

Data Sharing in Cross-Sector Collaborations

Insights from Integrated Data Systems

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Abstract

Data sharing is a key component of cross-sector collaborations to address the health and social needs of people and reduce inequities. However, achieving efficient exchange of information across partners from health care, public health, and social services can be challenging. Several states use integrated data systems to link administrative individual-level data across multiple health and human services programs to better understand and address the health and social needs of those who use such services. In this paper, we summarize findings from a study examining established integrated data systems to learn about the facilitators and barriers to successful cross-sector data-sharing efforts.

Commonly cited contextual factors that can facilitate data sharing include having a clear understanding of federal and state data use and privacy laws, executive leadership support, and an organizational culture that understands and values data. We learned that strategies that can promote data-sharing initiatives include establishing a legal framework for appropriate data use, implementing strong data governance, and advancing data literacy and the role of analytics in an organization's functions. Further, people skills are as important as technical skills; many of the barriers to cross-sector data sharing can be overcome by bringing the right people to the table, establishing effective relationships, and cultivating trust among all relevant stakeholders. Mistrust, including an agency's strong sense of protectiveness over its own data and a lack of public trust in government-sponsored data collection efforts, was identified as a key barrier to data sharing. Effective engagement of key stakeholders in data governance can serve as an important mechanism for cultivating trust in data-sharing initiatives, but finding ways to meaningfully and authentically engage program participants and community representatives in data-sharing collaborations remains a challenge.

Organizations considering cross-sector data sharing must recognize the importance of building trusting relationships with all stakeholders, including program participants and the public. For example, cross-sector partners can increase trust with the public by being transparent about which data are collected and how they are used; including community representation in the development, management, and oversight of data-sharing and analytic activities; and building community partners' capacities to effectively engage in data work.

Introduction

Individuals and families facing unmet social needs such as housing, food security, and education are at a higher risk for adverse health outcomes.¹ Given this, efforts to improve population health must extend beyond the medical care and public health sectors to address these needs and better coordinate efforts across the health and social service sectors.

Researchers have proposed *data sharing* as a key component of such cross-sector collaborations to both improve the health and well-being of people and communities and to address inequities (Landers et al. 2020). Several states use integrated data systems (IDS) to link administrative individual-level data across multiple health and human services to better understand and address a full range of their clients' health and social needs.²

To identify factors that facilitate cross-sector data sharing, we collected and analyzed data from publicly available sources, as well as from our interviews with national experts and stakeholders in two states with operational IDS. Among our key findings are that understanding privacy laws, leadership buy-in, and the type of organizational culture that values data are important for data-sharing efforts. We also found that establishing legal frameworks and governance structures and promoting data literacy are promising strategies to foster such conditions. Finally, we found that in data-sharing efforts, people skills are at least as important as technical skills—and that people and communities whose data are being collected and shared are often absent from discussions and decisionmaking about cross-sector data collaborations.

Background

The Cross-Sector Alignment Theory of Change (hereafter “Theory of Change”) posits that when health care, public health, and social service systems align across four core enablers—shared purpose, data, financing, and governance—they can better work together to address inequities in community health and well-being (Landers et al. 2020). To achieve this goal, however, such

¹ Centers for Disease Control and Prevention, “Social Determinants of Health: Know What Affects Health,” March 9, 2021, <https://www.cdc.gov/socialdeterminants/index.htm>.

² “Network Sites,” University of Pennsylvania, Actionable Intelligence for Social Policy, accessed March 22, 2021, <https://www.aisp.upenn.edu/network-sites-map>.

cross-sector efforts often face barriers, with data sharing identified as a top challenge (Erickson et al. 2017; Spillman et al. 2017). To promote data sharing in cross-sector alignment efforts, we examined well-established IDS to learn about key data-sharing facilitators and barriers.

A primary objective of IDS is to link individual-level data across various public programs, thus providing a comprehensive picture of the interconnected needs of individuals across health, social services, and other sectors (Byrne et al. 2012).³ IDS can improve decisionmaking in public administration and policymaking by enabling various data analytics for program monitoring and evaluation, business operations, and case management. For example, IDS can be used in longitudinal, population-based research to examine service utilization, the risk and protective factors of program users, and utilization costs (Byrne et al. 2012; Culhane et al. 2010; Cutuli et al. 2016).

Prior research has found that effective IDS use is facilitated by establishing four key components: a governance structure, a legal framework, technology and security infrastructure, and data standards (Culhane et al. 2018; Fantuzzo and Culhane 2015). A *governance structure* articulates the purpose and manages the policies, procedures, and technologies needed for data sharing and use. This IDS governance should include diverse stakeholders, including executive leaders, frontline workers, researchers and data analysts, program beneficiaries, and the public at large (Culhane et al. 2018). Government data must be shared and used within the *legal framework* of various federal and state laws and regulations (Culhane et al. 2010). To protect and secure data while records are being shared and analyzed, agencies must invest in appropriate *technology and security infrastructure* (Fantuzzo et al. 2017). Finally, data owners must define and agree on common *data standards* to ensure that they share reliable, quality data (Culhane et al. 2018).

Challenges to creating and using IDS include misunderstanding data confidentiality laws, public mistrust of government data collection, limited organizational resources, and the potential of IDS to perpetuate inequity. Inconsistencies among federal, state, and local laws and regulations that guide administrative data use, as well as variations in how public agencies interpret these guidelines, often result in a complex, time-consuming process of negotiating data-sharing agreements (Culhane et al. 2010; Culhane et al. 2018; Schmit, Kelly, and Bernstein

³ “Integrated Data Systems Map,” University of Pennsylvania, Actionable Intelligence for Social Policy, accessed March 22, 2021, <https://www.aisp.upenn.edu/integrated-data-systems>.

2019). Another challenge to data sharing is a lack of public trust in government, including suspicions about the government collecting personal data and fear of privacy breaches of protected personal information (Culhane et al. 2018). Data sharing can be further hampered by insufficient resources, including a lack of executive leadership, inadequate funding for staff and infrastructure, and limited technical capabilities (Casey, Li, and Berry 2016; Culhane et al. 2018; Fantuzzo et al. 2017). Finally, cross-sector data sharing can help maintain the status quo and perpetuate—or worsen—inequities by reinforcing racist policies and practices or enabling inequitable resource allocation (Hawn et al 2020; Kleninberg et al. 2019).

Our goal in studying established IDS is to understand which factors appear to be critical for successful cross-sector data-sharing efforts. Although we focus on just one core enabler of cross-sector alignment (Landers et al. 2020), developing and implementing IDS requires alignment across various stakeholders, and our findings can therefore inform other dimensions of cross-sector partnerships.

Methods

We conducted a total of 16 interviews: 4 with national experts in cross-sector data sharing and 12 with stakeholders in two states (Oregon and Washington) with operational IDS. Table 1 shows the key feature of IDS in each of these states. Our state interviewees included state officials in health and human services agencies and external researchers and consumer advocates. We identified study informants through an environmental scan of publicly available IDS information and through a snowball approach, whereby interviewees provided us with suggestions for additional interviewees. We conducted phone interviews between March and August 2020 and subsequently transcribed and analyzed the interviews to identify key insights and common themes. Because we interviewed a small number of stakeholders, we may not have captured some important experiences and perspectives, particularly from outside government.

Table 1. Key Features of IDS in Two States: Washington and Oregon

	Washington’s Integrated Client Database	Oregon’s Integrated Client Services
Organization	<ul style="list-style-type: none"> ▫ Developed in 1995 and maintained by the Research and Data Analysis Division within the Department of Social and Health Services (DSHS) 	<ul style="list-style-type: none"> ▫ Developed in 2005 and maintained by the Office of Forecasting, Research, and Analysis within the Department of Human Services (DHS)
Purpose	<ul style="list-style-type: none"> ▫ Integrates and warehouses risk, service utilization, expenditure, and outcome data for individuals served by the Washington State DSHS, Health Care Authority, and Department of Children, Youth, and Families ▫ Pulls in data from more than 30 state agency data systems 	<ul style="list-style-type: none"> ▫ Matches individual-level data from programs within DHS, the Oregon Health Authority, and external agencies, such as the Department of Corrections, Housing and Community Services, and the Youth Authority ▫ Pulls in data from more than 15 state agency data systems
Data topics	<ul style="list-style-type: none"> ▫ Birth outcomes; mortality; health care and public health; child welfare; early childhood; education; justice; economic security (e.g., TANF, SNAP); homelessness/housing; federal (e.g., CMS, VA) 	<ul style="list-style-type: none"> ▫ Birth outcomes; mortality; health care and public health; child welfare; early childhood; education; justice; economic security; homelessness/housing
Functions	<ul style="list-style-type: none"> ▫ Supports policy-driven analytics to perform program evaluation, performance measurement, predictive modeling, forecasting, geographical analysis, and policy analysis 	<ul style="list-style-type: none"> ▫ Supports planning, reporting, forecasting, informing policy, measuring performance, and conducting research and analysis

Sources: Information for Washington’s Integrated Client Database is from “About Research and Data Analysis,” Washington State Department of Social and Health Services, accessed March 22, 2021, <https://www.dshs.wa.gov/ffa/research-and-data-analysis/about-rda>; “AISP Network: Washington State’s Integrated Client Databases (ICDB),” University of Pennsylvania, Actionable Intelligence for Social Policy, accessed March 22, 2021, <https://www.aisp.upenn.edu/network-site/washington-state>; and David Mancuso, *Integrated Client Databases* (Olympia, WA: Washington State Health and Human Services, 2020). Information for Oregon’s Integrated Client Services is from “Integrated Client Services Overview,” Oregon Department of Health and Human Services, accessed March 22, 2021, <https://www.oregon.gov/dhs/BUSINESS-SERVICES/OFRA/Pages/ICS.aspx>; and “AISP Network: Oregon Integrated Client Services,” University of Pennsylvania, Actionable Intelligence for Social Policy, accessed March 22, 2021, <https://www.aisp.upenn.edu/network-site/oregon>.
Notes: IDS is integrated data systems. TANF is Temporary Assistance for Needy Families. SNAP is Supplemental Nutrition Assistance Program. CMS is Centers for Medicare & Medicaid Services. VA is US Department of Veterans Affairs.

Findings

Many of the facilitators, barriers, and strategies uncovered in our interviews were consistent with prior IDS research. Key interview informants commonly cited leadership, organizational culture, and legal considerations as important factors in promoting or hindering data-sharing efforts. Informants also identified approaches—including a governance process—that can help overcome barriers to data sharing, promote greater use of data in policy and program decisions, reinforce collaboration among distinct partners, and help institutionalize and sustain data-sharing practices. Table 2 summarizes frequently cited factors and strategies for cross-sector data sharing, which we discuss in more detail below.

Table 2. Factors and Strategies for Cross-Sector Data Sharing

Contextual factors that affect data sharing	Strategies that promote data sharing
<ul style="list-style-type: none">□ Privacy laws□ Leadership buy-in□ Organizational culture□ Public mistrust□ Crisis events	<ul style="list-style-type: none">□ Create legal framework□ Establish data governance□ Promote data literacy and analytics□ Invest in people and relationships

Source: Key informant interviews conducted between March and August 2020.

Contextual Factors That Affect Data Sharing

Our informants identified five key factors that impact data sharing.

Privacy Laws

Interview informants frequently cited federal and state laws and regulations that guide administrative data use as a major challenge for data-sharing efforts. Informants recounted stories of drawn-out data-use negotiations and projects that never materialized because of data owners' inabilities or unwillingness to navigate ambiguous and narrowly defined federal guidance on how data can be used for research and analysis. Further, concerns about violating existing legal statutes have allegedly led some agencies to totally forgo sharing data or, at best, have made the sharing process long and painful.

Leadership Buy-In

Almost unanimously, our informants named executive-level leadership as one of the most important and effective factors in promoting data use and sharing across state government departments and agencies. Although some informants noted that a legislative mandate or executive directive can support greater data use in public policy, such requirements can be ineffectual without real leadership on the issue.

Leadership buy-in is necessary to secure funding for both the staff and infrastructure needed to support data collection, sharing, and analysis, as well as guide data-sharing initiatives through challenges (such as navigating privacy laws). Indeed, a lack of leadership buy-in can be detrimental to data-sharing efforts. As one informant explained, the power of a good leader is in demonstrating how to use data in decisionmaking and everyday operations and in fostering an organizational culture in which data are understood and valued.

Organizational Culture

Informants identified ways in which organizational culture can create barriers to data sharing, such as by lacking commitment to sharing data, overprotecting data, and the inherently siloed nature of government workflows.

For example, one informant noted that governments tend to overemphasize data collection—often in response to reporting requirements—and underemphasize data use to inform decisions within their own agency’s realm, let alone in the realms of other stakeholders. Similarly, government agencies often prioritize service delivery over data development, particularly when budgets are tight. Even if agencies collect the data, a lack of prioritization and investment in data quality and analytics infrastructure can undermine data integrity, which further disincentivizes data sharing.

Many informants emphasized an agency’s protectiveness over its own data as a key barrier preventing some data-owning institutions from sharing their data with others. Sometimes, this protectiveness stems from concerns about the potential of data misuse or misinterpretation, but informants also noted that some data owners shy away from data sharing to avoid embarrassment if their data were found to be of poor quality or analyses showed that a program is underperforming compared with similar programs.

Another deterrent to data sharing cited was *siloing*—that is, limited interactions with other agencies and departments across and outside a particular state government. An organizational culture in which interagency collaboration is not actively promoted (or is discouraged outright) does not easily lend itself to cross-sector data-sharing efforts. Some informants cautioned that, even when various agencies are consolidated into one department, it does not necessarily lead to better data exchange among previously siloed agencies. Factors such as protectiveness (of one’s turf, for example) can be difficult to uproot, and building relationships and trust across agencies takes time and resources that may be difficult to sustain if not prioritized; hence, the importance of leadership buy-in.

Public Mistrust

Consistent with findings in the literature, several informants noted that public mistrust of government data-collection activities can jeopardize the collected data’s accuracy and comprehensiveness if, for example, program participants are reluctant to provide their personal data or give permission to agencies to share their deidentified data with other entities. In

addition, heightened public scrutiny of government data collection following publicized data breaches may make data-owning entities less willing to participate in data-sharing initiatives.

Some informants said that public mistrust and the general population's lack of data literacy also make it difficult to engage program beneficiaries and community members in decisionmaking about data. As data-sharing experts recognize, data collaboratives rarely engage individuals and communities whose data they are collecting and integrating. Consequently, the power over data typically rests with the entities that collect them, as opposed to with the "data subjects."

Moreover, access to administrative data is often inequitable; for example, data are more accessible to university researchers than to community-based organizations. One informant suggested that, at a minimum, organizations that are collecting information from individuals need to be transparent about why and how their data will be used and protected. Several publications offer guidance to data administrators on how to inclusively engage all relevant stakeholders—including individuals and communities—in data discussions (see appendix resources 2, 8, and 11).

Crisis Events

Finally, some informants noted that crisis events can serve as both an impetus for and a hindrance to cross-sector data sharing, either by highlighting the need for data and data collaborations to effectively respond to the crisis or by constraining resources for data work. To address the opioid epidemic, for example, Massachusetts recently developed a cross-sector database to inform more systematic and targeted interventions (Wiseman 2019).

Several informants suggested that the COVID-19 pandemic could spur similar cross-sector data integration efforts, as states that have a history of data use and sharing in public programs may harness these capabilities more effectively when a crisis hits (see appendix resources 3, 9, and 11). Washington State developed a public-facing COVID-19 Data Dashboard to inform the state's reopening strategy by adding new data sources to its existing IDS.⁴ On the other hand, some noted that crises could undermine data-related activities if governments prioritize funding services over data development.

⁴ "COVID-19 Data Dashboard," Washington State Department of Health, updated March 20, 2021, <https://www.doh.wa.gov/Emergencies/COVID19/DataDashboard>.

Strategies That Promote Data Sharing

Our informants identified four key strategies to promote data sharing.

Create a Legal Framework

Collaboration partners can overcome the challenges related to navigating privacy regulations by establishing an appropriate legal framework driven by the data-sharing initiative's needs and objectives. For example, a legal framework for linking individual-level data for case management will differ from one in which data are linked but analyzed only on an aggregate level (see appendix resources 4 and 6).

One informant said that reframing research questions so that they are within the bounds of allowable data use could facilitate access to particular datasets. For example, state education departments may be more likely to give permission to link education data with data from other sectors if the inquiry's primary objective is to evaluate childhood outcomes related to the education system rather than to noneducation systems. Informants also said it would be helpful to have clearer federal and state guidance on allowable administrative data use for research and analysis.

Finally, several people pointed out that each state department and agency typically has its own set of rules, procedures, and documentation requirements for releasing data, which can become burdensome when requesting data from multiple agencies. Establishing IDS can help standardize and streamline data-sharing processes. For example, the Research and Data Analysis Division that operates Washington State's IDS developed a set of standard data-sharing agreements for each data contributor that can be easily tailored for specific projects (Kitzmilller 2014).

Establish Data Governance

Informants overwhelmingly cited data governance as a key strategy for facilitating transparency and accountability in data collection, linkage, protection, and use. Establishing agreed-upon written protocols about how, by whom, and for what purposes data will be linked and used can ease data owners' data security concerns (see appendix resources 1, 5, and 7).

Several informants said that while executive leadership buy-in is essential to data-sharing initiatives, agency leaders might not have the technical expertise to make decisions about data-sharing policies and terms of use. Given this, governance bodies should include midlevel

program staff and skilled data analysts who are deeply knowledgeable about agency programs and data capabilities.

To cultivate trust and overcome data protectiveness, informants suggested three effective practices:

- engaging data-owning agencies in governance
- promptly notify them of any inquiries or projects that involve their data
- seeking their input when interpreting findings

Although the literature encourages the engagement of program participants in IDS governance—and the experts we interviewed described doing so as a best practice—we found that this is rarely implemented in practice for reasons discussed earlier.

Promote Data Literacy and Analytics

Although having a data-sharing champion at the leadership level is critical, many informants noted that frequent turnover in leadership positions could easily undermine data sharing and usage practices if an organization does not instill the value of data sharing in its culture. Further, state governments need to focus on valuing data at all organizational levels, from the data collection point all the way to data analysis, interpretation, and presentation to decisionmakers (see appendix resources 5 and 10).

Informants identified several ways in which organizations can cultivate this shared appreciation for data and promote data literacy, including to

- build internal data analytics capabilities (e.g., by hiring skilled data analysts),
- educate staff about data importance, and
- elevate the role of research and analysis in agency functions.

According to one interviewee, data's importance can be further demonstrated by investing in data collection practices, which ensures a commitment to quality data collection and ultimately increases trust in data and data analytics. States can also establish an office responsible for managing all state data and analytic activities to maximize data's value and utility in policy and programmatic functions; some states, for example, hire a chief data officer.

Invest in People and Relationships

Finally, multiple informants emphasized that people and relationships are at least as important to data-sharing initiatives as the technology and infrastructure that underpin IDS. Although

technology obviously matters, informants noted that even the fanciest analytics platform will not realize its full potential without the right people at the table who understand data and can establish and maintain effective relationships and agree on a shared purpose for data sharing.

In particular, informants highlighted the role of midlevel staff expertise in driving data-sharing initiatives; often these staff can shape organizational decisions, facilitate conversations with agency leaders, and develop policies and standards for data use and exchange. Data practices and tools that are institutionalized across the organization help sustain the data focus even when leadership and policy priorities change.

A few informants warned against outsourcing data analytics to external consultants, which they said can cause many problems, including losing access to the data. Instead, informants recommended focusing on building internal capacity both in infrastructure and in the personnel needed to understand and use data effectively.

Furthermore, established data-sharing initiatives, such as IDS, can facilitate cross-sector collaboration because, rather than being just a one-off project, IDS create infrastructure in which organizations can continually link and analyze data and add new data sources, thus opening doors to additional inquiries and partnerships. According to our interviewees, partners who realize the potential of integrated data and become more savvy users of IDS may become more motivated to pursue cross-sector projects, which further enhances cross-sector collaboration.

Discussion

IDS are a promising tool for harnessing the power of cross-sector data. They can help organizations develop a comprehensive understanding of a community's complex health and social needs, identify possible solutions, and measure the impacts of interventions on the health and well-being of individuals and their communities.

Many organizations considering cross-sector partnerships to advance health outcomes are intimidated by the technical demands associated with building expansive data infrastructure. We found, however, that data-sharing initiatives are often about people, relationships, and trust. As one of our informants described it, data sharing is about relationship management. People are an organization's most essential asset for driving change, whether they are cultivating data literacy, establishing reciprocal relationships that enable effective collaborations, or giving meaning to

data and acting upon it. It takes people—including executive leaders, midlevel program staff, and data analysts—to create a culture in which data-driven approaches to everyday operations, policy challenges, and everything in between are second nature. In the end, even an organization that builds the most sophisticated data analytics engine needs skilled people to translate its output into ideas and to develop policies and implement programs that affect change.

The ultimate lesson for successful cross-sector collaborations is the importance of developing trusting relationships, including with the general public. Governance was highlighted by many as a key mechanism that can facilitate buy-in and trust building among data collaboration partners, reinforcing its fundamental role in cross-sector partnerships (Landers et al. 2020). We also learned that effectively engaging key stakeholders in governance can help overcome mistrust of data-sharing initiatives, and yet community members are often underrepresented or missing in discussions and decisions about data. This suggests that—while strong community engagement is a key underpinning of cross-sector alignment efforts (Landers et al. 2020)—finding ways to meaningfully and authentically engage community representatives in cross-sector alignment’s data-sharing component remains a challenge.

Cross-sector partners can engage and build trust with the public around data in three key ways. First, they can be transparent about which data are collected and how they are used, such as by investing in communications with program participants and the public. Second, they can include community representatives in developing, managing, and overseeing cross-sector data-sharing and analytic activities, such as through partnerships with trusted community-based organizations. Finally, they can strengthen the analytic capacity of community-based organizations, such as by providing training and education on research and program evaluation.

Appendix A. Data Sharing and Integrated Data Systems Resources

The following are resources to help facilitate various aspects of data sharing and several organizations that offer additional information and support.

Guides and Toolkits

- [Accountable Communities for Health: Data Sharing Toolkit](#). This toolkit offers guidance and insights on how to improve data sharing across sectors to drive better health outcomes. Drawing on the Communities for Health concept, the toolkit walks users through seven key parameters for effective data sharing: purpose, relationships/buy-in, funding, governance and privacy, data and data sharing, technical infrastructure, and analytic infrastructure (Rittenhouse, Ament, and Shortell 2016).
- [Centering Racial Equity throughout Data Integration](#). This toolkit, produced by Actionable Intelligence for Social Policy (AISP), offers both exemplary and problematic practices for employing racial equity framing throughout the six-phase data life cycle. The toolkit provides guidance to a wide audience of stakeholders seeking to center racial equity in administrative data sharing (Kleinberg et al. 2019).
- [COVID-19 Data Sharing](#). This is a collection of AISP’s network activities on state and local data-sharing efforts in response to the pandemic. Network sites have utilized integrated data to create dashboards and other visualization tools to relay updates about the virus—such as tracking cases, capacity, and resource use—to policymakers.⁵
- [Handbook on Using Administrative Data for Research and Evidence-Based Policy](#). This comprehensive handbook offers guidance for policymakers, researchers, and data providers on how to increase their use of administrative data to inform evidence-based decisionmaking (Cole et al. 2020).

⁵ “COVID-19 Data Sharing Network Activities: Research and Response,” University of Pennsylvania, Actionable Intelligence for Social Policy, accessed March 22, 2021, <https://www.aisp.upenn.edu/covid-19-data-sharing>.

- [IDS Governance: Setting Up for Ethical and Effective Use](#). This guide contains the best IDS practices related to governance, including building a vision, mission, and principles on ethical IDS use; stakeholder mapping; establishing common policies and procedures; considering key governance and security documents; and examining IDS staff capacity (e.g., skills, competencies and training; Gibbs et al. 2017).
- [Legal Guide to Administrative Data Sharing for Economic and Workforce Development](#). This guide, produced by the State Data Sharing Initiative, features guidelines for understanding data confidentiality laws and developing data-sharing agreements to uphold the protection and security of administrative data (State Data Sharing Initiative 2018).
- [National Neighborhood Indicators' Partnership \(NNIP\) Resource Guide to Data Governance and Security](#). This guide provides resources and best practices for developing strong data governance and ensuring data security (Hendey, Gold, and Pettit 2018).
- [Nothing to Hide: Tools for Talking \(and Listening\) about Data Privacy for Integrated Data Systems](#). This step-by-step toolkit provides IDS stakeholders with tools and strategies to support and lead privacy-sensitive and inclusive stakeholder engagement efforts (AISP 2018).
- [Responsible Data Use Playbooks](#). Aimed at public- and private-sector leaders, this guide describes how to design and implement data-sharing collaborations to increase the impact of their response and recovery plans.
- [Unlocking the Value of Data Sharing: A Look across Five Sectors](#). This publication offers guidance on how to identify cross-sector partners and develop a common purpose for data sharing (Eckhart and Browne 2018).
- [Why Am I Always Being Researched? COVID-19 Edition](#). This guidebook, produced by Chicago Beyond, helps community organizations, researchers, and funders address unintended bias in research, specifically as it relates to the pandemic (Chicago Beyond 2020).

Organizations

- [Actionable Intelligence for Social Policy](#) is a national organization offering various resources and insights on the value of data sharing. AISP operates a network of 26 IDS run by state and local governments with cross-sector data agreements across multiple projects for policy and program improvement. It also has 10 learning communities of state partners working to develop their data-sharing capacities.
- [BrightHive](#), a data technology company, operates a Data Trust program to provide partners with a legal, governance, and technical framework to securely integrate data across sources and increase their collective impact. In response to the pandemic, BrightHive has also designed Responsible Data Use Playbooks, which include information on data sharing in contact tracing and job-seeking activities for recently laid-off workers.
- [Data across Sectors for Health](#), supported by the Robert Wood Johnson Foundation, is an initiative led by both the Illinois Public Health Institute and Michigan Public Health Institute to promote data integration efforts for more effective public health interventions and policies.
- [State Data Sharing Initiative](#), sponsored by the Center for Regional Economic Competitiveness, aims to advance better evidence-based policymaking by promoting the exchange of state administrative records to inform policy analysis and program evaluation.
- [Stewards of Change Institute](#) is a nonprofit think tank that promotes information sharing to drive improvements in individual and community health and well-being. Further, through its National Interoperability Collaborative, Stewards of Change aims to build a network to advance data sharing across sectors to address social determinants of health.

References

- AISP (Actionable Intelligence for Social Policy). 2018. *Nothing to Hide: Tools for Talking (and Listening) about Data Privacy for Integrated Data Systems*. Philadelphia: University of Pennsylvania, Actionable Intelligence for Social Policy.
- Byrne, T., S. Metraux, M. Moreno, D. P. Culhane, H. Toros, and M. Stevens. 2012. “Los Angeles County’s Enterprise Linkages Project: An Example of the Use of Integrated Data Systems in Making Data-Driven Policy and Program Decisions.” *California Journal of Politics and Policy* 4 (2): 95–112. <https://doi.org/10.5070/p2gk54>.

- Casey, C., J. Li, and M. Berry. 2016. "Interorganizational Collaboration in Public Health Data Sharing." *Journal of Health Organization and Management* 30 (6): 855–71. <https://doi.org/10.1108/jhom-05-2015-0082>.
- Chicago Beyond. 2020. "Why Am I Always Being Researched? COVID-19 Edition." Chicago: Chicago Beyond.
- Cole, S., I. Dhaliwal, A. Sautmann, and L. Vilhuber, eds. 2020. *Handbook on Using Administrative Data for Research and Evidence-Based Policy*. Cambridge, MA: Abdul Latif Jameel Poverty Action Lab and Massachusetts Institute of Technology.
- Culhane, D. P., J. Fantuzzo, H. L. Rouse, V. Tam, and J. Lukens. 2010. "Connecting the Dots: The Promise of Integrated Data Systems for Policy Analysis and Systems Reform." Philadelphia: University of Pennsylvania.
- Cutuli, J. J., R. M. Goerge, C. Coulton, M. Schretzman, D. Crampton, B. J. Charvat, N. Lalich, et al. 2016. "From Foster Care to Juvenile Justice: Exploring Characteristics of Youth in Three Cities." *Children and Youth Services Review* 67, 84–94. <https://doi.org/10.1016/j.childyouth.2016.06.001>.
- Eckhart, P., and K. Browne. 2018. "Unlocking the Value of Data Sharing: A Look across Five Sectors." Chicago: Data Across Sectors for Health.
- Erickson, J., B. Milstein, L. Schafer, K. E. Pritchard, C. Levitz, C. Miller, and A. Cheadle. 2017. *Progress along the Pathway for Transforming Regional Health: A Pulse Check on Multi-sector Partnerships*. Cambridge, MA: Rippel, ReThink Health.
- Fantuzzo, J., and D. P. Culhane. 2015. *Actionable Intelligence: Using Integrated Data Systems to Achieve a More Effective, Efficient, and Ethical Government*. London: Palgrave Macmillan.
- Fantuzzo, J., C. Henderson, K. Core, and D. Culhane. 2017. *The Integrated Data System Approach: A Vehicle to More Effective and Efficient Data-Driven Solutions in Government*. Philadelphia: University of Pennsylvania, Actionable Intelligence for Social Policy.
- Gibbs, L., A. Hawn Nelson, E. Dalton, J. Cantor, S. Shipp, and A. D. Jenkins. 2017. "IDS Governance: Setting Up for Ethical and Effective Use." Philadelphia: University of Pennsylvania, Actionable Intelligence for Social Policy.
- Hawn Nelson, A., A. D. Jenkins, S. Zanti, M. Kats, E. Berkowitz, T. C. Burnett, and D. Culhane. 2020. *A Toolkit for Centering Racial Equity throughout Data Integration*. Philadelphia: University of Pennsylvania, Actionable Intelligence for Social Policy.
- Hendey, L., A. Gold, and K. L. S. Pettit. 2018. *NNIP'S Guide to Data Governance and Security*. Washington, DC: National Neighborhood Indicators Partnership.
- Kitzmilller, E. M. 2014. "IDS Case Study: Washington State." Philadelphia: University of Pennsylvania, Actionable Intelligence for Social Policy.
- Kleinberg, J., J. Ludwig, S. Mullainathan, and C. R. Sunstein. 2019. "Discrimination in the Age of Algorithms." *Journal of Legal Analysis* 10, 113–74. <https://doi.org/10.1093/jla/laz001>.
- Landers, G. M., K. J. Minyard, D. Lanford, and H. Heishman. 2020. "A Theory of Change for Aligning Health Care, Public Health, and Social Services in the Time of COVID-19." *American Journal of Public Health* 110 (S2): S178–S180. <https://doi.org/10.2105/AJPH.2020.305821>.
- Rittenhouse, D. R., A. Ament, and S. M. Shortell. 2016. *Accountable Communities for Health: Data-Sharing Toolkit*. Berkeley, CA: University of California, Berkeley, School of Public Health, Center for Healthcare Organizational Innovation Research.
- Schmit, C., K. Kelly, and J. Bernstein. 2019. "Cross Sector Data Sharing: Necessity, Challenge, and Hope." *Journal of Law, Medicine and Ethics* 47 (2 suppl.): 83–86. <https://doi.org/10.1177/1073110519857325>.
- Spillman, Brenda C., Josh Leopold, Eva H. Allen, and Pam Blumenthal. 2017. "Developing Housing and Health Collaborations: Opportunities and Challenges." Washington, DC: Urban Institute.
- State Data Sharing Initiative. 2018. "Legal Guide to Administrative Data Sharing for Economic and Workforce Development." Arlington, VA: State Data Sharing Initiative.
- Wiseman, Jane. 2019. "Data Driven Approaches to Fighting the Opioid Crisis." Boston: Institute for Excellence in Government.