

Data Linkage and Integration for Research and Statistical Purposes: an Annotated Bibliography

August 2024

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Introduction

Data linkage¹ and integration² activities bring together separate data tables, systems, or sources to provide program staff in states, Tribes, territories, and localities as well as researchers a richer understanding of the populations and communities they seek to serve. Such an understanding may then lead to improvements in programs, policies, and services. To do this effectively, programs need technical infrastructure, data governance, data analysis and visualization skills, and high-quality community engagement. Written guides and resources can support efforts to develop or access these essential capabilities for data linkage and integration.

In 2021, a team from SRI International, AnLar, and Actionable Intelligence for Social Policy (AISP) sought to understand how states, Tribes, territories, and localities use technical assistance (TA) services to support their efforts to link and integrate internal and external datasets for program operations, research, and statistical purposes. This work included an environmental scan of relevant TA resources, which identified over 60 unique resources developed by TA organizations to support states, Tribes, territories, and localities in data linkage and integration.

This annotated bibliography is designed to build capacity and coordination around data linkage and integration. It is intended to be a point in time snapshot of the field as of 2021, with selective updates made by the team in 2023. All links are current and operational as of 2024. This product is not intended to be routinely updated. It is also true that it may not be comprehensive or reflect the full constellation of resources available. Inclusion of any of these sources is not a direct endorsement by ACF.

¹ In its most basic form, data linkage refers to joining two or more static datasets by matching a common identifier or identifiers found in each data source, such as social security number, name, or physical address.

² Data integration also requires record matching; however, integration results in the long-term merger of data flows from two or more sources. This merger produces a dataset that continually updates whenever data in one original source changes.

Criteria for Inclusion

This annotated bibliography offers a starting point for individuals and organizations looking for guidance and information that can help identify critical roles and processes to support work related to data linkage or integration using administrative data. It is not meant to be exhaustive or reflect a comprehensive list of TA resources on data linkage and integration. Each resource included meets the following criteria:

- Comes from federal and non-federal programs, grants, organizations, or initiatives that have expertise in data and provide TA to states, Tribes, territories, localities and/or across agencies
- Focuses on linking or integrating human services³ data for program operations, research, or statistical purposes
- Addresses, at least in part, data linkage and/or integration
- Is publicly available at no cost

³ Human services focus on meeting human needs through prevention and remediation of problems using applied knowledge and having a commitment to improving the overall quality of the human condition.

Components of this Bibliography

Each entry for every resource included here contains the resource name, overview, organization name, audience, service area, focus area, web address, and citation. Table 1 details these components and provides the related definitions. To maintain the original intention of the author(s), the overviews for each resource have been taken directly from the resource or publicly available summary on the website from which it can be accessed.

Table 1. Components and Definitions

Components	Definitions
Resource Name	The name of the resource
Overview	A summary of the resource taken directly from the resource or an associated website
Organization Name	The name of the nonprofit organization, for-profit organization, university, or government agency that funded authorship of the resource to support states, Tribes, territories, or localities
Audience	The government or public/private agency for which the resource would apply, including: <ul style="list-style-type: none"> • Federal • State/Territory • Local • Tribes • Researcher • Funder
Service Area	Distinct business area for which the resource would apply, including: <ul style="list-style-type: none"> • Child Welfare • Early Childhood • Education • Epidemiology • Healthcare • Social Services
Focus Area	Data linkage or integration area(s) of focus including: <ul style="list-style-type: none"> • Data Analysis & Use • Data Governance • Technical Infrastructure • Community Engagement
Web Address	The link that provides access to the resource
Citation	The APA citation of the resource

Data Linkage and Integration Resources

For ease of use and searchability, Table 2 provides a summary of the resources by resource name, organization, audience, service area, and focus area. The resources are listed alphabetically. Click on each resource name to see the full entry within this document.

Table 2. Resources by Organization, Audience, Service Area, and Focus Area

Resource Name	Organization	Audience						Service Area						Focus Area			
		Federal	States/Territories	Local	Tribes	Funders	Researchers	Child Welfare	Early Childhood	Education	Epidemiology	Healthcare	Social Services	Data Analysis & Use	Data Governance	Technical Infrastructure	Community Engagement
10 Fundamentals of Coordinated State Early Care and Education Data Systems: Inaugural State Analysis	Early Childhood Data Collaborative		✓						✓	✓					✓		
A Path to Social License: Guidelines for Trusted Data Use	Data Futures Partnership	✓	✓	✓		✓	✓	✓	✓	✓	✓	✓	✓		✓		✓
A Planning Guide for Linking Data to Support Program Improvement in Early Care and Education (Report # 2016-39)	Child Trends	✓	✓	✓					✓						✓		
A Toolkit for Centering Racial Equity Throughout Data Integration	Actionable Intelligence for Social Policy (AISP)	✓	✓	✓		✓	✓	✓	✓	✓		✓	✓	✓	✓		✓

Resource Name	Organization	Audience						Service Area						Focus Area			
		Federal	States/Territories	Local	Tribes	Funders	Researchers	Child Welfare	Early Childhood	Education	Epidemiology	Healthcare	Social Services	Data Analysis & Use	Data Governance	Technical Infrastructure	Community Engagement
Advanced Linkage Methodology	Massive Data Institute (MDI)						✓	✓	✓	✓	✓	✓	✓	✓		✓	
Applying a Race Equity Lens to Build Thriving Communities: Centering Racial Equity Across the Data Lifecycle	Actionable Intelligence for Social Policy (AISP)	✓	✓	✓		✓	✓	✓		✓		✓	✓	✓			✓
Building + Sustaining State Data Integration Efforts: Legislation, Funding, and Strategies	Actionable Intelligence for Social Policy (AISP)		✓					✓	✓	✓	✓	✓	✓		✓		
Building a Multistate Governance System	Multistate Longitudinal Data Exchange (MLDE)		✓							✓					✓		
Building Data Sharing Infrastructures at the State Level: Context, Stakeholders, Technology	Virginia Tech Bioinformatics Institute		✓					✓	✓	✓	✓	✓	✓		✓	✓	
The CARE Principles for Indigenous Data Governance	Committee on Data (CODATA)				✓		✓	✓		✓		✓	✓		✓		✓

Resource Name	Organization	Audience						Service Area						Focus Area			
		Federal	States/Territories	Local	Tribes	Funders	Researchers	Child Welfare	Early Childhood	Education	Epidemiology	Healthcare	Social Services	Data Analysis & Use	Data Governance	Technical Infrastructure	Community Engagement
Case Study Report – Montgomery County, MD’s Electronic Integrated Case Management System (eICM)	Office of Planning, Research and Evaluation (OPRE)	✓	✓	✓	✓			✓		✓					✓	✓	✓
Case Study Report – Iowa’s Integrated Data System for Decision-Making (I2D2)	Office of Planning, Research and Evaluation (OPRE)	✓	✓	✓	✓			✓						✓	✓	✓	✓
Challenges in Administrative Data Linkage for Research	Actionable Intelligence for Social Policy (AISP)						✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	
CITI Module: Ethical and Appropriate Uses of Administrative Data for Research and Evaluation	Actionable Intelligence for Social Policy (AISP)	✓	✓	✓			✓	✓	✓	✓	✓	✓	✓	✓	✓		
Confidentiality Toolkit (OPRE Report 2021-175)	Office of Planning, Research and Evaluation (OPRE)	✓	✓	✓	✓			✓				✓	✓		✓		
Connecting the Dots: The Promise of Integrated Data Systems for Policy Analysis and Systems Reform	Actionable Intelligence for Social Policy (AISP)	✓	✓	✓		✓	✓	✓	✓	✓		✓		✓	✓		

Resource Name	Organization	Audience						Service Area						Focus Area			
		Federal	States/Territories	Local	Tribes	Funders	Researchers	Child Welfare	Early Childhood	Education	Epidemiology	Healthcare	Social Services	Data Analysis & Use	Data Governance	Technical Infrastructure	Community Engagement
Data Direction 5: Linking Data to Understand Children's Academic Progress from Early Care and Education Through Elementary School	Child Trends			✓					✓	✓				✓	✓		
Data Integration Toolkit	Center for the Integration of IDEA Data (CIID)		✓							✓					✓	✓	
Data Interoperability Maturity Model	National Archives of Australia	✓	✓	✓				✓	✓	✓	✓	✓	✓		✓	✓	
Data Linking Toolkit	The Center for Early Childhood Data Systems (DaSy)		✓						✓						✓		
Data Sharing Agreement Checklist for IDEA Part C and Part B 619 Agencies and Programs	The Center for Early Childhood Data Systems (DaSy)	✓	✓	✓					✓						✓		
Data Sharing to Build Effective and Efficient Benefits Systems	Benefits Data Trust		✓	✓			✓			✓		✓		✓			

Resource Name	Organization	Audience						Service Area						Focus Area			
		Federal	States/Territories	Local	Tribes	Funders	Researchers	Child Welfare	Early Childhood	Education	Epidemiology	Healthcare	Social Services	Data Analysis & Use	Data Governance	Technical Infrastructure	Community Engagement
Data Sharing: Courts and Child Welfare	U.S. Department of Health and Human Services Administration for Children and Families		✓	✓				✓							✓		
Developmental Impacts of the COVID-19 Pandemic on Young Children: A Conceptual Model for Research with Integrated Administrative Data Systems	Actionable Intelligence for Social Policy (AISP)						✓		✓					✓	✓		✓
Diffusion of an Innovation: Lessons from the Multistate Longitudinal Data Exchange	Multistate Longitudinal Data Exchange (MLDE)		✓	✓			✓			✓				✓	✓	✓	
Envisioning a New Future: Building Trust for Data Use	Urban Institute					✓							✓				✓
Evidence-Based Policymaking: What Human Service Agencies Can Learn from Implementation Science and Integrated Data Systems	University of Pennsylvania, University of North Carolina-Charlotte	✓	✓	✓				✓		✓	✓	✓	✓	✓			

Resource Name	Organization	Audience						Service Area						Focus Area			
		Federal	States/Territories	Local	Tribes	Funders	Researchers	Child Welfare	Early Childhood	Education	Epidemiology	Healthcare	Social Services	Data Analysis & Use	Data Governance	Technical Infrastructure	Community Engagement
Expanding TANF Program Insights: A Toolkit for State and Local Agencies on How to Access, Link, and Analyze Unemployment Insurance Wage Data	TANF Data Collaborative		✓	✓									✓	✓		✓	
Finding a Way Forward: How to Create a Strong Legal Framework for Data Integration	Actionable Intelligence for Social Policy (AISP)	✓	✓	✓	✓			✓	✓	✓	✓	✓	✓		✓		
Forum Guide to Supporting Data Access for Researchers: A State Education Agency Perspective (NFES 2012-809)	National Center for Education Statistics		✓							✓				✓	✓		
Forum Guide to the Teacher-Student Data Link: A Technical Implementation Resource. (NFES 2013-802)	National Center for Education Statistics		✓	✓						✓					✓	✓	
Getting Started: Incorporating Head Start Data in an SLDS	Statewide Longitudinal Data System State Support Team (SLDS SST)		✓						✓						✓		

Resource Name	Organization	Audience						Service Area						Focus Area			
		Federal	States/Territories	Local	Tribes	Funders	Researchers	Child Welfare	Early Childhood	Education	Epidemiology	Healthcare	Social Services	Data Analysis & Use	Data Governance	Technical Infrastructure	Community Engagement
How Tulsa Is Preserving Privacy and Sharing Data for Social Good	Asemio			✓					✓				✓	✓	✓	✓	
Improving Data Infrastructure to Meet Student and Learner Information Needs	Day One Project	✓								✓						✓	
Interagency Data Disclosure: A Tip Sheet in Interagency Collaboration	Education for Homeless Children and Youth (EHCY) Program		✓	✓				✓							✓		✓
Introduction to Data Security Breach Preparedness with Model Data Security Breach Preparedness Guide	International Association of Privacy Professionals (IAPP)	✓	✓	✓				✓	✓	✓	✓	✓	✓		✓		
Joint Guidance on the Application of the Family Educational Rights and Privacy Act (FERPA) and the Health Insurance Portability and Accountability Act of 1996 (HIPAA) to Student Health Records	Privacy Technical Assistance Center (PTAC)			✓						✓		✓			✓		

Resource Name	Organization	Audience						Service Area						Focus Area			
		Federal	States/Territories	Local	Tribes	Funders	Researchers	Child Welfare	Early Childhood	Education	Epidemiology	Healthcare	Social Services	Data Analysis & Use	Data Governance	Technical Infrastructure	Community Engagement
The Learning Center for Families' Use of Data to Support Children's Healthy Development	Child Trends		✓	✓					✓			✓		✓			
Legal Issues in the Use of Electronic Data Systems for Social Science Research	Children's Data Network						✓	✓		✓	✓	✓	✓		✓		
Linking Child Welfare and Medicaid Data: Lessons Learned from Two States (OPRE Report 2023-038)	Assistant Secretary for Planning and Evaluation (ASPE) and the Office of Planning, Research and Evaluation (OPRE)		✓	✓	✓			✓						✓	✓		
Narrowing Technology Solutions for Integrated Data System (IDS) Initiatives	Actionable Intelligence for Social Policy (AISP), Asemio		✓	✓			✓	✓	✓	✓	✓	✓	✓			✓	
Nothing to Hide: Tools for Talking (and Listening) About Data Privacy for Integrated Data Systems	Actionable Intelligence for Social Policy (AISP), Future of Privacy Forum	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓		✓
Privacy and Data Security is for Everyone	International Association of Privacy Professionals (IAPP)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓		

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Promoting Data Sharing Approaches	Topos Partnership	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓		✓		✓
Protecting the Privacy of Personal Information in Integrated Data Systems: Disclosure Avoidance Methods	Data Integration Support Center (DISC)	✓	✓	✓				✓		✓		✓	✓		✓		
Quality Framework for Integrated Data Systems	Actionable Intelligence for Social Policy (AISP)	✓	✓	✓				✓	✓	✓	✓	✓	✓		✓		
Recommendations for Ensuring the Quality of Linked Human Services Data Sources	Chapin Hall at the University of Chicago, Family Self-Sufficiency Data Center		✓	✓			✓		✓						✓		
Record Linkage Innovations for the Human Services	Chapin Hall at the University of Chicago, Family Self-Sufficiency Data Center		✓	✓			✓		✓					✓		✓	
Researching the CCDF Program by Linking Administrative Data with Data from the CCDF Policies	Office of Planning, Research and Evaluation (OPRE)		✓		✓		✓		✓				✓	✓			

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Database: A How-To Guide (OPRE Report 2016-24)																	
Roadmap for Effective Data Use and Research Partnerships between State Education Agencies and Education Researchers	Data Quality Campaign		✓	✓			✓			✓				✓	✓		✓
Roadmap for Foster Care and K-12 Data Linkages: Key Focus Areas to Ensure Quality Implementation	Data Quality Campaign, Legal Center for Foster Care & Education		✓	✓				✓		✓				✓	✓		
The SEEDS of Indigenous Population Health Data Linkage	Other				✓							✓			✓		
SLDS Early Childhood Integrated Data System Guide	Statewide Longitudinal Data System State Support Team (SLDS SST)		✓						✓						✓	✓	
SLDS Early Childhood Integrated Data System Self-Assessment	Statewide Longitudinal Data System State		✓						✓						✓	✓	

Resource Name	Organization	Audience						Service Area						Focus Area			
		Federal	States/Territories	Local	Tribes	Funders	Researchers	Child Welfare	Early Childhood	Education	Epidemiology	Healthcare	Social Services	Data Analysis & Use	Data Governance	Technical Infrastructure	Community Engagement
	Support Team (SLDS SST)																
SLDS Guide – Interagency Data Governance: Roles and Responsibilities	Statewide Longitudinal Data System State Support Team (SLDS SST)		✓							✓					✓		
Strength in Numbers: Supporting Quality Improvement in Early Care and Education Programs Through Linking Administrative Data (Publication 2016-36)	Child Trends		✓	✓				✓	✓					✓	✓		
Strengthening Integrated Data Capacity: The Federal Landscape	KB Stack Consulting	✓	✓	✓									✓	✓	✓	✓	✓
Toolkit: Data Sharing for Child Welfare Agencies and Medicaid	Comprehensive Child Welfare Information System		✓		✓			✓							✓	✓	
Tribal Data Linkage Toolkit	CSTE				✓						✓				✓	✓	

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		Federal	States/Territories	Local	Tribes	Funders	Researchers	Child Welfare	Early Childhood	Education	Epidemiology	Healthcare	Social Services	Data Analysis & Use	Data Governance	Technical Infrastructure	Community Engagement
Using and Linking Administrative Datasets for Family Self-Sufficiency Programs	Chapin Hall at the University of Chicago, Family Self-Sufficiency Data Center						✓		✓	✓		✓	✓	✓	✓		
Using Integrated Data Systems to Improve Case Management and Develop Predictive Modeling Tools	Annie E. Casey Foundation		✓	✓				✓				✓	✓	✓			
Using Integrated Data to Identify and Solve Housing Conditions that Harm School Readiness: A Cleveland Case Study	Annie E. Casey Foundation						✓			✓			✓	✓			
Working with Administrative Data in Early Childhood and Related Fields: A List of Resources	Child Trends, Urban Institute		✓						✓					✓	✓		

Annotated Resource List

NOTE: The Overviews provided for each resource are direct quotes from publicly available information, to preserve the original intention of the authors.

10 Fundamentals of Coordinated State Early Care and Education Data Systems: Inaugural State Analysis

Overview: "This brief presents highlights of an analysis of a survey of 48 states and the District of Columbia on state implementation of ten essential components of coordinated early care and education (ECE) data systems. Suggestions are offered in response to the finding that current systems, though they collect large amounts of data on children, providers, and program sites, are often inadequate for the needs of state ECE policymakers in assessing data and formulating policy."

Organization Name: Early Childhood Data Collaborative

Audience: State/Territory

Service Area(s): Early Childhood, Education

Focus Area(s): Data Governance

Web Address: <https://cms.childtrends.org/wp-content/uploads/2019/09/10-Fundamentals-of-Coordinated-State-Early-Care-and-Education-Systems.pdf>

Citation: Early Childhood Data Collaborative. (2011). *10 fundamentals of coordinated state early care and education data systems: Inaugural state analysis*. Washington, DC: Early Childhood Data Collaborative. <https://cms.childtrends.org/wp-content/uploads/2019/09/10-Fundamentals-of-Coordinated-State-Early-Care-and-Education-Systems.pdf>

A Path to Social License: Guidelines for Trusted Data Use

Overview: "For New Zealand organisations seeking to use personal data, these Guidelines promote practices that will improve the levels of comfort and trust among those individuals providing data as well as within the wider community. The Guidelines list the eight questions that matter most to New Zealanders. The Guidelines include guidance on how to answer those questions in a manner that is best suited to building trust. The Guidelines also provide advice on when organisations may need the additional step of active community engagement. For New Zealanders, the Guidelines are a tool to help them decide on their level of trust and comfort with an organisation's proposed use of their data. The Guidelines list the eight questions New Zealanders should expect to have answered by organisations seeking to use personal data."

Organization Name: Data Futures Partnership

Audience: Federal, State/Territory, Local, Funder, Researcher

Service Area(s): Child Welfare, Early Childhood, Education, Epidemiology, Healthcare, Social Services

Focus Area(s): Data Governance, Community Engagement

Web Address: https://aisp.upenn.edu/wp-content/uploads/2019/08/Trusted-Data-Use_2017.pdf

Citation: Data Futures Partnership. (2017). *A Path to Social License: Guidelines for Trusted Data Use*. https://aisp.upenn.edu/wp-content/uploads/2019/08/Trusted-Data-Use_2017.pdf.

A Planning Guide for Linking Data to Support Program Improvement in Early Care and Education (Report # 2016-39)

Overview: "Linking data collected by early care and education (ECE) programs to data collected by other agencies provides a unique opportunity for early childhood leaders to understand the full experiences of the children and families they serve. ECE programs can benefit from linking their data because linked data can improve program quality, improve services for children, reduce the data collection burden on families and staff, and inform strategic planning. Linked data has many uses, including to help shape the delivery of the services, individualize the care provided to children, avoid duplication of services, and clarify the goals of the program itself. In this resource, data are considered "linked" when information from two or more separate data systems or databases are shared, connected, combined, or merged. These data systems or databases may be housed in the same program or in multiple programs or agencies. Linking data can occur

in various ways ranging from simple, (e.g., sharing a spreadsheet) to more complex (e.g., merging two databases into a single file), to very complex (e.g., fully integrating data across multiple agencies). However, all linked data can provide useful information to support ECE program improvement. There are many practices that ECE programs can engage in to make data linkage possible and ensure that their linking efforts are successful. This resource focuses on six of the best practices that ECE programs can institute to facilitate the process of data linkage.”

Organization Name: Child Trends

Audience: Federal, State/Territory, Local

Service Area(s): Early Childhood

Focus Area(s): Data Governance

Web Address: <https://researchconnections.org/childcare/resources/32710>

Citation: Friese, S., Maxwell, K. L., Epstein, D., & Abrams, J. (2016). *A planning guide for linking data to support program improvement in early care and education (Report # 2016-39)*. Bethesda, MD: Child Trends.

<https://researchconnections.org/childcare/resources/32710>

A Toolkit for Centering Racial Equity Throughout Data Integration

Overview: "Cross-sector data sharing and integration transform information about individuals into actionable intelligence that can be used to understand community needs, improve services, and build stronger communities. Yet, use of cross-sector data can also reinforce legacies of racist policies and produce inequitable resource allocation, access, and outcomes. Since 2019, AISP has led a diverse workgroup of civic data stakeholders to co-create strategies and identify best practices to center racial equity in data integration efforts. Centering racial equity is not a single, discrete step. This toolkit describes positive and problematic practices for centering racial equity across the data life cycle."

Organization Name: Actionable Intelligence for Social Policy (AISP)

Audience: Federal, State/Territory, Local, Funder, Researcher

Service Area(s): Child Welfare, Early Childhood, Education, Healthcare, Social Services

Focus Area(s): Data Analysis & Use, Data Governance, Community Engagement

Web Address: <https://www.aisp.upenn.edu/centering-equity/>

Citation: Hawn Nelson, A., Jenkins, D., Zanti, S., Katz, M., Berkowitz, E., et al. (2020). *A Toolkit for Centering Racial Equity Throughout Data Integration*. Actionable Intelligence for Social Policy, University of Pennsylvania. <https://www.aisp.upenn.edu/centering-equity/>

Advanced Linkage Methodology

Overview: "During this Linkage Seminar, Amy O'Hara and Dean Resnick discussed the Fellegi-Sunter record linkage paradigm, the use of frequency-based name weights, the use of string-distance comparison weighting, the use of the expectation-maximization algorithm, blocking strategies, and more. In this seminar, Dean provided an overview of these methods and how they have been applied in record linkage projects NORC has conducted."

Organization Name: Massive Data Institute (MDI)

Audience: Researcher

Service Area(s): Early Childhood

Focus Area(s): Data Analysis & Use

Web Address: <https://mccourt.georgetown.edu/news/advanced-linkage-methodology-with-dean-resnick/>

Citation: Resnick, D. (2021). *Advanced linkage methodology with Dean Resnick*. Massive Data Institute. <https://mccourt.georgetown.edu/news/advanced-linkage-methodology-with-dean-resnick/>

Applying a Race Equity Lens to Build Thriving Communities: Centering Racial Equity Across the Data Lifecycle

Overview: "This piece from the American Public Human Services Administration (APHSA) magazine highlights and summarizes AISP's May 2020 publication, 'A toolkit for centering racial equity throughout data integration'. In it, they argue that 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. Yet, the way that cross-sector data are used can also reinforce legacies of racist policies and produce inequitable resource allocation, access, and outcomes."

Organization Name: Actionable Intelligence for Social Policy (AISP)

Audience: Federal, State/Territory, Local, Funder, Researcher

Service Area(s): Child Welfare, Education, Healthcare, Social Services

Focus Area(s): Data Analysis & Use, Community Engagement

Web Address: <https://www.aisp.upenn.edu/resource-article/applying-a-race-equity-lens-to-build-thriving-communities-centering-racial-equity-across-the-data-lifecycle/>

Citation: Zanti, S., Katz, M., and Hawn Nelson, A., (2020). *Applying a race equity lens to build thriving communities: Centering racial equity across the data lifecycle*. American Public Human Services Administration, Policy and Practice.

https://www.aisp.upenn.edu/wp-content/uploads/2020/08/PP_August2020_RacialEquity_AISP.pdf.

Building + Sustaining State Data Integration Efforts: Legislation, Funding, and Strategies

Overview: "The economic and social impacts of the COVID-19 pandemic have heightened demand for cross-agency data capacity, as policymakers are forced to reconcile the need for expanded services with extreme fiscal constraints. In this context, integrated data systems (IDS) – also commonly referred to as data hubs, data collaboratives, or state longitudinal data systems – are a valuable resource for data-informed decision making across agencies. IDS utilize standard governance processes and legal agreements to grant authority for routine, responsible use of linked data, and institutionalize roles across partners with shared priorities. Despite these benefits, creating and sustaining IDS remains a challenge for many states. Legislation and executive action can be powerful mechanisms to overcome this challenge and promote the use of cross-agency data for public good. This brief is organized in three parts. First, we offer examples of these three approaches from states that have used legislation and/or executive orders to enable data integration, as well as key considerations related to each. Second, we discuss state and federal funding opportunities that can help in implementing legislative or executive actions on data sharing and enhancing long-term sustainability of data sharing efforts. Third, we offer five foundational strategies to ensure that legislative or executive action is both ethical and effective."

Organization Name: Actionable Intelligence for Social Policy (AISP)

Audience: State/Territory

Service Area(s): Child Welfare, Early Childhood, Education, Epidemiology, Healthcare, Social Services

Focus Area(s): Data Governance

Web Address: <https://www.aisp.upenn.edu/resource-article/building-sustaining-state-data-integration-efforts-legislation-funding-and-strategies/>

Citation: Zanti, S., Jenkins, D., Berkowitz, E., Hawn Nelson, A., Burnett, T., & Culhane, D. (2021). *Building and Sustaining State Data Integration Efforts: Legislation, Funding, and Strategies*. Actionable Intelligence for Social Policy. University of Pennsylvania. <https://aisp.upenn.edu/resource-article/building-sustaining-state-data-integration-efforts-legislation-funding-and-strategies/>

Building a Multistate Governance System

Overview: "This brief explores that process and the stages of developing a governance system for a multistate state data exchange project, the Multistate Longitudinal Data Exchange (MLDE). The MLDE is designed to help states and regions develop a more holistic view of education and employment pathways, which in turn helps to inform practitioners, policymakers, and researchers. The MLDE enables analysis of the linkages between education and employment trajectories; how these trajectories cross state lines; and how best to improve policies and programs serving students and workers. This brief explores how the MLD developed its governance system, the challenges that arose, and how the Western Interstate Commission for Higher Education (WICHE) and the multistate team adapted to meet those challenges. The brief is based on research and evaluation activities conducted over the past five years by Rutgers' Education & Employment Research Center (EERC), which included over 40 interviews

with state leaders and WICHE representatives, observations of user group meetings, surveys, and MLDE document analysis."

Organization Name: Multistate Longitudinal Data Exchange (MLDE)

Audience: State/Territory

Service Area(s): Education

Focus Area(s): Data Governance

Web Address: <https://www.wiche.edu/key-initiatives/multistate-longitudinal-data-exchange/mlde-issue-brief-governance/>

Citation: McKay, H., Haviland, S., Michael, S. (2020). Building a multistate governance system. (2020). MLDE Issue Brief. Boulder, CO: MLDE. <https://www.wiche.edu/key-initiatives/multistate-longitudinal-data-exchange/mlde-issue-brief-governance/>

Building Data Sharing Infrastructures at the State Level: Context, Stakeholders, Technology

Overview: "This presentation uses the Virginia Longitudinal Data System (VLDS) as an example to explain best practices to implement a linked data system in a state. The economic and social impacts of the COVID-19 pandemic have heightened demand for cross-agency data capacity, as policymakers are forced to reconcile the need for expanded services with extreme fiscal constraints. In this context, integrated data systems (IDS) – also commonly referred to as data hubs, data collaboratives, or state longitudinal data systems – are a valuable resource for data-informed decision making across agencies. IDS utilize standard governance processes and legal agreements to grant authority for routine, responsible use of linked data, and institutionalize roles across partners with shared priorities. Despite these benefits, creating and sustaining IDS remains a challenge for many states. Legislation and executive action can be powerful mechanisms to overcome this challenge and promote the use of cross-agency data for public good."

Organization Name: Virginia Tech Bioinformatics Institute

Audience: State/Territory

Service Area(s): Child Welfare, Early Childhood, Education, Epidemiology, Healthcare, Social Services

Focus Area(s): Data Governance, Technical Infrastructure

Web Address:

https://opremethodsmeeting.org/docs/2015/Schroeder_DataLinkageStateLevel.pdf

Citation: Schroeder, A. D. (2015). *Building data sharing infrastructures at the state level: Context, stakeholders, technology*. Paper presented at the Office of Planning, Research, and Evaluation meeting, The Promises and Challenges of Administrative Data in Social Policy Research, Washington, DC.

https://opremethodsmeeting.org/docs/2015/Schroeder_DataLinkageStateLevel.pdf

The CARE Principles for Indigenous Data Governance

Overview: "Concerns about secondary use of data and limited opportunities for benefit-sharing have focused attention on the tension that Indigenous communities feel between (1) protecting Indigenous rights and interests in Indigenous data (including traditional knowledges) and (2) supporting open data, machine learning, broad data sharing, and big data initiatives. The International Indigenous Data Sovereignty Interest Group (within the Research Data Alliance) is a network of nation-state based Indigenous data sovereignty networks and individuals that developed the 'CARE Principles for Indigenous Data Governance' (Collective Benefit, Authority to Control, Responsibility, and Ethics) in consultation with Indigenous Peoples, scholars, non-profit organizations, and governments. The CARE Principles are people- and purpose-oriented, reflecting the crucial role of data in advancing innovation, governance, and self-determination among Indigenous Peoples. In this first formal publication of the CARE Principles, we articulate their rationale, describe their relation to the FAIR Principles, and present examples of their application."

Organization Name: Committee on Data (CODATA)

Audience: Tribes, Researcher

Service Area(s): Child Welfare, Education, Healthcare, Social Services

Focus Area(s): Data Governance, Community Engagement

Web Address: <https://datascience.codata.org/articles/10.5334/dsj-2020-043/>

Citation: Carroll, S. R., Garba, I., Figueroa-Rodríguez, O. L., Holbrook, J., Lovett, R., Materechera, S., Hudson, M. (2020). *The CARE Principles for Indigenous Data Governance*. Data Science Journal, 19(1), 43. DOI: <http://doi.org/10.5334/dsj-2020-043>

Case Study Report – Montgomery County, MD’s Electronic Integrated Case Management System (eICM): Data Sharing for Program Operations while Protecting Privacy

Overview: “This Case Study Report is intended for staff at all levels of government who work within agencies that promote the well-being of children and families. It explains how Montgomery County, Maryland’s Department of Health & Human Services (“DHHS”) enterprise integrated case management system (eICM) shares data across more than 70 DHHS programs, allowing staff to better understand their clients, more efficiently serve them, and improve their outcomes. The report discusses why the eICM was implemented; how the eICM works; how the eICM team overcame various data privacy and confidentiality challenges; and how the eICM benefits the residents served. It includes several lessons learned and recommendations from the people who developed and use the eICM. Along with the report, we posted the full and abridged copy of DHHS’ Notice of Privacy Protections (NoPP) as a separate editable document. It describes how DHHS may use and disclose recipients’ health and other personal information and informs recipients of their legal rights regarding this information. We hope it can be a starting point for other organizations seeking similar arrangements.”

Organization Name: Office of Planning, Research, and Data (OPRE)

Audience: Federal, State/Territory, Local

Service Area(s): Child Welfare, Education

Focus Area(s): Data Governance, Technical Infrastructure, Community Engagement

Web Address: <https://www.acf.hhs.gov/opre/report/case-study-report-montgomery-county-mds-electronic-integrated-case-management-system>

Citation: Gabay, Mary, Frank Bennici, Tom Krenzke, and Janice Machado. 2022. Case Study Report, Montgomery County, MD’s Electronic Integrated Case Management System (eICM): Data Sharing for Program Operations while Protecting Privacy, OPRE Report 2022-111, Washington, DC: Office of Planning, Research, and Evaluation, Administration for Children and Families, U.S. Department of Health and Human Services.

Case Study Report – Iowa’s Integrated Data System for Decision-Making (I2D2)

Overview: “This Case Study Report is intended for staff at all levels of government who work within offices and agencies that promote the well-being of children and families. It explains how Iowa’s Integrated Data System for Decision-Making (I2D2) shares human services, education, and health data across programs to conduct data analyses that inform policy, support program decision-making, and improve outcomes for Iowa’s children and families. The report discusses why I2D2 began; how I2D2 works; some of the projects that demonstrate I2D2’s value; how the I2D2 team overcame various data privacy, confidentiality, and security challenges; and I2D2’s long-term sustainability goals. It includes several lessons learned and recommendations from the people who developed and operate I2D2. It also includes copies of legal agreements used to facilitate some of the data sharing activities. Along with the report, we also posted the legal agreements as separate editable documents. We hope they can be a starting point for other organizations seeking similar arrangements.”

Organization Name: Office of Planning, Research, and Data (OPRE)

Audience: Federal, State/Territory, Local

Service Area(s): Child Welfare

Focus Area(s): Data Analysis & Use, Data Governance, Technical Infrastructure, Community Engagement

Web Address: <https://www.acf.hhs.gov/opre/report/case-study-report-iowas-integrated-data-system-decision-making-i2d2>

Citation: Gabay, Mary, Tom Krenzke, Frank Bennici, and Janice Machado. (2022). Case Study Report, Iowa’s Integrated Data System for Decision-Making: Creating a Data Sharing Initiative Intentionally, OPRE Report 2022-33, Washington, DC: Office of Planning, Research, and Evaluation, Administration for Children and Families, U.S. Department of Health and Human Services.

Challenges in Administrative Data Linkage for Research

Overview: "Linkage of population-based administrative data is a valuable tool for combining detailed individual-level information from different sources for research. While not a substitute for classical studies based on primary data collection, analyses of linked administrative data can answer questions that require large sample sizes or detailed data on hard-to-reach populations, and generate evidence with a high level of external validity and applicability for policy making. There are unique challenges in the appropriate research use of linked administrative data, for example with respect to bias from linkage errors where records cannot be linked or are linked together incorrectly. For confidentiality and other reasons, the separation of data linkage processes and analysis of linked data is generally regarded as best practice. However, the 'black box' of data linkage can make it difficult for researchers to judge the reliability of the resulting linked data for their required purposes. This article aims to provide an overview of challenges in linking administrative data for research. We aim to increase understanding of the implications of (i) the data linkage environment and privacy preservation; (ii) the linkage process itself (including data preparation, and deterministic and probabilistic linkage methods) and (iii) linkage quality and potential bias in linked data. We draw on examples from a number of countries to illustrate a range of approaches for data linkage in different contexts."

Organization Name: Actionable Intelligence for Social Policy (AISP)

Audience: Researcher

Service Area(s): Child Welfare, Early Childhood, Education, Epidemiology, Healthcare, Social Services

Focus Area(s): Data Analysis & Use, Data Governance, Technical Infrastructure

Web Address: <https://www.aisp.upenn.edu/resource-article/challenges-in-administrative-data-linkage-for-research/>

Citation: Harron, K., Dibben, C., Boyd, J., Hjern, A., Azimae, M., Barreto, M.L., Goldstein, H. (2017). *Challenges in administrative data linkage for research*. Big Data & Society, July-December 2017, 1-12.

CITI Module: Ethical and Appropriate Uses of Administrative Data for Research and Evaluation

Overview: "The module discusses the benefits and limitations of utilizing administrative data for research, evaluation, and analytic purposes, including an overview of ethical use; privacy and security; legal considerations; study design, analysis, and reporting; and data management. This module works to: provide learners with an expert overview of administrative data reuse; enhance an organization's Human Subjects Research training for social-behavioral-educational learners; offer various examples of innovative uses of administrative data and additional resources for further learning. The target audience for this module are analysts and researchers in academic institutions (graduate students, postdoctoral fellows, and professors), government agencies (state, federal, and local), independent research organizations (for example, think tanks), and private companies."

Organization Name: Actionable Intelligence for Social Policy (AISP)

Audience: Federal, State/Territory, Local, Researcher

Service Area(s): Child Welfare, Early Childhood, Education, Epidemiology, Healthcare, Social Services

Focus Area(s): Data Analysis & Use, Data Governance

Web Address: <https://www.aisp.upenn.edu/resource-article/citi-module-ethical-and-appropriate-uses-of-administrative-data-for-research-and-evaluation/>

Citation: Hawn Nelson, A., and Culhane, D. (2020). *Ethical and appropriate uses of administrative data for research and evaluation*. CITI Program. <https://about.citiprogram.org/course/human-subjects-research-2>

Confidentiality Toolkit (OPRE Report 2021-175)

Overview: "This Toolkit is intended for staff at all levels of government who work within offices and agencies that promote the well-being of children and families and would like to know more about how responsibly sharing records with other offices and agencies can enhance service delivery and research efforts, processes that can help assure record sharing goals are successful, and important confidentiality considerations related to sharing records."

Organization Name: Office of Planning, Research and Evaluation (OPRE)

Audience: Federal, State/Territory, Local, Tribes

Service Area(s): Child Welfare, Healthcare, Social Services

Focus Area(s): Data Governance

Web Address: <https://www.acf.hhs.gov/opre/report/confidentiality-toolkit>

Citation: Gabay, M., Pickett, D., Bennici, F., Krenzke, T., Machado, J. (2021). *Confidentiality toolkit (OPRE Report 2021-175)*. Washington, DC: Office of Planning, Research, and Evaluation, Administration for Children and Families, U.S. Department of Health and Human Services. <https://www.acf.hhs.gov/opre/report/confidentiality-toolkit>

Connecting the Dots: The Promise of Integrated Data Systems for Policy Analysis and Systems Reform

Overview: "This article explores the use of integrated administrative data systems in support of policy reform through interagency collaboration and research. The legal, ethical, scientific and economic challenges of interagency data sharing are examined. A survey of eight integrated data systems, including states, local governments and university-based efforts, explores how the developers have addressed these challenges. Some exemplary uses of the systems are provided to illustrate the range, usefulness and import of these systems for policy and program reform. Recommendations are offered for the broader adoption of these systems and for their expanded use by various stakeholders."

Organization Name: Actionable Intelligence for Social Policy (AISP)

Audience: Federal, State/Territory, Local, Funder, Researcher

Service Area(s): Child Welfare, Early Childhood, Education, Healthcare

Focus Area(s): Data Analysis & Use, Data Governance

Web Address: https://repository.upenn.edu/spp_papers/146/

Citation: Culhane, D. P., Fantuzzo, J., Rouse, H. L., Tam, V., & Lukens, J. (2010). *Connecting the dots: The promise of integrated data systems for policy analysis and systems reform*. Actionable Intelligence for Social Policy. https://repository.upenn.edu/spp_papers/146

Data Direction 5: Linking Data to Understand Children's Academic Progress from Early Care and Education Through Elementary School

Overview: "This brief is one of a set of five "Data Directions" that present issues ECE staff may encounter if they are interested in or attempting to share or link their data with other agencies. Each Data Direction presents a hypothetical scenario, and then outlines possible action steps programs could use to address the issues raised. This fifth Data Direction presents an example of a specific data linkage project and possible steps to take in order to link ECE program data with public school data."

Organization Name: Child Trends

Audience: Federal, Local

Service Area(s): Early Childhood, Education

Focus Area(s): Data Analysis & Use, Data Governance

Web Address: <https://researchconnections.org/childcare/resources/32709>

Citation: Friese, S., Richards, D.E., Maxwell, K. Data Direction 5: Linking data to understand children's academic progress from early care and education through elementary school, Publication 2016-35. Bethesda, MD: Child Trends. <https://aspe.hhs.gov/sites/default/files/pdf/207876/DataDirection5TrackProgress.pdf>

Data Integration Toolkit

Overview: "The CIID Data Integration Toolkit contains action-oriented steps and corresponding resources to help State Education Agencies (SEAs) and technical assistance (TA) providers integrate their Individuals with Disabilities Education Act (IDEA) Part B data with their State Longitudinal Data Systems (SLDSs) using the Common Education Data Standards (CEDS). The Toolkit provides a road map of typical steps and tasks required for successful data integration using CEDS; it draws directly from state experiences and reflects current data management best practices. The Toolkit provides instructions for project managers and IT staff as they prepare for, complete, and sustain data integration projects."

Organization Name: Center for the Integration of IDEA Data (CIID)

Audience: State/Territory

Service Area(s): Education

Focus Area(s): Data Governance, Technical Infrastructure

Web Address: <https://ciidta.communities.ed.gov/#program/toolkit>

Citation: Center for the Integration of IDEA Data (CIID). (2021). Data integration toolkit. U.S. Department of Education: Office of Special Education Programs. <https://ciidta.communities.ed.gov/#program/toolkit>

Data Interoperability Maturity Model

Overview: "This resource lets you assess your agency's progress towards data interoperability. It can be used to: self-evaluate your current level of data interoperability maturity; identify gaps in your data interoperability maturity; plan improvements to reach the level of maturity your agency needs."

Organization Name: National Archives of Australia

Audience: Federal, State/Territory, Local

Service Area(s): Child Welfare, Early Childhood, Education, Epidemiology, Healthcare, Social Services

Focus Area(s): Data Governance, Technical Infrastructure

Web Address: <https://iapp.org/resources/article/data-interoperability-maturity-model/>

Citation: National Archives of Australia (n.d.). *Data interoperability maturity model DIMM*. National Archives of Australia.

https://iapp.org/media/pdf/resource_center/national_archives_australia_data_interoperability_model.pdf

Data Linking Toolkit

Overview: "The Center for Early Childhood Data Systems (DaSy Center) is a national technical assistance center that works with states to support the Individuals with Disabilities Education Act (IDEA) early intervention and early childhood special education state programs in building high quality data systems and using data to improve results for young children with disabilities and their families. This Data Linking Toolkit comprises multiple sections that include downloadable tools to support Part C and Part B 619 (early childhood) program staff as they consider, prepare, and successfully link their data."

Organization Name: The Center for Early Childhood Data Systems (DaSy)

Audience: State/Territory

Service Area(s): Early Childhood

Focus Area(s): Data Governance

Web Address: <https://dasycenter.org/data-linking-toolkit/>

Citation: Mauzy, D., & Bull, B. (with Walsh, S., & Harmon, G.). (2022). *The DaSy Data Linking Toolkit*. In DaSy Toolkits and Guides Series. <http://dasycenter.org/data-linking-toolkit>

Data Sharing Agreement Checklist for IDEA Part C and Part B 619 Agencies and Programs

Overview: "This document is an adaptation of the 2012 "Data Sharing Agreement Checklist" that was intended for K–12 audiences. This adaptation of the original document is intended for Individuals with Disabilities Education Act (IDEA) Part C early intervention and Part B 619 preschool special education. This document summarizes the requirements for the written agreements under the audit or evaluation exception¹ that is specified in FERPA and that also applies to the IDEA."

Organization Name: The Center for Early Childhood Data Systems (DaSy)

Audience: Federal, State/Territory, Local

Service Area(s): Early Childhood

Focus Area(s): Data Governance

Web Address:

https://dasycenter.sri.com/downloads/DaSy_papers/DaSy_Data_Sharing_Agreement_Checklist_Acc.pdf

Citation: The Center for IDEA Early Childhood Data Systems. (2014). Data sharing agreement checklist for IDEA Part C and Part B 619 Agencies and Programs. DaSy The Center for IDEA Early Childhood Data Systems. Privacy Technical Assistance Center.

Data Sharing to Build Effective and Efficient Benefits Systems

Overview: "Data sharing across benefit programs can help close this gap and provide critical assistance to people in need. This resource is designed to support administering government agencies and other sectors like health care, higher education, and research entities scope and implement successful data sharing projects, with legal considerations in mind. The Playbook serves as a step-by-step guide to conducting impactful work through data sharing, informed by Benefits Data Trust's (BDT's) nearly 20 years of experience, as well as interviews with 35 city, state, federal officials and other experts in the benefits access and data sharing spaces. It prepares readers for the issues they need to consider and discuss with agency lawyers, administrators, and other relevant stakeholders to ensure that data sharing is permissible and secure, and includes examples and templates to guide and inspire efforts at your institution."

Organization Name: Benefits Data Trust

Audience: State/Territory, Local, Researcher

Service Area(s): Education, Epidemiology, Healthcare

Focus Area(s): Data Analysis & Use

Web Address: https://bdtrust.org/data-sharing-to-build-effective-and-efficient-benefits-systems_january-2023.pdf

Citation: Saffold, J.Y., Gibbons Straughan, B., & Weiss, A. (2023). *Data sharing to build effective and efficient benefits systems*. Benefits Data Trust, Philadelphia, PA.
https://bdtrust.org/data-sharing-to-build-effective-and-efficient-benefits-systems_january-2023.pdf

Data Sharing: Courts and Child Welfare

Overview: "The U.S. Department of Health and Human Services Administration for Children and Families (ACF) offers this technical assistance guidance to courts and child welfare agencies to assist and support the creation of automated, bi-directional (two-way) data exchanges between their respective information systems. This document summarizes the benefits of data exchanges, identifies data categories to consider in data-sharing agreements, provides tips for overcoming common challenges, and highlights examples of successfully operating state and locally administered data exchanges."

Organization Name: U.S. Department of Health and Human Services Administration for Children and Families

Audience: State/Territory, Local

Service Area(s): Child Welfare

Focus Area(s): Data Governance

Web Address: <https://www.aisp.upenn.edu/resource-article/data-sharing-courts-and-child-welfare/>

Citation: United States Department of Health and Human Services Administration for Children and Families. (2018). *Data sharing: Courts and child welfare*.
https://www.acf.hhs.gov/sites/default/files/cb/data_sharing_toolkit.pdf

Developmental Impacts of the COVID-19 Pandemic on Young Children: A Conceptual Model for Research with Integrated Administrative Data Systems

Overview: "The COVID-19 pandemic made its mark on the entire world, upending economies, shifting work and education, and exposing deeply rooted inequities. A particularly vulnerable, yet less studied population includes our youngest children, ages zero to five, whose proximal and distal contexts have been exponentially affected with unknown impacts on health, education, and social-emotional well-being. Integrated administrative data systems could be important tools for understanding these impacts. This article has three aims to guide research on the impacts of COVID-19 for this critical population using integrated data systems (IDS). First, it presents a conceptual data model informed by developmental-ecological theory and epidemiological frameworks to study young children. This data model presents five developmental resilience pathways (i.e. early learning, safe and nurturing families, health, housing, and financial/employment) that include direct and indirect influencers related to COVID-19 impacts and the contexts and community supports that can affect outcomes. Second, the article outlines administrative datasets with relevant indicators that are commonly collected, could be integrated at the individual level, and include relevant linkages between children and families to facilitate research using the conceptual data model."

Third, this paper provides specific considerations for research using the conceptual data model that acknowledge the highly-localized political response to COVID-19 in the US. It concludes with a call to action for the population data science community to use and expand IDS capacities to better understand the intermediate and long-term impacts of this pandemic on young children."

Organization Name: Actionable Intelligence for Social Policy (AISP)

Audience: Researcher

Service Area(s): Early Childhood

Focus Area(s): Data Analysis & Use, Data Governance, Community Engagement

Web Address: <https://ijpds.org/article/view/1651/3280>

Citation: Rouse, H. L., Bulotsky Shearer, R.J., Idzikowski, S.S., Hawn Nelson, A., Needle, M., Katz, M.F., Bailey, J., Lane, J.T., Berkowitz, E., Zanti, S., Pena, A. and Reeves, M. (2021). *Developmental impacts of the COVID-19 pandemic on young children: A conceptual model for research with integrated administrative data systems*. International Journal of Population Data Science, 5(4). doi: 10.23889/ijpds.v5i4.1651.

Diffusion of an Innovation: Lessons from the Multistate Longitudinal Data Exchange

Overview: "This brief examines the diffusion of a data innovation from 2014 to 2019: the introduction of the Multistate Longitudinal Data Exchange (MLDE), a collaborative system both within and between state data agencies. It is based on research and evaluation activities conducted over the past five years by Rutgers' Education & Employment Research Center (EERC) including data collected from over 40 interviews with state leaders and Western Interstate Commission for Higher Education (WICHE) representatives, observations of user group meetings, surveys, and MLDE document analysis. This brief presents the salient factors that contributed to the emergence of early adopters of the new data exchange. Specifically, what made these groups want to join? What concerns did they have? How might future exchange organizers build on the interests of early adopters as well as respond to their own issues of concern?"

Organization Name: Multistate Longitudinal Data Exchange (MLDE)

Audience: State/Territory, Local, Researcher

Service Area(s): Education

Focus Area(s): Data Analysis & Use, Data Governance, Technical Infrastructure

Web Address: <https://www.wiche.edu/key-initiatives/multistate-longitudinal-data-exchange/mlde-issue-brief-diffusion/>

Citation: McKay, H., Haviland, S., Michael, S. (2020). Diffusion of an innovation: Lessons from the Multistate Longitudinal Data Exchange. MLDE Issue Brief. Boulder, CO: MLDE. <https://www.wiche.edu/key-initiatives/multistate-longitudinal-data-exchange/mlde-issue-brief-diffusion/>

Envisioning a New Future: Building Trust for Data Use

Overview: "The culmination of a three part landscape review prepared with and for the Data Funders Collaborative (DFC), this paper aims to provide a common language for funders to understand the opportunities and challenges to improving engagement and building trust with communities and offers a range of approaches to consider for future investments."

Organization Name: Urban Institute

Audience: Funder

Service Area(s): Social Services

Focus Area(s): Community Engagement

Web Address:

<https://drive.google.com/file/d/1hGR4rK0Um239XJkDWPIRX9g2aLgWc53E/view>

Citation: Hendey, L & Pettit, K. L. S. (2021). *Envisioning a new future: Building trust for data use*. Washington, DC: Urban Institute

Evidence-Based Policymaking: What Human Service Agencies Can Learn from Implementation Science and Integrated Data Systems

Overview: "The evidence-based policymaking movement compels government leaders and agencies to rely on the best available research evidence to inform policy and program decisions, yet how to do this effectively remains a challenge. This paper

demonstrates how the core concepts from two emerging fields—Implementation Science (IS) and Integrated Data Systems (IDS)—can help human service agencies and their partners realize the aims of the evidence-based policymaking movement. An IS lens can help agencies address the role of context when implementing evidence-based practices, complement other quality and process improvement efforts, simultaneously study implementation and effectiveness outcomes, and guide de-implementation of ineffective policies. The IDS approach offers governance frameworks to support ethical and legal data use, provides high-quality administrative data for in-house analyses, and allows for more time-sensitive analyses of pressing agency needs. Ultimately, IS and IDS can support human service agencies in more efficiently using government resources to deliver the best available programs and policies to the communities they serve. Although this paper focuses on examples within the United States context, key concepts and guidance are intended to be broadly applicable across geographies, given that IS, IDS, and the evidence-based policymaking movement are globally relevant."

Organization Name: University of Pennsylvania, University of North Carolina-Charlotte

Audience: Federal, State/Territory, Local

Service Area(s): Child Welfare, Education, Epidemiology, Healthcare, Social Services

Focus Area(s): Data Analysis & Use

Web Address: <https://link.springer.com/article/10.1007/s43477-021-00028-x>

Citation: Zanti, S. & Thomas, L. (2021). *Evidence-based policymaking: What human service agencies can learn from implementation science and integrated data systems*. Journal of Global Implementation Research and Applications, 1, pages 304–314. <https://doi.org/10.1007/s43477-021-00028-x>

Expanding TANF Program Insights: A Toolkit for State and Local Agencies on How to Access, Link, and Analyze Unemployment Insurance Wage Data

Overview: "This is a toolkit AISP co-wrote with MDRC under the TANF Data Initiative with methods for how to access, link, and analyze TANF and UI data. It includes a good summary of what we know to be common barriers to cross-sector data sharing, solutions to address those barriers, a comparison of key methods for linking data, and detailed analytic guidance specific to linking UI and TANF records."

Organization Name: TANF Data Collaborative

Audience: State/Territory, Local

Service Area(s): Social Services

Focus Area(s): Data Analysis & Use, Technical Infrastructure

Web Address: <https://www.acf.hhs.gov/opre/report/expanding-tanf-program-insights-toolkit-state-local-agencies-how-access-link-analyze>

Citation: Yang, E., Zanti, S., Burnett, T.C., Hendra, R., Culhane, D., Htet, Z., Jenkins, D., Preel-Dumas, C., & Small, E. (Under Federal Review). *Expanding TANF program insights: A toolkit for state and local agencies on how to access, link, and analyze unemployment insurance wage data [Technical Report]*. OPRE Report 2022-226. Washington, DC: Office of Planning, Research, and Evaluation, Administration for Children and Families, U.S. Department of Health and Human Services.

Finding a Way Forward: How to Create a Strong Legal Framework for Data Integration

Overview: "This report was created by Actionable Intelligence for Social Policy (AISP) to support the essential and challenging work of exchanging, linking, and using data across government agencies. Cross-sector data sharing and integration has become more routine and commonplace, and for good reason. When governments and their partners bring together data safely and responsibly, policymakers and practitioners are better equipped to understand the complex needs of individuals and families, allocate resources where they're needed most to improve services, and measure the impacts of policies and programs holistically. Data sharing and integration is also not without risks, and clear legal frameworks are essential to mitigate those risks, protect privacy, and guide responsible data use. Designing the appropriate legal framework for the context can be a complex task and a test of endurance. This resource was created to frame out key considerations and provide effective practices for agencies working to "find a way forward" to share and integrate data."

Organization Name: Actionable Intelligence for Social Policy (AISP)

Audience: Federal, State/Territory, Local, Tribes

Service Area(s): Child Welfare, Early Childhood, Education, Epidemiology, Healthcare, Social Services

Focus Area(s): Data Governance

Web Address: <https://aisp.upenn.edu/resource-article/finding-a-way-forward-how-to-create-a-strong-legal-framework-for-data-integration/>

Citation: Hawn Nelson, A., Kemp, D., Jenkins, D., Rios Benitez, J., Berkowitz, E., Burnett, TC, Smith, K., Zanti, S., Culhane, D. (2022). Finding a way forward: How to create a strong legal framework for data integration. Actionable Intelligence for Social Policy. Philadelphia, PA: University of Pennsylvania.

Forum Guide to Supporting Data Access for Researchers: A State Education Agency Perspective (NFES 2012-809)

Overview: "This guide recommends policies, practices, and templates that can be adopted and adapted by SEAs as they consider how to most effectively respond to requests for data about the education enterprise, including data maintained in longitudinal data systems. These recommendations reflect sound principles for managing the flow of data requests, establishing response priorities, monitoring appropriate use, protecting privacy, and ensuring that research efforts are beneficial to the education agency as well as the research community."

Organization Name: National Center for Education Statistics

Audience: State/Territory

Service Area(s): Education

Focus Area(s): Data Analysis & Use, Data Governance

Web Address: <https://nces.ed.gov/pubs2012/2012809.pdf>

Citation: National Forum on Education Statistics. (2012). *Forum guide to supporting data access for researchers: A state education agency perspective (NFES 2012-809)*. U.S. Department of Education. Washington, DC: National Center for Education Statistics. <https://nces.ed.gov/pubs2012/2012809.pdf>

Forum Guide to the Teacher-Student Data Link: A Technical Implementation Resource (NFES 2013-802)

Overview: "This publication is a practical guide for implementing a teacher-student data link (TSDL) that supports a range of uses at the local, regional, and state levels. The guide addresses the considerations for linking teacher and student data from multiple perspectives, including governance, policies, data components, business rules, system requirements, and practices. It provides references to promising practices for high quality data linkages, including TSDL-specific processes such as roster verification and the establishment of the Teacher of Record. The information and opinions published here are those of the Forum and do not necessarily represent the policy or views of the U.S. Department of Education or NCES."

Organization Name: National Center for Education Statistics

Audience: State/Territory, Local

Service Area(s): Education

Focus Area(s): Data Governance, Technical Infrastructure

Web Address: <https://nces.ed.gov/pubs2013/2013802.pdf>

Citation: National Forum on Education Statistics. (2013). *Forum guide to the teacher-student data link: A technical implementation resource (NFES 2013-802)*. U.S. Department of Education. Washington, DC: National Center for Education Statistics. <https://nces.ed.gov/pubs2013/2013802.pdf>

Getting Started: Incorporating Head Start Data in an SLDS

Overview: "This resource addresses how to incorporate Head Start Data in an SLDS by discussing reasons for integrating Head Start data, who to involve when, and strategies for engagement."

Organization Name: Statewide Longitudinal Data System State Support Team (SLDS SST)

Audience: State/Territory

Service Area(s): Early Childhood

Focus Area(s): Data Governance

Web Address: https://nces.ed.gov/programs/slds/pdf/headstart_GettingStarted.pdf

Citation: SLDS State Support Team. (2012). *Getting started: Incorporating Head Start data in an SLDS*. Washington, DC: National Center for Education Statistics, Institute of Education Sciences. https://nces.ed.gov/programs/slds/pdf/headstart_GettingStarted.pdf

How Tulsa Is Preserving Privacy and Sharing Data for Social Good

Overview: "Data sharing between organizations addressing social risk factors has the potential to amplify impact by increasing direct service capacity and efficiency. Unfortunately, the risks of and restrictions on sharing personal data often limit this potential, and adherence to regulations such as HIPAA and FERPA can make data sharing a significant challenge. Through the development of new technologies such as secure multi-party computation (MPC), communities have an opportunity to share individual-level data without exposing personally identifiable information (PII). In this white paper, we describe the process of using MPC technology to answer questions that can aid service providers in exploring the barriers that underserved populations may be facing. The first question we asked: what is the overlap of populations served by two distinct organizations? The results of the overlap analysis confirmed that a significant opportunity exists to increase access to services for a subset of individuals through better outreach."

Organization Name: Asemio

Audience: Local

Service Area(s): Early Childhood, Social Services

Focus Area(s): Data Analysis & Use, Data Governance, Technical Infrastructure

Web Address: <https://www.aisp.upenn.edu/resource-article/how-tulsa-is-preserving-privacy-and-sharing-data-for-social-good/>

Citation: Bean, A., Jaynes, J., Sexton, T.J. (2019). How Tulsa is preserving privacy and sharing data for social good. Tulsa, OK: Asemio. https://dashconnect.org/wp-content/uploads/2019/08/2019.07.15_-_DASH-CIC-START-Final-White-Paper.pdf

Improving Data Infrastructure to Meet Student and Learner Information Needs

Overview: "This paper is part of a series offering recommendations to the Biden administration, this paper makes the case for additional federal funding to support upgrades to the Statewide Longitudinal Data Systems to enable states to effectively monitor and address long term pandemic learning loss while ensuring this generation of students stays on track for college and career in the aftermath of the pandemic."

Organization Name: Day One Project

Audience: Federal

Service Area(s): Education

Focus Area(s): Technical Infrastructure

Web Address: https://drive.google.com/file/d/1R1-vrycPXzuMuFiV_YsnemxwjEvhqlyp/view

Citation: Garg, K., Garcia, A., & Hart, N. (2021). Day One Project. *Improving data infrastructure to meet student and learner information needs*. https://drive.google.com/file/d/1R1-vrycPXzuMuFiV_YsnemxwjEvhqlyp/view

Interagency Data Disclosure: A Tip Sheet in Interagency Collaboration

Overview: "This tip sheet, developed by the U.S. Department of Education (ED) in coordination with the U.S. Interagency Council on Homelessness (USICH), will help state and local education agency (SEA and LEA) homeless education programs, housing and human service agencies, and organizations serving homeless families, children, and youths better coordinate their services by disclosing student data and information with each other."

Organization Name: Education for Homeless Children and Youth (EHCY) Program

Audience: State/Territory, Local

Service Area(s): Child Welfare

Focus Area(s): Data Governance, Community Engagement

Web Address: <https://oese.ed.gov/files/2021/05/ehcy-interagency-data-disclosure.pdf>

Citation: Education for Homeless Children and Youth (EHCY) Program. *Interagency data Disclosure: A tip sheet in interagency collaboration*. (May 2015). U.S. Department

of Education and U.S. Interagency Council on Homelessness.
<https://oese.ed.gov/files/2021/05/ehcy-interagency-data-disclosure.pdf>

Introduction to Data Security Breach Preparedness with Model Data Security Breach Preparedness Guide

Overview: "This document is comprised of steps and actions to be prepared against data security breaches. Included are Steps for Immediate Mitigation and Incident Analysis, Developing a Notification Plan for Business Customer, Developing a Notification Plan for Affected Persons, Communication Steps, and Actions Following a Data Security Breach."

Organization Name: International Association of Privacy Professionals (IAPP)

Audience: Federal, State/Territory, Local

Service Area(s): Child Welfare, Early Childhood, Education, Epidemiology, Healthcare, Social Services

Focus Area(s): Data Governance

Web Address: https://iapp.org/media/pdf/resource_center/22-15_intro_to_data_security_breach_preparedness.authcheckdam.pdf

Citation: Wolf, C. and Lovells, H. (2012). *Introduction to data security breach preparedness with model data security breach preparedness guide*.
https://iapp.org/media/pdf/resource_center/22-15_intro_to_data_security_breach_preparedness.authcheckdam.pdf

Joint Guidance on the Application of the Family Educational Rights and Privacy Act (FERPA) and the Health Insurance Portability and Accountability Act of 1996 (HIPAA) to Student Health Records

Overview: "The U.S. Department of Education and the Office for Civil Rights at the U.S. Department of Health and Human Services released updated joint guidance addressing the application of the Family Educational Rights and Privacy Act (FERPA) and the Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy Rule to records maintained on students. The guidance, which was first issued in November 2008, clarifies for school administrators, health care professionals, families, and others how FERPA and HIPAA apply to education and health records maintained about students. The revised guidance includes additional frequently asked questions and answers addressing when a student's health information can be shared without the written consent of the parent or eligible student under FERPA, or without written authorization under the HIPAA Privacy Rule."

Organization Name: Privacy Technical Assistance Center (PTAC)

Audience: Local

Service Area(s): Education, Healthcare

Focus Area(s): Data Governance

Web Address: <https://studentprivacy.ed.gov/resources/joint-guidance-application-ferpa-and-hipaa-student-health-records>

Citation: U.S. Department of Education and U.S. Department of Health and Human Services. (2019). *Joint guidance on the application of the Family Educational Rights and Privacy Act (FERPA) and the Health Insurance Portability and Accountability Act of 1996 (HIPAA) to student health records*.
https://studentprivacy.ed.gov/sites/default/files/resource_document/file/2019%20HIPAA%20FERPA%20Joint%20Guidance%20508.pdf

The Learning Center for Families' Use of Data to Support Children's Healthy Development

Overview: "The Learning Center for Families provides health, family support, and school readiness services in a rural community. This case study describes how the program accesses and matches health data from a variety of other agencies in the community to link important information to better serve children and families. This case study highlights an example of linking data that involves staff from multiple different agencies sharing data on children and families with staff at another agency."

Organization Name: Child Trends

Audience: State/Territory, Local

Service Area(s): Early Childhood, Healthcare

Focus Area(s): Data Analysis & Use

Web Address: <https://researchconnections.org/sites/default/files/pdf/rc32662.pdf>

Citation: King, C., Maxwell, K. L., Abrams, J. & Epstein, D. (2016). *Case study 2: The Learning Center for Families' use of data to support children's healthy development (Report #2016-29)*. Bethesda, MD: Child Trends.
<https://researchconnections.org/sites/default/files/pdf/rc32662.pdf>

Legal Issues in the Use of Electronic Data Systems for Social Science Research

Overview: "This paper provides an overview of legal issues in using and linking large datasets for social science research. The paper is based on three assumptions. First, linked datasets are essential in conducting services research and policy analyses. Second, it is usually legally possible to collect information and create and link data, though the legal rules for different categories of information may vary. Third, while privacy and confidentiality laws are critical in thinking about these issues, the legal rules governing the security of data are as important. The paper has four sections. The first briefly summarizes federal and state laws that affect the privacy of several types of information that social science researchers may wish to access. The second discusses Institutional Review Boards (IRBs), including important proposed changes in the federal rules governing IRBs. The third summarizes the relevant law on the security of electronic health data, primarily that found in the regulations implementing the Health Insurance Portability and Accountability Act (HIPAA). The paper concludes with a brief discussion of enforcement and penalties for violating confidentiality laws."

Organization Name: Children's Data Network

Audience: Researcher

Service Area(s): Child Welfare, Education, Epidemiology, Healthcare, Social Services

Focus Area(s): Data Governance

Web Address: https://www.datanetwork.org/wp-content/uploads/2017/02/0033_12_SP2_Legal_Issues_Data_Systems_000.pdf

Citation: Petrila, J., (n.d.). *Legal issues in the use of electronic data systems for social science research*. Tampa, FL: University of South Florida.
https://www.datanetwork.org/wp-content/uploads/2017/02/0033_12_SP2_Legal_Issues_Data_Systems_000.pdf

Linking Child Welfare and Medicaid Data: Lessons Learned from Two States (OPRE Report 2023-038)

Overview: "The document is intended to provide information to state, tribal, and local child welfare, Medicaid, and behavioral health agencies that are interested in linking their Medicaid and child welfare data. The document may also be of interest to HHS agencies whose mission involves improving outcomes and services delivered to children served by child welfare agencies and the Medicaid program. Research organizations and technical assistance providers that collaborate with local agencies on similar projects or that study the relationship between Medicaid and child welfare may also benefit from the information provided. Finally, children and family advocacy organizations, which have been pressing for greater integration and coordination between child welfare and Medicaid, may value the lessons learned from this project."

Organization Name: Assistant Secretary for Planning and Evaluation (ASPE) and the Office of Planning, Research and Evaluation (OPRE)

Audience: State/Territory, Local, Tribes

Service Area(s): Child Welfare

Focus Area(s): Data Analysis & Use, Data Governance

Web Address: https://www.acf.hhs.gov/sites/default/files/documents/opre/ccould_lessons_learned_mar_ch2023.pdf

Citation: Mark, T.L., Dolan, M., Allaire, B., Bradley, C. (2022). *Linking child welfare and Medicaid data: Lessons learned from two states (OPRE Report 2023-038)*. Washington, DC: Office of Planning, Research, and Evaluation, Administration for Children and Families, Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services.
https://www.acf.hhs.gov/sites/default/files/documents/opre/ccould_lessons_learned_mar_ch2023.pdf

Narrowing Technology Solutions for Integrated Data System (IDS) Initiatives

Overview: "AISP enlisted support from Asemio to develop materials to help AISP and network partners understand the technology options that support improved social policy planning and analysis as well as identify opportunities for innovation. This initiative produced a shared framework to facilitate the discussion and comparison of available products, strategies, and partners that support cross-sector data sharing efforts along with a set of recommendations to guide further service, platform, and partner development. The shared framework was created to help describe technology products that support data sharing for improved social policy planning and analysis. The landscape of data sharing platforms in this domain is still emerging, and technology evolves quickly. Given this, it can be challenging to understand and compare available tools and strategies. The framework is intended to support alignment of discussions of new and existing products, strategies, and partners."

Organization Name: Actionable Intelligence for Social Policy (AISP), Asemio

Audience: State/Territory, Local, Researcher

Service Area(s): Child Welfare, Early Childhood, Education, Epidemiology, Healthcare, Social Services

Focus Area(s): Technical Infrastructure

Web Address: <https://aisp.upenn.edu/resource-article/narrowing-technology-solutions-for-integrated-data-system-ids-initiatives/>

Citation: Asemio & Actionable Intelligence for Social Policy (2022). *Narrowing technology solutions for integrated data system (IDS) Initiatives*. Actionable Intelligence for Social Policy, University of Pennsylvania. Actionable Intelligence for Social Policy. Philadelphia, PA: University of Pennsylvania.

Nothing to Hide: Tools for Talking (and Listening) About Data Privacy for Integrated Data Systems

Overview: "This toolkit provides integrated data systems (IDS) stakeholders with the necessary tools to support and lead privacy-sensitive, inclusive stakeholder engagement efforts. A narrative step by step guide to IDS communication and engagement is supplemented with action-oriented appendices, including worksheets, checklists, exercises, and additional resources."

Organization Name: Actionable Intelligence for Social Policy (AISP), Future of Privacy Forum

Audience: Federal, State/Territory, Local, Tribes, Funder, Researcher

Service Area(s): Child Welfare, Early Childhood, Education, Epidemiology, Healthcare, Social Services

Focus Area(s): Data Governance, Community Engagement

Web Address: https://drive.google.com/file/d/1664CzuQ_zEVv4O1MN8nB9qk8XnEsqxEA/view

Citation: Future of Privacy Forum & Actionable Intelligence for Social Policy. (2018). *Nothing to hide: Tools for talking (and listening) about data privacy for integrated data systems*.

https://drive.google.com/file/d/1664CzuQ_zEVv4O1MN8nB9qk8XnEsqxEA/view

Privacy and Data Security is for Everyone

Overview: "Privacy and data security is for everyone" is a commonly accepted statement, is largely true, and is completely misleading. There is virtually no company in the U.S. that does not have specific legal obligations and risks related to the privacy and security of personal data. The details may change, depending on the industry and a company's practices. But for most companies, there is a core set of common obligations in an exceedingly complicated area, where the compliance challenges and legal risks are only growing. In this white paper, get an overview of the privacy law environment in the U.S., and learn about some broadly reaching laws that likely affect your organization.

Organization Name: International Association of Privacy Professionals (IAPP)

Audience: Federal, State/Territory, Local, Tribes, Funder, Researcher

Service Area(s): Child Welfare, Early Childhood, Education, Epidemiology, Healthcare, Social Services

Focus Area(s): Data Governance

Web Address: <https://iapp.org/resources/article/privacy-and-data-security-is-for-everyone/>

Citation: Nahra, K., Rein, W., (2018). *Privacy and data security is for everyone*. Portsmouth, NH: IAPP. <https://iapp.org/resources/article/privacy-and-data-security-is-for-everyone/>

Promoting Data Sharing Approaches

Overview: "This report and accompanying Toolkit intend to help communicators talk about and promote a wide range of data sharing with broad audiences. The goal is to identify ways of creating more constructive and supportive dialog with more people, and to explore ways to navigate challenges so they don't derail the conversation."

Organization Name: Topos Partnership

Audience: Federal, State/Territory, Local, Tribes, Funder, Researcher

Service Area(s): Child Welfare, Early Childhood, Education, Epidemiology, Healthcare, Social Services

Focus Area(s): Data Governance, Community Engagement

Web Address: https://drive.google.com/file/d/1EHNYay9d4-sT_kEOwfxjChpqOooi36oH/view

Citation: Topos Partnership. (2019). *Promoting data sharing approaches*. https://drive.google.com/file/d/1EHNYay9d4-sT_kEOwfxjChpqOooi36oH/view

Protecting the Privacy of Personal Information in Integrated Data Systems: Disclosure Avoidance Methods

Overview: "The process used to protect the confidentiality and privacy of personal information within an integrated data system is called disclosure avoidance. This brief focuses on key methods and considerations for strong disclosure avoidance."

Organization Name: Data Integration Support Center (DISC)

Audience: Federal, State/Territory, Local

Service Area(s): Child Welfare, Education, Healthcare, Social Services

Focus Area(s): Data Governance

Web Address: <https://disc.wested.org/wp-content/uploads/2023/01/DISC-Protecting-Privacy-of-Personal-Information.pdf>

Citation: Terrell, J., & Tiderman, L. (2023). *Protecting the privacy of personal information in integrated data systems: Disclosure avoidance methods*. Washington, DC: WestEd. <https://disc.wested.org/wp-content/uploads/2023/01/DISC-Protecting-Privacy-of-Personal-Information.pdf>

Quality Framework for Integrated Data Systems

Overview: "While every community is different, there are five key components of quality that set successful efforts apart. The Quality Framework for Integrated Data Systems outlines best practices and guiding questions related to each component to help you on your data sharing journey."

Organization Name: Actionable Intelligence for Social Policy (AISP)

Audience: Federal, State/Territory, Local

Service Area(s): Child Welfare, Early Childhood, Education, Epidemiology, Healthcare, Social Services

Focus Area(s): Data Governance

Web Address: <https://aisp.upenn.edu/resource-article/6227-2/>

Citation: Jenkins, D., Berkowitz, E., Burnett, T., Culhane, D., Hawn Nelson, A., Smith, K., and Zanti, S. (2021). *Quality framework for integrated data systems*. Actionable Intelligence for Social Policy. Philadelphia, PA: University of Pennsylvania. <https://aisp.upenn.edu/quality-framework-for-integrated-data-systems/>

Recommendations for Ensuring the Quality of Linked Human Services Data Sources

Overview: "There is a great deal of interest in the public sector and among researchers in linking public sector administrative datasets, particularly from state and local agencies, to better understand the impacts of human service programs, to target services, and to assess questions of family well-being. We lay out several threats to the quality of those

data sources and the validity of associated research. First, the record linkage research literature and existing best practices do not discuss this use case, which has important, unique methodological characteristics. Second, it is difficult to assess match quality and even harder to compare quality across different matches. Finally, the current trajectory of research and software development is toward expanding the use of complex or proprietary methods at a cost to transparency and without specific consideration of these quality questions. We lay out recommendations for practitioners and the field for paying more attention to linkage quality and the ultimate accuracy of linked data sources."

Organization Name: Chapin Hall at the University of Chicago, Family Self-Sufficiency Data Center

Audience: State/Territory, Local, Researcher

Service Area(s): Early Childhood

Focus Area(s): Data Governance

Web Address: <https://www.chapinhall.org/wp-content/uploads/Recommendations-for-Ensuring-the-Quality.pdf>

Citation: Wiegand, E. R. & George R. M. (2019). *Recommendations for ensuring the quality of linked human services data sources*. Washington, DC: Family Self-Sufficiency and Stability Research Consortium. <https://www.chapinhall.org/wp-content/uploads/Recommendations-for-Ensuring-the-Quality.pdf>

Record Linkage Innovations for the Human Services

Overview: "While an array of technical solutions and an extensive research base address problems of record linkage or deduplication, research and innovation tend to occur in discrete spaces, and often studies are published in very technical language. This report characterizes the landscape of approaches to record linkage, with particular attention to recent innovations. We aim to assist users and analysts working to combine state and local administrative data sources for analyses of family well-being and family self-sufficiency. We particularly highlight methods with the potential to increase either the accuracy or the efficiency of those matches."

Organization Name: Chapin Hall at the University of Chicago, Family Self-Sufficiency Data Center

Audience: State/Territory, Local, Researcher

Service Area(s): Early Childhood

Focus Area(s): Data Analysis & Use, Technical Infrastructure

Web Address: <https://www.chapinhall.org/wp-content/uploads/PDF/Record-Linkage-Innovations-for-the-Human-Services.pdf>

Citation: Wiegand, E. R. & George R. M. (2019). *Record linkage innovations for the human services*. Washington, DC: Family Self-Sufficiency and Stability Research Consortium. <https://www.chapinhall.org/wp-content/uploads/PDF/Record-Linkage-Innovations-for-the-Human-Services.pdf>

Researching the CCDF Program by Linking Administrative Data with Data from the CCDF Policies Database: A How-To Guide (OPRE Report 2016-24)

Overview: "This brief suggests answering questions about setting policies for the Child Care and Development Fund (CCDF) by linking case-level information on subsidized families and children with detailed policies from the federally funded CCDF Policies Database."

Organization Name: Office of Planning, Research and Evaluation (OPRE)

Audience: State/Territory, Tribes, Researcher

Service Area(s): Early Childhood, Social Services

Focus Area(s): Data Analysis & Use

Web Address: <https://researchconnections.org/sites/default/files/pdf/rc31998.pdf>

Citation: Giannarelli, L., Minton, S., & Durham, C. (2016). *Researching the CCDF program by linking administrative data with data from the CCDF Policies Database: A how-to guide (OPRE Report 2016-24)*. Washington, DC: U.S. Administration for Children and Families, Office of Planning, Research and Evaluation. <https://researchconnections.org/sites/default/files/pdf/rc31998.pdf>

Roadmap for Effective Data Use and Research Partnerships between State Education Agencies and Education Researchers

Overview: "This document provides a roadmap and state examples for partnerships between researchers and education agencies. There are eight focus areas that guide the road map: Relationship building and creating a vision; Data governance; Data sharing agreements and processes; Quality Data; Public Engagement and Communication; Privacy and Security; Analysis, Reporting and Use; and Capacity Building."

Organization Name: Data Quality Campaign

Audience: State/Territory, Local, Researcher

Service Area(s): Education

Focus Area(s): Data Analysis & Use, Data Governance, Community Engagement

Web Address: <https://dataqualitycampaign.org/wp-content/uploads/2017/10/DQC-SEA-Ed-Research-Roadmap-10112017.pdf>

Citation: Data Quality Campaign (2017). *Roadmap for effective data use and research partnerships between state education agencies and education researchers*. Washington, DC: Data Quality Campaign. <https://dataqualitycampaign.org/wp-content/uploads/2017/10/DQC-SEA-Ed-Research-Roadmap-10112017.pdf>

Roadmap for Foster Care and K-12 Data Linkages: Key Focus Areas to Ensure Quality Implementation

Overview: "This report explains ways child welfare agencies and state education agencies can link data to improve outcomes for children in foster care."

Organization Name: Data Quality Campaign, Legal Center for Foster Care & Education

Audience: State/Territory, Local

Service Area(s): Child Welfare, Education

Focus Area(s): Data Analysis & Use, Data Governance

Web Address: <https://dataqualitycampaign.org/wp-content/uploads/2017/02/DQC-Foster-Care-Roadmap-02282017.pdf>

Citation: Data Quality Campaign, & Legal Center for Foster Care & Education. (2017). *Roadmap for foster care and K-12 data linkages: Key focus areas to ensure quality implementation*. Washington, DC: Data Quality Campaign. <https://dataqualitycampaign.org/wp-content/uploads/2017/02/DQC-Foster-Care-Roadmap-02282017.pdf>

The SEEDS of Indigenous Population Health Data Linkage

Overview: "Globally, the ways that Indigenous data are collected, used, stored, shared, and analyzed are advancing through Indigenous data governance movements. However, these discussions do not always include the increasingly sensitive nature of linking Indigenous population health (IPH) data. During the International Population Data Linkage Network Conference in September of 2018, Indigenous people from three countries (Canada, New Zealand, and the United States) gathered and set the tone for discussions around Indigenous-driven IPH data linkage."

Organization Name: University of Pennsylvania, University of North Carolina-Charlotte

Audience: Federal, State/Territory, Local, Tribes

Service Area(s): Healthcare

Focus Area(s): Data Governance

Web Address: <https://doi.org/10.23889/ijpds.v6i1.1417>

Citation: Rowe, R., Russo Carroll, S., Healy, C., Walker, J.D., & Rodriguez-Lonebear, D. (2021). *The SEEDS of Indigenous population health data linkage*. International Journal of Population Data Science, 6(1). <https://doi.org/10.23889/ijpds.v6i1.1417>

SLDS Early Childhood Integrated Data System Guide

Overview: "The Early Childhood Integrated Data System Guide is one part of the SLDS Early Childhood Integrated Data System Toolkit, which was originally created in 2011 to support states working to create an Early Childhood Integrated Data System (ECIDS). Since then, states have used the Toolkit for purposes beyond the initial intent, including state planning for the ECIDS; education for other sectors (e.g., K12, workforce, and university partners); support for state conversations as a communication tool/resource; and identification of strengths to promote within the state and potential weaknesses

requiring additional support. The revised SLDS Early Childhood Integrated Data System Toolkit now takes a broader focus beyond initial planning for an ECIDS to include implementation and continuous improvement. Based on seven components of ECIDS planning and development, the Toolkit was designed for use by any state regardless of where it is in the process of developing an ECIDS."

Organization Name: Statewide Longitudinal Data System State Support Team (SLDS SST)

Audience: State/Territory

Service Area(s): Early Childhood

Focus Area(s): Data Governance, Technical Infrastructure

Web Address:

[https://www.aemcorp.com/hubfs/AEM%20Micro%20website/Publications/SLDS%20Early%20Childhood%20Integrated%20Data%20System%20Guide%20\(pdf\)%20\(1\).pdf](https://www.aemcorp.com/hubfs/AEM%20Micro%20website/Publications/SLDS%20Early%20Childhood%20Integrated%20Data%20System%20Guide%20(pdf)%20(1).pdf)

Citation: Coffey, M., Chatis, C., Sellers, J., and Taylor, R. (2014). *SLDS early childhood integrated data system guide*. U.S. Department of Education. Washington, DC: National Center for Education Statistics.

SLDS Early Childhood Integrated Data System Self-Assessment

Overview: "This supplemental resource, known as the SLDS Early Childhood Integrated Data System Self-Assessment, was created to help states assess their needs as they integrate early childhood data into an early childhood data system and the P-20W+ (early childhood through workforce and beyond) statewide longitudinal data system (SLDS)."

Organization Name: Statewide Longitudinal Data System State Support Team (SLDS SST)

Audience: State/Territory

Service Area(s): Early Childhood

Focus Area(s): Technical Infrastructure

Web Address: <https://slds.ed.gov/#communities/pdc/documents/8969>

Citation: Cochenour, M., Chatis, C., Sellers, J., & Taylor, R. (2014). *SLDS early childhood integrated data system self-assessment*. Washington, DC: National Center for Education Statistics. <https://slds.ed.gov/#communities/pdc/documents/8969>

SLDS Guide – Interagency Data Governance: Roles and Responsibilities

Overview: "This brief describes areas where the IT governance program and data governance programs overlap. These areas require collaboration to that ensure efforts of both programs are streamlined, effective, and meet the goals of the organization. Roles and responsibilities are explained for: a data governance coordinator, IT governance coordinator, executive board, data governance committee, data steward committee, and data steward."

Organization Name: Statewide Longitudinal Data System State Support Team (SLDS SST)

Audience: State/Territory

Service Area(s): Education

Focus Area(s): Data Governance

Web Address:

<https://slds.ed.gov/services/PDCService.svc/GetPDCDocumentFile?fileId=35107>

Citation: Chatis, C. & Gosa, K. (2019). *SLDS guide: Interagency data governance: Roles and responsibilities*. U.S. Department of Education. Washington, DC: National Center for Education Statistics.

Strength in Numbers: Supporting Quality Improvement in Early Care and Education Programs Through Linking Administrative Data (Publication 2016-36)

Overview: "This brief focuses on understanding the benefits and challenges for local ECE programs in sharing and receiving (i.e., linking) their data with other organizations at the local or state level to improve services for young children and families."

Organization Name: Child Trends

Audience: State/Territory, Local

Service Area(s): Child Welfare, Early Childhood

Focus Area(s): Data Analysis & Use, Data Governance

Web Address: <https://researchconnections.org/sites/default/files/pdf/rc32660.pdf>

Citation: King, C., Epstein, D., Maxwell, K. L., Lin, V. K., Abrams, J., Hutchison, L., & Burgess, K. (2016). *Strength in numbers: Supporting quality improvement in early care and education programs through linking administrative data (Publication 2016-36)*. Bethesda, MD: Child Trends.

<https://researchconnections.org/sites/default/files/pdf/rc32660.pdf>

Strengthening Integrated Data Capacity: The Federal Landscape

Overview: "This short landscape review captures the past efforts and current opportunities to change how federal, state, and local governments use integrated data to improve the effectiveness and efficiency of a broad range of government functions."

Organization Name: KB Stack Consulting

Audience: Federal, State/Territory, Local

Service Area(s): Social Services

Focus Area(s): Data Analysis & Use, Data Governance, Technical Infrastructure, Community Engagement

Web Address:

<https://drive.google.com/file/d/1JGJgOSwRvINuduXoB39MSQUN9HA1d6XU/view>

Citation: Stack, K. (2021). *Strengthening integrated data capacity: The federal landscape*. KB Stack Consulting.

<https://drive.google.com/file/d/1JGJgOSwRvINuduXoB39MSQUN9HA1d6XU/view>

Toolkit: Data Sharing for Child Welfare Agencies and Medicaid

Overview: "This document describes the population served by both agencies, provides the legal framework for sharing information, summarizes the opportunities and benefits of sharing data, provides tips for overcoming challenges, provides guidance for establishing partnerships and developing a strategic design for bi-directional data exchanges, highlights examples of successfully operating state and locally administered data exchanges and finally, provides cost-allocation guidance. The information and recommendations herein do not establish requirements or supersede existing laws or official guidance."

Organization Name: Comprehensive Child Welfare Information System

Audience: State/Territory, Tribes

Service Area(s): Child Welfare

Focus Area(s): Data Governance, Technical Infrastructure

Web Address: <https://www.acf.hhs.gov/sites/default/files/documents/cb/data-sharing-and-medicaid-toolkit.pdf>

Citation: U.S. Department of Health and Human Services Administration for Children and Families (ACF) and Centers for Medicare & Medicaid Services (CMS). (n.d.).

Toolkit: Data sharing for child welfare agencies and Medicaid.

<https://www.acf.hhs.gov/sites/default/files/documents/cb/data-sharing-and-medicaid-toolkit.pdf>

Tribal Data Linkage Toolkit

Overview: "Record linkage is the process of comparing records across data sets to identify individuals contained in both. In Indian Country, one common example involves taking a data source with accurate information about American Indian/Alaska Native ancestry and linking it with a second dataset to improve the quality of race coding in the second database. This toolkit promotes first determining if the purpose of linking is deterministic or probabilistic. Promotes the practice of linking data as standard practice to ensure that race data is appropriately coded particularly for individuals of American Indian/Alaska Native ancestry. There are quotes from state epidemiologist, tools (data linkage technologies), and sample documents (IRB protocol, data sharing agreements, confidentiality pledge, and a Link Methods Protocol - also IRB)."

Organization Name: CSTE

Audience: State/Territory, Tribes

Service Area(s): Epidemiology

Focus Area(s): Data Governance, Technical Infrastructure

Web Address: <https://www.cste.org/page/TribalDataLinkage>

Citation: CSTE (n.d.). Tribal data linkage toolkit.

<https://www.cste.org/page/TribalDataLinkage>

Using and Linking Administrative Datasets for Family Self-Sufficiency Programs

Overview: "Linking together administrative data sources from programs managed at the state and local levels is a prerequisite to many analyses of program effectiveness and family well-being. However, the availability and quality of data on individual and family characteristics vary between programs, with implications for how data sources can be linked and used. This paper documents a series of interviews with record linkage practitioners and data experts who routinely work with state and local administrative data in the human services. We provide detailed summaries of data sources commonly used in family self-sufficiency research and describe the strengths and weaknesses of data elements for identifying individuals and families across sources. We then highlight several overall characteristics unique to the human services record linkage use case. This report is intended for analysts and researchers looking to develop new sources of linked data to support family self-sufficiency research and analysis or to understand the particular challenges these data sources represent for record linkage."

Organization Name: Chapin Hall at the University of Chicago, Family Self-Sufficiency Data Center

Audience: Researcher

Service Area(s): Early Childhood, Education, Healthcare, Social Services

Focus Area(s): Data Analysis & Use, Data Governance

Web Address: <https://www.chapinhall.org/wp-content/uploads/Using-and-Linking-Administrative-Data.pdf>

Citation: Wiegand, E. R. & George R. M. (2019). *Using and linking administrative datasets for family self-sufficiency programs*. Washington, DC: Family Self-Sufficiency and Stability Research Consortium. <https://www.chapinhall.org/wp-content/uploads/Using-and-Linking-Administrative-Data.pdf>

Using Integrated Data Systems to Improve Case Management and Develop Predictive Modeling Tools

Overview: "This brief describes the innovative uses of integrated data systems (IDS) data, how it shapes decision-making on the ground and how it improves outcomes for vulnerable children, families and adults. The human services departments in Allegheny County, Pennsylvania and Washington state are leaders in using an integrated data system to develop predictive modeling tools used by frontline case managers in the child welfare system and in the Medicare-Medicaid systems. These departments also share IDS data with their service provider networks to empower caseworkers and improve service coordination."

Organization Name: Annie E. Casey Foundation

Audience: State/Territory, Local

Service Area(s): Child Welfare, Healthcare, Social Services

Focus Area(s): Data Analysis & Use

Web Address: <https://aisp.upenn.edu/resource-article/using-integrated-data-systems-to-improve-case-management-and-develop-predictive-modeling-tools/>

Citation: Auspo, P. (2017). Using integrated data systems to improve case management and develop predictive modeling tools. Baltimore, MD: The Annie E. Casey Foundation.

Using Integrated Data to Identify and Solve Housing Conditions that Harm School Readiness: A Cleveland Case Study

Overview: "This case study shows how data systems can be combined to identify educational risk factors and then develop and implement solutions for addressing them. It shares a detailed account of strategies — made possible through data systems developed by the Poverty Center — that various stakeholders utilized to protect children in Cleveland from lead exposure and its damaging effects on school readiness. The information presented is geared toward researchers and leaders who are interested in learning about the practical application of linked data."

Organization Name: Annie E. Casey Foundation

Audience: Researcher

Service Area(s): Education, Social Services

Focus Area(s): Data Analysis & Use

Web Address: <https://www.aecf.org/resources/using-integrated-data-to-identify-and-solve-housing-conditions-that-harm-sc>

Citation: The Annie E. Casey Foundation. (2018). *Using integrated data to identify and solve housing conditions that harm school readiness: A Cleveland case study*. Baltimore, MD.

Working with Administrative Data in Early Childhood and Related Fields: A List of Resources

Overview: "This list includes resources useful to researchers and agency staff who analyze state-level early care and education (ECE) administrative data for research purposes. The term administrative data refers to information about individual children, families, and/or providers of early care and education and other family benefits that is collected and maintained as part of the operation of government programs. The resource list emphasizes materials that explain how to acquire, use, manage, link, and analyze administrative data in early childhood or related fields."

Organization Name: Child Trends, Urban Institute

Audience: State/Territory

Service Area(s): Early Childhood

Focus Area(s): Data Analysis & Use, Data Governance

Web Address: <https://www.researchconnections.org/childcare/resources/39039>

Citation: Lin, V.-K. B., Maxwell, K., King, C., Martinchek, K., & Isaacs, J. B. (2021). *Working with administrative data in early childhood and related fields: A list of resources (OPRE Report No. 2021-21)*. Washington, DC: Administration for Children and Families, Office of Planning, Research and Evaluation.

https://www.acf.hhs.gov/sites/default/files/documents/opre/working-administrative-data-january-2021_0.pdf