Services had to address privacy and data security concerns surrounding youth SOGIE data, the implications of sharing these data with external stakeholders, and the complexities and costs of updating information technology (IT) systems. Additionally, the department engaged with IT staff to ensure they knew the importance of these changes in order to mitigate harm during the design process.

#### Racial Equity in Data Access

Critically assess which data can be used and viewed, by who, when, and for what purposes. Data accessincluding whether data are open, restricted, or unavailable-should be carefully considered based upon how the release of such data may disproportionately impact some individuals and communities more than others. Alternatively, not making certain data available, such as data that contextualizes community challenges, may also lead to disparate impacts.

#### **Table 3: Positive and Problematic Practices, Data Access**

Positive Practices	Problematic Practices
Open data	
Open data that have been identified as valuable through engagement with individuals represented within the data	Ongoing open data that is based upon problematic indexes or algorithms, with a history of discriminatory impact on communities (e.g., release of "teacher effectiveness scores" and "school report cards")
Clear data release schedules and information on where to go and how to access data once they are released	Releasing data that can be re-identified (e.g., data released by small geographies may be identifiable by local residents)
Restricted data	
Adhering to data management best practices for data access, including clear data destruction parameters (if applicable) following use	Assuming that data management best practices are being followed without explicit protocols and oversight in place
Utmost care given to de-identification and anonymization of data prior to release	Releasing data that can be re-identified (e.g., data that have not been properly anonymized or include aggregate or subgroup data without suppressing small cell sizes)
Accessible data request process with clear policies and procedures for submitting a request and how requests are evaluated	Unwillingness to release data, or limiting access to researchers or individuals with an "in"

#### Unavailable data

Clear documentation of why data are	Refusal to release data when release is
unavailable (e.g., specific statute, legislation,	permissible and would not pose an undue
data quality explanation, data are not digitized,	burden
undue burden in data preparation)	

**Work in Action:** The Birth through Eight Strategy for Tulsa (BEST) data collaborative in Tulsa, OK provides an example of balancing access to integrated data while protecting privacy and data security. The collaborative was formed to address race, equity, and service overlap challenges in the community, and brought together data from 32 programs across local government, nonprofit, private-sector, and philanthropic organizations to do so. BEST piloted a platform utilizing privacy-preserving record linkage that supported data integration while keeping individual and organizational data private and secure. The platform's use of cryptographic technology allows researchers to integrate data more quickly, at lower cost, while enhancing privacy for individuals and organizations.

#### Racial Equity in Algorithms/Statistical Tools

Use of algorithmic tools by the government is becoming increasingly common. It is important to understand that no algorithms are race neutral as they reflect the biases of the data that feed them and the people who create them. To center racial equity, strategies and tools should be utilized to ensure transparency, assess bias, and determine the positive and negative consequences of using such statistical tools.

#### Table 4: Positive and Problematic Practices, Algorithms and Statistical Tools

Positive Practices	Problematic Practices
Involving diverse stakeholders in early conversations about the purpose of an algorithm prior to development and implementation	Developing and implementing algorithms for human services without stakeholder involvement or alignment across multiple agencies
Clearly identifying and communicating potential benefits and risks to stakeholders	Implementing an algorithm with no clear benefit to individuals included in the data
Human-led algorithm use (i.e., human can override algorithm at any point in process)	Elevating algorithmic decision making over judgment of seasoned practitioners; no human involvement
Using "early warning" indicators to provide meaningful services and supports to clients	Using "early warning" indicators for increased surveillance, punitive action, monitoring, or "threat" amplification via a risk score

Work in Action: In May 2018, New York City convened a task force to assess the use and proliferation of automated decision systems (ADS) across city services. Prior to the task force's first public forum, four graduate students built a website, *Automating. NYC*, designed to make ADS conversations more accessible to the community. They worked with city agencies to develop case studies across social services systems, adapted nontechnical activities to demonstrate algorithmic concepts, and incorporated individual stories to accompany technical explanations. The site also included practical action steps and allowed community members to ask informed questions about how ADS contribute to unjust systems, with the hope that future systems are built to benefit the community.

#### Table 5: Positive and Problematic Practices, Data Analysis

Positive Practices	Problematic Practices
Using participatory research to bring multiple perspectives to the interpretation of the data	Describing outcomes without examining larger systems, policies, and social conditions that contribute to disparities in outcomes (e.g., poverty, housing segregation, access to education)
Engaging domain experts (e.g., agency staff, caseworkers) and methods experts (e.g., data scientists, statisticians) to ensure that the data model used is appropriate to examine the research questions in local context	Applying a "one size fits all" approach to analysis (i.e., what works in one place may not be appropriate elsewhere)
Correlating place to outcomes (e.g., overlaying redlining data to outcomes)	Leaving out the role of historical policies in the interpretation of findings
Using appropriate comparison groups to contextualize findings	Making default comparisons to White outcomes (e.g., assuming White outcomes are normative)
Disaggregating data and analyzing intersectional experiences (e.g., looking at race by gender)	Disregarding the individual or community context in the method of analysis and interpretation of results

**Work in Action:** #ChangeFocusNYC, a participatory action research project born out of a partnership between New York City's Administration for Children's Services (ACS) and Department of Education, aims to understand experiences of New York City youth involved with multiple city agencies and recommend policies that could benefit them. Fifteen youth were chosen to partner with academics to design and implement #ChangeFocusNYC. Youth investigators participated in all research phases and were essential contributors during development of the analytic plan. Collaboratively generated answers to research questions are helping ACS work toward a system in which young people are continuously engaged in shaping the institutions that impact their lives.

## Racial Equity in Data Analysis

A racial equity lens during data analysis incorporates individual, community, political, and historical contexts of race to inform analyses, conclusions, and recommendations. Solely relying on statistical outputs will not necessarily lead to insights without careful consideration of data quality, disaggregation, and statistical power. However, disaggregation is also a series of tradeoffs. Without disaggregating data by subgroup, analyses can unintentionally gloss over inequity and lead to invisible experiences. Alternatively, creating a subgroup may shift the focus to a population that is already over-surveilled. Given the complex series of decisions inherently involved in centering racial equity within analysis, iterative work with strong participation from a variety of stakeholders is critical.

# Racial Equity in Reporting and Dissemination

Ensure analyses and results are made available to the public in a variety of formats, avoiding jargon that is specific to internal staff or academic audiences. Pay particular attention to which data are highlighted, how they are framed, and the general readability and accessibility of communication. For some projects, it may even be possible to transform dissemination into an opportunity for community conversation, allowing you to supplement quantitative findings with informative qualitative feedback and lived experience.

#### Table 6: Positive and Problematic Practices, Reporting and Dissemination

Positive Practices	Problematic Practices
Developing differentiated messaging for different audiences that considers the appropriate level of detail and technical jargon, language, length, format, etc.	Using intentionally dense language with low readability, especially for non-native language learners
Reporting data in an actionable form to improve the lives of those represented in the data (e.g., analyzing food purchase data to identify food deserts and guide development of grocery stores)	Reporting data that are not actionable or that are intended to be punitive (e.g., analyzing food purchase data to remove recipients from Temporary Assistance for Needy Families [TANF] or other benefits)
Acknowledging structural racism or other harms to communities that are embedded in the data	Attempting to describe individual experiences with aggregate or "whole population" data without analyzing disparate impact based on race, gender, and other intersections of identity
Providing clear documentation of the data analysis process along with analytic files, so that others can reproduce the results	Obscuring the analytic approach used in a way that limits reproducibility

Work in Action: The City of Asheville, NC created a story map, "Mapping Equity in Asheville," which links racial demographics over time to location. Major increases in population, tourism, and economic activity over the past decade have had unintended negative consequences for low-income residents and residents of color, leading to widespread gentrification and displacement. Publishing results of geospatial analyses online in a user-friendly format has allowed Asheville residents to better understand the connection between racialized policies and physical location, particularly with regard to redlining practices. The story map provides valuable information to government and community members to inform policy, programming, and resource allocation.

## Conclusion

While centering racial equity throughout the data life cycle is a new consideration for many public agencies, there are actionable steps every site can take, right now, with whatever resources are available, to center racial equity. Perhaps the most promising finding that emerged through all stages of this project is that sites are eager to learn and improve their practices. The twelve "Work in Action" sites featured in the toolkit (see page 50) have worked toward more equitable power relations, the cocreation of innovative solutions, the healing of some harm, and made progress toward authentic communication across racialized hierarchies and segregated spaces.

All public-serving agencies are at a pivotal moment, one in which the use of data is accelerating in both exciting and concerning ways. We have access to greater amounts of data than at any other point in our history, but practice lags behind, placing BIPoC at the greatest risk of the "data-ification of injustice."<sup>8</sup>

Working toward racial equity is not an end goal, but a process, and there are countless places to begin across the data life cycle. Acknowledging history, harm, and the potentially negative implications of data integration for groups marginalized by inequitable systems is a key first step, but it is only a first step. To center racial equity, we must center the voices, stories, expertise, and knowledge of communities in decision making. With inclusive participatory governance around data access and use, administrative data reuse can support collective action with shared power to improve outcomes and harness data for social good. We must continue to build understanding and support for adopting positive practices by acknowledging the harm of current problematic practices throughout the data life cycle. To move these conversations forward and see positive equitable practices normed,

resourced, and adopted, we must cultivate spaces where public data users can come together and debate these nuanced topics in good faith to ensure ethical administrative data reuse.

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#### **PANDEMIC** continued from page 29

This focus on impact, known as the Human Services Value Curve,<sup>13</sup> serves to remind us not to lose sight of our ultimate goal: sustained well-being of children and youth, healthier families and communities, opportunities for employment and economic independence, and fairness and equity across all the places we live.

The Human Services Value Curve helped inform the National Imperative report, along with a strategy playbook developed earlier by the Alliance, to infuse research-based practices and values to guide CBOs in achieving excellence and last impact. The guidebook, "Commitments of High-Impact Nonprofit Organizations,"<sup>14</sup> offered a framework and foundational direction that led to the north star solutions. When applied through the framework of the commitments, these north stars offer a clear road map and path forward for the human services ecosystem that can reshape the future of health and human services for the achievement of breakthrough results that can create a more healthy and equitable society.

#### The North Stars—Road Map to Transformational Solutions

The following provides a brief preview of the themes of each of the five north stars from the report and how they can help reshape the delivery of more equitable H/HS in a way that will not only adapt to the challenges and inequities of today's pandemic but can prepare and guide us for future disruptive events.

#### **Commitment to Outcomes**

This pandemic, and the inequities and health disparities it has revealed, is forcing both public human services agencies and CBOs to reframe the way we lead and operate. This means shifting from a focus on services delivered (i.e., number of foster beds filled) to outcomes achieved (i.e., children successfully living with their families or children achieving other lasting permanency). This shift will enable more human services-sector participants-community-based organizations, public-sector partners, and funders-to invest in innovation and new capabilities.

It is not an easy shift to make. The long-standing systemic inequities illuminated by COVID-19, along with the growing understanding that health extends beyond health clinic care to include the social determinants, underscores the urgency for H/HS to partner more deeply to develop high-impact, equitable solutions that lead to longterm, positive outcomes in population health and well-being.

As we continue to seek ways to improve health outcomes during and

after the pandemic, with an intent to move to a preventive system with upstream solutions, it is critical that public and private funders invest fully in human services as part of the community infrastructure that contributes to health and well-being. These investments must include resources that build the capacity for better outcome measurements.

### **Capacity for Innovation**

The pandemic has demonstrated our ability to change dramatically in a matter of days and impact the context in which people live their lives. It has also revealed the consequences and challenges that arise when we implement strategies that lack a human-centered design approach, providing further support for the critical need for the human services ecosystem to invest in its capacity to innovate with community voice and lived experience at the center.

The scale of innovation that will be needed to address this challenge will require engaging all voices and focusing on community strengths that result in high-impact, sustainable solutions that further build community capacity and resiliency. Community-based human services organizations are uniquely positioned in proximity to people and communities. By increasing their capacity for innovation they can help to