Black Researchers Collective

October 2025

The War on Data

Ensuring Data Access and Integrity for Communities in Illinois

A policy brief addressing the federal data crisis in the United States

Setting the Stage

My grandfather, who grew up as a sharecropper in Blytheville, Arkansas, on a plantation that likely held his grandfather's family captive as slaves, taught me the value of education. Although he was not formally credentialed in the ways we typically think an educated person should be, for a long time, he was the smartest man I knew.

"If you don't want a Black man to know something, put it in a book," he would remind us, a reflection of the narrative used against us. It was paramount for him that his grandkids understood the negative stereotypes circulating about Black people. To combat that narrative, he encouraged us to read. To educate ourselves. Anywhere. Everywhere. As much as possible.

Before I could fully grasp the depth of his lessons, I would rummage through the old books on his bookshelf, searching for the thing that a Black man was supposed to know, only to find that it was the knowing itself he was referring to: the kind that only comes from having access to more information than you currently know. Simply put, that information is what we call data.

Somewhere along the way, we picked up the notion that data is too complicated to understand, something confined to academia, beyond our reach. But that's a myth. Yes, there is data that lives in those spaces, and plenty of it, but much of the data we encounter every day is tied to the business of our own lives.

Our Personally Identifiable Information (PII), which refers to our names, email addresses, social security numbers, driver's license numbers, dates of birth, race, gender, sexual orientation, etc.; all of it is data. And all of it is ours to protect.

You've likely seen or experienced what others do when they have access to your data, whether it's tailoring ads to your preferences for profit or (mis)using it in ways that don't serve you. Others are not going to protect it for you. It's up to us as individuals, communities, and as a village to protect our own.

In 1971, President Richard Nixon declared the War on Drugs, a declaration that made drugs public enemy number one. What followed was not a war on substances, but a war on people. Entire communities were criminalized, families dismantled, and generations marked by surveillance and stigma. The rhetoric of "protection" became the mask for control.

Today, more than fifty years later, we are witnessing another quiet but equally devastating front: The War on Data. It may not fill jails, but it erases stories. It may not destroy homes, but it distorts the truth and invalidates lived experiences. People who understand the true value of data know this, and not only exploit it but also weaponize it for their own convenience. Since the Trump Administration took office in January 2025, thousands of federal data connected to our lives have disappeared. When you erase key data related to the people, you're also erasing the documented, real experiences of everyday people and, subsequently, the financial resources required to support their livelihoods and overall well-being. Just as the War on Drugs targeted Black bodies, this War on Data targets Black realities, deciding whose information counts, who gets distributed material resources, whose stories are visible, and whose experiences are rendered invisible. This war impacts more than just Black folx though. It impacts all of us.

When government websites remove data that reveal racial, gender, and sexual orientation inequities, when institutions collapse race categories into “Other,” when algorithms decide who gets access to housing, jobs, or care, these are not neutral acts. They are policy choices. And they have real consequences for our collective ability to see, name, and change the conditions that harm us.

My grandfather didn’t use the word data, but he understood its power. He knew that knowledge, and who gets to hold it, shapes freedom itself. To read was to reclaim access. To learn was to resist erasure. And to share what you know was to multiply power.

So when we talk about protecting our data, we’re not just talking about cybersecurity. We’re talking about safeguarding our people, our communities, and our right to self-determination. We’re talking about ensuring that the information collected about us is accurate, accessible, and accountable to us.

Because data, at its core, is not just numbers, it’s also about narratives, our experiences. It’s evidence of our existence. And if we don’t protect it, someone else will define it for us.

The War on Data is not theoretical. It’s happening now, in deleted public dashboards, defunded research programs, and the quiet rewriting of what counts as “truth” and what’s widely accepted as knowledge. But just as my grandfather taught me, knowing is the first act of power. The next act is using that knowledge to build systems that reflect who we are, in our fullness and complexity.

This brief is a call to action:

- To demand transparency
- To democratize data access
- To ensure that information serves the people it describes

Because protecting our data means protecting our democracy, and protecting our democracy means protecting all of us.

Glenance Green, PhD
(aka Dr. G)

Black Researchers Collective
Co-Founder and Executive Director

What is the War on Data?

A growing number of reputable organizations and experts have raised alarms about a ***federal data crisis***.[a] Groups such as *The Leadership Conference Education Fund*[1] and the *American Public Health Association*[2]—as well as institutions like *Harvard Law School Library*[3] and *Washington University Library*—have publicly responded and launched data preservation and advocacy efforts. A collaborative source dedicated to monitoring changes in federal datasets called Dataindex.us has been actively monitoring over 12,000 federal datasets, flagging when data becomes unavailable, reposted, or fails to release as expected. On February 3, 2025, the *New York Times*[4] published a comprehensive analysis revealing that more than 8,000 web pages across over a dozen U.S. government websites had been taken down since January 31, 2025—just eleven days after the Trump administration took office.

The data purges have disproportionately targeted information on race, ethnicity, sexual orientation and gender identity (SOGI), HIV, cancer, vaccines, veterans' care, hate crimes, and other public health and social indicators essential to the work of researchers, nonprofits, service providers, and community leaders. For Black-led and Black-serving community organizations, these actions are extremely detrimental. When detailed demographic data (also known as disaggregated data) is missing, our communities become **invisible** in both the data and the decisions that impact health, education, funding, and justice. **The communities we *are* and *serve* are the data**, and our stories, struggles, and needs should not be deleted. Disaggregated data reveal important trends and inequities that we otherwise would not know regarding key issues that we care about, such as maternal mortality. For example, data shows that Black women in the U.S. are 3–4 times more likely to die from pregnancy-related causes than white women[5], but when the data is disaggregated to examine whether this is the case with Black women across the Diaspora, we find that U.S.-born Black women experience higher maternal mortality rates than Black immigrant women from Africa and the Caribbean.[6] Research also shows that over time, the longer Black immigrant women live in the U.S., their maternal health outcomes worsen, eventually resembling those of the U.S.-born Black women,[7] pointing to racism and systemic stressors, not biology, as the root cause of this inequity.

Background and Context

We are living in a moment of disinformation, where data is being weaponized, erased, distorted, and devalued by political forces that seek to undermine equity and silence historically marginalized communities. Since the start of 2025, under the current federal administration, the attack on diversity, equity, and inclusion (DEI)[b,8,9] has escalated sharply.

DISINFORMATION:

False information deliberately and often covertly spread in order to influence public opinion or obscure the truth.[a]

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[a] This federal data crisis began shortly after the new administration took office in January 2025.

[b] Diversity means having a mix of different people (e.g., races, gender, abilities, or perspectives). Equity means giving each person the support they specifically need to succeed, not treating everyone the same. Inclusion means making sure everyone feels welcomed, respected and like they truly belong. In sum, DEI is about fairness, representation, and creating spaces where all voices matter. (See endnotes 9 and 10 for sources)

The mass erasure of data from federal data agency websites, commonly referred to as the ***federal data crisis***, is a coordinated effort to strip away the evidence base that community organizations, policymakers, and advocates rely on to diagnose problems, design solutions, and hold agencies accountable. **Research and data**, particularly when it is **disaggregated by race, gender, class, or ability**, are being flagged as inaccurate, politically motivated, or unsupported during this crisis. With this, we are also seeing an uptick in disinformation and misleading data narratives on the news and social media that obscure the truth about systemic inequities.

At its core, ***data* is information**, including numbers, words, images, and lived experiences that tell the story of who we are and how we live.

At its core, ***data* is information**, and ***research*** is a process of exploring or investigating that information that you are interested in learning more about. **Disaggregation** is the process of breaking down data into smaller, more specific subgroups, helping to identify disparities affecting Black people, queer and trans people, immigrants, and other marginalized communities that are often hidden in aggregated data.

Data is **power**; it shapes how problems are defined, who is held responsible, and who gets resourced. When data is erased or made inaccessible, it allows those in power to distort the narrative, dodge responsibility, and deepen inequity.[10] This is not only an issue on the federal level, it has real implications for Illinois, where policy decisions at the state and local level rely heavily on data to guide funding, services, and accurate representation.[11]

EXAMPLE: BIRTH JUSTICE IN ILLINOIS

Efforts to safeguard and expand access to disaggregated data are foundational to advancing birth justice in Illinois. In 2021, the introduction of SB 1041[12] *(The Consumer Choice in Maternal Care for African American Mothers Program Act), authored by the Holistic Birth Collective, sponsored by Representative Mary Flowers, and championed by the Illinois Birth Justice Coalition, was grounded in data showing stark disparities in maternal outcomes. This bill proposed a Medical Voucher Program and Maternity Episode Payment Model to improve maternal care for Black women. Although it passed the House but stalled in the Senate, organizations such as the Black Midwifery Collective*[13] *have continued to use disaggregated data to advocate for culturally competent care, community-led solutions, and policy change.*

The example above underscores why protecting public data is not just a technical issue, it is a matter of life, death, and justice for Black mothers and birthing people across the state. One Black Researchers Collective (BRC) participant who works as a doula put it plainly: "*Erasure of data = more dead moms and babies.*" The loss of disaggregated maternal health data prevents tailored interventions and life-saving advocacy for Black mothers, who already face disproportionate risks. The rapid deletion of diversity-related data is a strategic act that limits our ability to organize, advocate, and build power. As a result, Illinois could risk losing millions in federal funding, worsening pressing issues such as maternal mortality and subsequently erasing Black communities from policy decisions. Illinois must act now to safeguard disaggregated data to protect the identities, health, and livelihood to ensure that Black communities are seen, heard, and served.

How Black-Led Organizations Use Data Now

In the spring of 2025, over 95 participants from 40+ Black-led and Black-serving organizations across Illinois convened a series of **Civic Data Forums**[c] organized by the Black Researchers Collective. These forums served as a primary data source for this brief, offering firsthand insights into how these organizations engage with federal and local data. The findings from these forums have shown that Black-led and Black-serving organizations across Illinois already use disaggregated data in essential ways:

1. **To track enrollment, demographics, and disparities** through platforms like Cityspan, Smartsheet, Salesforce, Airtable, and government databases (Illinois Department of Public Health, Chicago Department of Public Health, March of Dimes, Chicago Health Atlas, etc.).
2. **To guide programming** from maternal health and mental health to education, violence prevention, and economic development.
3. **To advocate for change** using voting data, Office for Civil Rights (OCR) complaints, and local business data to support campaigns for reparations, food justice, and criminal justice reform.
4. **To tell the truth** by countering harmful media narratives about young Black men with firsthand, community-based data and testimonies.

These are just some of the many ways that our community-based organizations (CBOs) across the state are using data. What would we do if we no longer had access to some of these data? What implications might that have for our communities and collective work? Losing access to these data would not only disrupt vital programming, but it would also silence the evidence our communities rely on to advocate, organize, and lead.

Future Needs & Threats

Black Illinoisans are eager to expand how they use data in service of their communities, according to data collected from BRC's Civic Data Forums. Some of the most cited goals for expanded use include:

1. **Building capacity and securing funding** based on accurate needs assessments
2. **Using data for business development**, such as launching Black-owned trucking companies, urban agriculture, fashion brands with insights into customer behavior, location targeting, and local economies
3. **Improving community health and education** by tracking access to hospitals, mental health care, school discipline outcomes, special education, and food/nutrition
4. **Advancing advocacy efforts** via pushing for naturalization of Legal Permanent Residents, monitoring outcomes of Cook County Sheriff's mental health programs, and expanding Black media platforms that center positive stories

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[c] Black Researchers Collective hosted three ***Civic Data Forums*** *in Springfield, IL during the 2025 Illinois legislative session and one in Peoria, IL during the Black Abundance Convening, surrounding the topic of data disaggregation and data accessibility in Illinois. The goal of these civic data forums was to raise awareness about the importance of data disaggregation in Illinois, build coalition strategies in an era where critical federal data is being erased, and advocate for a stronger infrastructure for publicly accessible state level data.*

However, these efforts are under threat. Disappearing federal datasets and the lack of coordinated publicly accessible state-level disaggregated data makes it harder to advocate for the needs of Black communities and Black-serving organizations. If data shapes policy, resource allocation, and public understanding, then we must fight for data integrity, accessibility, and accuracy. BRC's Civic Data Forums with Black nonprofits and CBOs across Illinois revealed the following urgent concerns:

- **Funding & Services:** Demographic data is required to advocate for state and federal resources. Without it, organizations risk losing access to life-sustaining funding streams.
- **Visibility & Legitimacy:** When race and sexual orientation and gender identity (SOGI) data are erased, Black communities are made invisible, undermining the legitimacy of our lived experiences and erasing our stories from public history.
- **Advocacy & Accountability:** Publicly accessible, disaggregated data allows communities to hold institutions accountable. Without it, narratives can be manipulated, and inequity becomes harder to prove and address.
- **Organizational Strategy:** Leaders emphasized the importance of comparing federal data with their own grassroots research. They reported fearing losing the ability to identify disparities, validate community needs, and make data-driven decisions without reliable federal benchmarks.

Evidence and Data

Protecting disaggregated data is a political and moral imperative. More importantly, federal data inaccessibility is not a future concern, it is a present-day crisis, already disrupting the work of nonprofits and endangering the communities they serve. This data is necessary for Black-led and Black-serving nonprofits in Illinois to tell their stories, secure funding, or design programs that meet communities' needs.

The Federal Landscape: Data Under Attack

According to *GrantStation*[14], a trusted resource for nonprofit funding and strategy, federal actions have already eroded public data infrastructure, silenced DEI efforts, and removed thousands of pages of content from federal websites, particularly those used by nonprofits for evidence-based programming, funding proposals, and public accountability.

The *Yale Daily News*[15] underscores how the loss of Center for Disease Control (CDC) data has already begun to impact public health. Epidemiologists and public health experts note that gaps in disease surveillance, especially related to COVID-19 and HIV, are growing due to the disappearance of real-time, population-specific data. This undermines prevention efforts and delays life-saving interventions.

The *Williams Institute* at UCLA[16] further confirms the impact of these actions on LGBTQ+ communities. Due to executive orders and the removal of LGBTQ-inclusive data, researchers and community organizations have lost access to national-level statistics that once helped guide inclusive policy and services.

If this is what universities with extensive resources are experiencing, what does this mean for smaller organizations that never had robust access to federal data in the first place? The consequences are even more severe. This federal crisis ripples down through state agencies and local organizations, especially as these groups may rely on publicly available datasets to support grant applications, design community programs, and advocate for policy change, but may lack the legal teams, data infrastructure, and archival capacity to respond to sudden data removals.[17]

In Illinois, for example, the loss of access to the Environmental Protection Agency (EPA's) EJScreen tool[d,18] and the CDC's Social Vulnerability Index[e,19] has disrupted the work of local environmental justice coalitions, which used these datasets to identify pollution hotspots and health disparities in Black and Brown communities.[20] Without these tools, their ability to secure funding and build evidence-based interventions has been significantly weakened. This cascading effect from federal erasure to state-level disruption to local disruption underscores the urgent need for coordinated inclusive strategies to preserve data access and integrity across all levels of governance.

A Model for Progress: Illinois Leads on Middle Eastern North African (MENA) Disaggregation

Illinois has already demonstrated what is possible when communities advocate for their identities and the government listens. In 2023, Illinois became a national leader by signing House Bill 3768 which officially recognized the Middle Eastern North African (MENA) category within state agencies.[21] This achievement, outlined in a state press release, was the result of grassroots organizing, community-based leadership, and a responsive government. This model offers an example of how inclusive data practices can strengthen public systems. Illinois must continue to build on this momentum by expanding disaggregation, improving data integrity, and protecting access to public datasets across all communities. Doing so ensures that policies, funding decisions, and services are grounded in accurate, representative data—and that all Illinoisans are counted, visible, and supported.

Calls To Action

The erasure and suppression of federal data, especially data related to race, gender identity, and sexual orientation, undermines public trust, weakens community power, and threatens the ability of Black-led nonprofits and community-based organizations to serve our people. We offer the following policy recommendations, grounded in community input and our lived experiences, and grouped by key stakeholders to highlight their importance, priority, and need for continued investment. It is important to acknowledge that several of the recommendations included herein may reference initiatives that state, county, and city agencies in Illinois, Black community-based organizations (CBOs) and nonprofits, and/or Illinois legislators have taken steps to address.

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[d] EJSCREEN is an environmental justice mapping and screening tool that provides EPA with a nationally consistent dataset and approach for combining environmental and demographic indicators. (see endnote 19 for source)
[e] The CDC's Social Vulnerability Index (SVI) summarizes the extent to which a community is socially vulnerable to disaster. Factors include economic data, data regarding education, family characteristics, housing language ability, ethnicity, and vehicle access. (see endnote 20 for source)

1. For Illinois Legislators and Policymakers: Legislate for Accountability and Equity

- **Pass Legislation to Prevent Data Suppression:** Introduce and support laws that prohibit the arbitrary deletion or concealment of publicly funded data, especially data used to track inequities.
- **Fund Community Data Infrastructure:** Allocate state funding for the development of local data hubs and publicly accessible repositories, capacity building training programs, and digital tools tailored to community-based organizations and underrepresented communities.
- **Include Community Voices in Data Policy:** Recommend state agencies to consult with local community-based organizations when setting data standards, definitions, and priorities—ensuring the data reflects lived experiences, not just institutional metrics.

2. For Illinois State, County, & City Agencies: Protect, Preserve, and Share Public Data

- **Create a Public Data Repository:** Establish an Illinois-based, publicly accessible digital repository to archive federal datasets at risk of deletion. This archive should include key demographic, health, education, and social data and should be managed by a trusted, independent body with input from community-based organizations.
- **Increase Transparency and Accessibility of Local-Level Data:** Build a centralized online data library for local-level data with user-friendly search tools and data explanations. This should include visualizations, tutorials, and plain-language summaries. Additionally, provide community training and literacy tools to help grassroots leaders interpret and use data.
- **Ensure Open Access to Existing Public Data:** Recommend that state, county, and city agencies proactively share the data they already collect in open, machine-readable formats. This includes disaggregated data on health, education, housing, and economic indicators. Agencies should publish regular updates and make data available through Application Programming Interfaces (APIs) and downloadable formats to support public use, research, and advocacy.
- **Support and Fund Community-Led Data Collection:** Provide grants and infrastructure support for Black and Brown nonprofits and CBOs to collect and store data in secure, community-owned systems. Partner with trusted local organizations, including community health workers and organizers, to gather data with cultural competence and integrity.

3. For Nonprofits and CBOs: Build Data Resilience and Collective Power

- **Create and Contribute to Community Data Collectives:** CBOs should form local and statewide data collaboratives to share, archive, and analyze data relevant to our communities. Multiple copies of data stored across organizations protect against deletion or suppression.

- **Collect Our Own Data:** Develop tools, surveys, and grassroots methods to capture lived experience of your communities, particularly where federal and state systems fail to do so. Integrate qualitative methods (interviews, stories, visuals) alongside traditional quantitative data.
- **Back Up and Secure Data:** Store digital and printed copies of key datasets, use layered security, encrypted servers, safe storage protocols, and train staff and community members on cybersecurity and data privacy.
- **Educate and Mobilize:** Host community forums, teach-ins, and roundtables on why data matters. Partner with trusted media outlets and influencers to raise awareness and shift the narrative. Distribute flyers, pamphlets, and social media content to explain how data loss affects funding, visibility, and lives.

In addition to the suggestions of our Civic Data Forum participants, Black Researchers Collective has compiled suggestions for how philanthropy can combat The War on Data. These suggestions are rooted on our institutional knowledge and experiences, and guided in part by the former suggestions.

4. For Philanthropy: Investing in Community Data Resilience & Ownership

- **Support Research, Evaluation, & Technical Assistance (RETA) Initiatives:** Fund RETA initiatives led by nonprofits and community-based organizations to build capacity for community-driven research, evaluation, and data use. Investments in RETA strengthen data literacy, accountability, and evidence-based decision-making, ensuring that communities can generate and apply their own knowledge to shape equitable policies and programs.
- **Invest in a Public Data Insurance & Preservation Fund:** Create a public data insurance & preservation fund that helps organizations recover from data loss, erasure, or restricted access, especially those managing community or equity-focused data. The fund would support recovery efforts, legal actions, and the development of independent, community-controlled repositories outside government systems.
- **Fund the Development of Community Data Portals:** Invest in community data portals that allow local organizations to securely share, archive, and analyze data collectively. Funding can support infrastructure (servers, maintenance, scalability) and training in data management and cybersecurity.

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Who We Are

Black Researchers Collective (BRC) is a Chicago-based capacity-building collective taking research to the streets. Our work is designed to activate and mobilize communities to use research and data to create and sustain change across Chicago communities and beyond. We aim to advance racial equity by training and equipping communities with research tools to be more civically engaged and policy-informed.

Authors and Contributors

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