

Resource List to Support Data Sharing for Collaborative Home Visiting Research



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BACKGROUND

One of HARC's objectives is to promote the use of data sharing and interoperability through data collaboratives and other partnerships. Sharing administrative data across the early childhood system, for example, can reduce programs' data burden, support practitioners in identifying gaps in and barriers to services, and introduce opportunities for more precise program research and evaluation.¹ The data exchange process can be difficult, complicated, and expensive to implement across its various forms (see below). Potential challenges include navigating legal issues, accommodating issues of data quality and alignment, and establishing a strong foundation in planning and governance.

This brief seeks to increase understanding of the process, necessary resources, and time investment required to facilitate data exchange and to share resources to aid in planning and decision-making. It presents resources gathered by the HARC team within and across the home visiting field that may be useful to home visiting administrators, data leads, and other early childhood program administrators. Resources are organized across six stages (envision, plan, generate or acquire, process and analyze, share, use, and reuse, preserve or discard) in keeping with an established research data framework.

Definition and Examples

- **Data Sharing:** the practice of providing partners with access to data that they can't access in their own systems.²
 - Example: To meet federal reporting requirements, a home visiting program provides a list of program participants to the state child welfare agency to obtain a de-identified rate of child maltreatment cases in the home visiting sample.
- **Data Integration:** a more complex type of data sharing that involves record linkage based on common data fields. These linked data are combined and de-identified to produce a separate file for analysis.²
 - Example: To inform a needs assessment and determine areas of higher concentrations of families with stressors, home visiting and birth records are linked at the child level to examine characteristics of families enrolled in home visiting programs in comparison to the county. This information was used to determine potential counties for program expansion or tailoring outreach activities to those populations.³
- **Data Interoperability:** the most complex type of data sharing that includes the automatic exchange of data between two systems with the ability to use that data once received.¹
 - Example: To streamline referrals, increase collaboration across service providers, and provide more continuous care, a home visiting program partners with a hospital and both home visitors and medical providers have access to program-relevant data in a shared data system.⁴

Methods

The HARC team compiled an initial list of resources to support data exchange by examining the following websites:

- [Office of Planning, Research, and Evaluation](#)
- [Maternal and Child Health Bureau](#)
- [Statewide Longitudinal Data Systems](#)
- [Center for IDEA Early Childhood Data Systems](#)
- [BUILD Initiative](#)
- [Early Childhood Data Collaborative](#)
- [Actionable Intelligence for Social Policy](#)

We also conducted a web search using the following terms: home visiting administrative data, home visiting linked data, home visiting integrated data, early childhood administrative data, early childhood linked data, data governance, and data destruction. The list was reviewed for content most useful to state home visiting and early childhood administrators and researchers as they plan for and use shared or integrated data. Resources were included if they: 1) addressed data linkage at the state level or the process of *facilitating* data exchange as a collaborative effort, 2) were adaptable for home visiting programs, and 3) used language applicable to the intended audience.

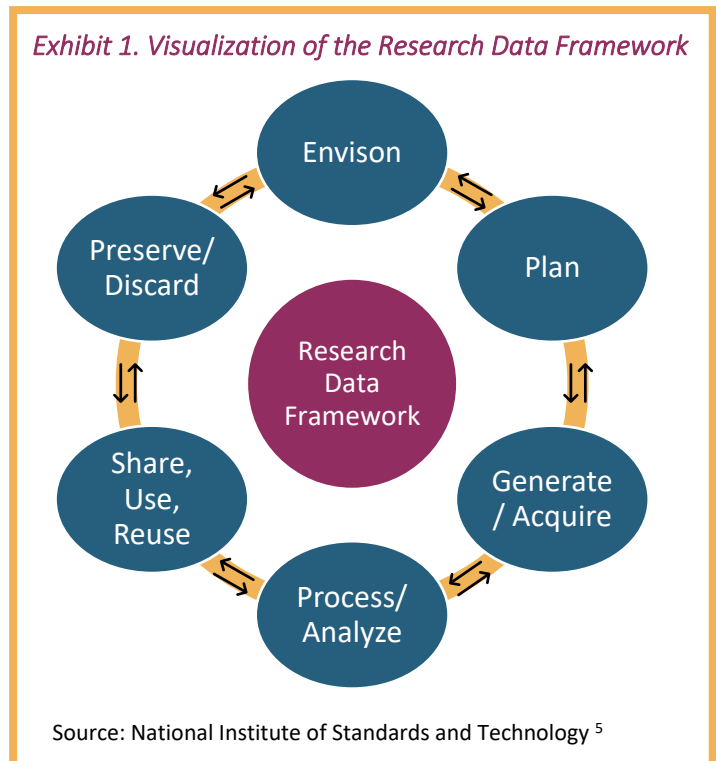
Research Data Framework

We used the Research Data Framework (RDaF) from the National Institute of Standards and Technology (NIST) ⁵ to organize the resources. The RDaF provides a strategy for managing data that recognizes research as a community-driven and cyclical process.

Its six stages (see Exhibit 1) can occur somewhat linearly or concurrently. Any stage can lead to another, and all may be revisited periodically.

The following pages present resources grouped by the six stages of the RDaF and further organized into substages for ease of review.

Click on each stage of the RDaF framework to the right to learn more about the stage and view selected resources.



RESOURCES

The **Envision** stage includes:

- Reviewing strategies and motivations of your data sharing and integration work.
- Making choices and decisions collaboratively and at a high level to inform the course of action that will achieve the goals.
- Building a supportive data culture, increasing buy-in, and seeking and sustaining funding.

Table 1. Envision

Format (length)	Description	Citation
Comprehensive Data Sharing Resources		
Toolkit (30 pages)	An overview of the data sharing and integration process including benefits, limitations, and risks, how to begin data sharing, and a selection of use cases. In-depth discussion and additional resources for data governance, legal considerations, data security, technical approaches, and developing a data model.	Actionable Intelligence for Social Policy. (2020). Introduction to Data Sharing and Integration . University of Pennsylvania.
Toolkit (26 pages)	An overview of the data sharing and integration process including project planning, interested party engagement, data governance, system design, data use, and sustainability.	Statewide Longitudinal Data System grant program state support team. (2021). Early Childhood Integrated Data Systems Toolkit . National Center for Education Statistics.
Toolkit (68 pages)	An overview of strategies to support sustainability through fostering demand, building staff capacity and partnerships, improving knowledge management and documentation, and securing funding.	Wiegand, E.R., Monahan, E.K., Geoghegan, R., Wavelet, M., Goerge, R.M. (2023). Strengthening analytics in government agencies: A toolkit for sustainable use . OPRE Report 2023-148. Washington, DC: Office of Planning, Research, and Evaluation, Administration for Children and Families, U.S. Department of Health and Human Services.
Buy-in & Data Culture		
Toolkit (webpages)	Information, guidance, and templates to help staff build data teams and support data culture at the state and local levels.	The Center for IDEA Early Childhood Data Systems. (2017) ^a . Data culture toolkit .
Podcast (23 minutes)	Benefits and strategies for engaging with university partners to support the use of early childhood data and build research to practice partnerships.	ECDDataWorks. (2022). Role of Research to Practice Partnerships in Using Early Childhood Data . University of Pennsylvania.

Format (length)	Description	Citation
Collaboration		
Brief (7 pages)	A step-by-step guide for engaging interested parties during the data integration process.	Kane, M., Lin, V.K. (2020). Engaging Stakeholders in Home Visiting Data Integration Efforts . Early Childhood Data Collaborative. Child Trends.
Podcast (19 minutes)	Discussion of the successes, challenges, and suggestions for creating early childhood integrated data teams and aligning organizational, human, and technical capacities across these teams.	ECDataWorks. (2022). Building the Right Team: ECIDS Teams, Infrastructure, and Composition . University of Pennsylvania.
Podcast (50 minutes)	Identifying partner roles in Early Childhood Integrated Data Systems (ECIDS) such as assigning a technical host, role assignments, sharing ownership, and including partner voice throughout the process.	ECDataWorks. (2021). Reevaluating the Positionality of ECIDS . University of Pennsylvania.
Article (8 pages)	Discussion of five challenges that occur when sharing data across agencies including: obtaining commitment from leadership, reaching agreement on decisions, setting up data sharing agreements, aligning data privacy and security requirements, and determining staff capacity. Includes an appendix of additional resources to support data coordination across agencies.	Maternal and Child Health Bureau. (2021). Coordinating Data Sharing Across Agencies: Strategies to Address Common Challenges . U.S. Department of Health and Human Services, Health Resources and Services Administration.
Crosswalk (Excel files, 24-page synthesis)	Includes a catalog, crosswalk, and synthesis of federal programs' elements including program eligibility, needs assessments, outcomes and performance measures, well-being goals and metrics, and equity goals and actions. This information can be used to identify areas of alignment that can be applied to data systems and better support data sharing.	Early Childhood Systems Collective Impact Project. (2022). ECSCIP: Catalog and Crosswalk . Office of the Assistant Secretary for Planning and Evaluation.
Funding		
Brief (8 pages)	Discussion of four funding strategies to support data integration activities, including allocating funds for data system planning, leveraging large data infrastructures, ensuring sufficient staffing to support data integration work, and identifying ongoing funding for analysis and use of data.	King, C., Perkins, V. (2020). Strategies for Financing the Integration of Home Visiting and Early Childhood Data Systems . Early Childhood Data Collaborative. Child Trends.

Format (length)	Description	Citation
Report (41 pages)	Overview of funding techniques and organizational strategies from five states and one county, as well as links to federal agency evaluation policies to inform funding decisions.	Womer, J., Stack, K. (2023). Blending and braiding funds: Opportunities to strengthen state and local data and evaluation capacity in human services . The Policy Lab, Brown University.
<p>^a Despite this resource being slightly older, it presents easily accessible, well-organized, and actionable ways of supporting and improving data culture within state and local teams.</p>		

The **Planning** stage includes:

- Developing policy questions and use case scenarios.
- Building a data governance strategy and determining a system model.
- Preparing and negotiating legal documents and planning for privacy, security, and consent.
- Planning and selecting technology, selecting data formats and storage solutions, and hiring personnel.
- Incorporating principles of diversity, equity, and inclusion throughout the process.

Table 2. Plan

Format (length)	Description	Citation
Framework (13 pages)	Best practices and guiding questions for developing high-quality integrated data systems through governance, legal agreements, technical tools, and staff capacity.	Actionable Intelligence for Social Policy. (n.d.). Quality Framework for Integrated Data Systems . University of Pennsylvania.
Developing Policy Questions or Use Case Scenarios		
Brief (6 pages)	Guidance for the development of policy questions using integrated home visiting data across home visiting and early childhood programs, and between home visiting and early childhood programs longitudinally.	Steber, K., King, C. (2019). Developing Policy Questions to Guide Integration of Home Visiting and Other Early Childhood Data . The Early Childhood Data Collaborative.
Brief (7 pages)	Presents a process to identify essential questions by identifying end users, key questions, sub-questions, data fields to inform those questions, where data are collected, potential changes needed for data collection, and linking data to answer those questions.	Cochenour, M., Porowski, S. (2013) ^b . Answering Key Questions with an Early Childhood Data System . Early Childhood Data Sharing Working Group, National Center for Education Statistics, Institute of Education Sciences.

Format (length)	Description	Citation
Brief (15 pages)	Presents opportunities for multi-generational research questions that can be answered with linked data across individuals, families, or households. Includes benefits, challenges, and use case examples.	Jenkins, D., Berkowitz, E., Burnett, TC, Culhane, D., Hawn Nelson, A., Katz, M., Smith, K., & Zanti, S. (2021). Expanding Mobility: The Power of Linked Administrative Data for Multi-Gen Analysis . Actionable Intelligence for Social Policy. University of Pennsylvania.
Brief (3 pages)	Infographic with a review of what questions can be answered with various data sources and two case studies demonstrating the process of identifying research questions with topics focusing on who is participating, what services are delivered, and how much service is received.	Brennan, E., Manno, M., Steimle, S. (2019). Using Data to Understand Your Program . OPRE Report 2019-90. Washington, DC: Office of Planning, Research, and Evaluation, Administration for Children and Families, U.S. Department of Health and Human Services.
Legal Considerations: Developing Legal Agreements ^c, Privacy, Security, and Consent		
Article (29 pages)	Frames key concepts related to consent, explores federal laws governing the sharing of administrative data, examines ethical implications of consent, and outlines the role of governance and consent frameworks to ensure ethical data use.	Kemp, D., Hawn Nelson, A., & Jenkins, D. (2023). Yes, No, Maybe? Legal & Ethical Considerations for Informed Consent in Data Sharing and Integration . Actionable Intelligence for Social Policy. University of Pennsylvania.
Brief (5 pages)	Three steps to determine when and how family consent is needed for integration of home visiting data.	Lin, V-K., Crowne, S. (2020). Steps for obtaining consent from stakeholders to share home visiting data . Early Childhood Data Collaborative. Child Trends.
Brief (6 pages)	Description of entities, laws, and regulations that ensure data privacy and security of home visiting data for integration. Includes questions to inform data privacy and security processes.	Lin, V-K., Crowne, S. (2020). Privacy and security considerations when integrating home visiting data . Early Childhood Data Collaborative. Child Trends.
Framework (39 pages)	Framework presenting steps to review relationships, develop a use case, create a data flow map, conduct the legal analysis, and establish and document agreements for sharing. Includes five use cases demonstrating the process.	Bernstein, J., Chrysler, D., Eckart, P. (2022). Pathways to yes: A legal framework for achieving data sharing for health, well-being, and equity . Data Across Sectors for Health. The Network for Public Health Law.
Report (54 pages)	Includes an overview of federal laws impacting data sharing for several potential data-contributing agencies. ^d	Office of Policy and Management. (2020). Legal issues in interagency data sharing . Report prepared pursuant to Public Act No. 19-153, Connecticut.

Format (length)	Description	Citation
Example MOUs	Collection of Data Sharing Agreements for Health and Healthcare and Education, including state agencies, providers, research intermediaries, non-profit agencies, universities, schools, and others.	National Neighborhood Indicators Partnership. (2018). Collection of Example Data-Sharing Agreements: Health + Healthcare & Education . Urban Institute.
Data Governance		
Brief (6 pages)	Overview of how a data governance body can support the integration of home visiting data in an ECIDS. Includes examples of state data governance structures and recommendations for how home visiting leaders can be involved in data governance.	Kane, M., King, C. (2020). Including home visiting programs in early childhood data governance bodies . Early Childhood Data Collaborative, Child Trends.
Article (14 pages)	Four questions to consider when establishing a governance process to determine whether and how to move forward at each stage of data integration: Is this legal? Is this ethical? Is this a good idea? How do we know (and who decides)?	Hawn Nelson, A. & Zanti, S. (2023). Four questions to guide decision-making for data sharing and integration . <i>International Journal of Population Data Science</i> , 8:4:02. doi:10.23889/ijpds.v8i4.2159
Brief (14 pages)	Detailed guide of data policies and processes throughout the data lifecycle. Includes a data policy and process self-assessment and action planning template.	Chatis, C. Gosa, K. (2019). Developing effective data policies and processes . Institute of Education Sciences.
Technology & Personnel		
Toolkit (8 pages + slides)	Toolkit to help evaluate new tools, define components of an integrated data infrastructure, and support planning efforts for updates. Includes information to build a vendor evaluation matrix, narrow down possible vendors, or inform an RFP process.	Actionable Intelligence for Social Policy and Asemio. (2022, February 1). Narrowing Technology for Integrated Data System (IDS) Initiatives . University of Pennsylvania.
Article (43 pages)	Provides key considerations in building and sustaining an integrated data system (e.g., staffing, data management, security, and privacy) and technology approaches that can be helpful in overcoming challenges with integrating data. Includes linked resources such as use cases, job descriptions, and technical solutions.	Actionable Intelligence for Social Policy, MetroLab Network, National Neighborhood Indicators Project. (2018). Technology for civic data integration . University of Pennsylvania.

Format (length)	Description	Citation
Brief (5 pages)	Discusses technology options for storing home visiting data at the state and local levels as well as recommendations for navigating these systems when integrating home visiting data with other early childhood data.	Epstein Richards, D. (2020). Navigating data systems when integrating home visiting data . The Early Childhood Data Collaborative, Child Trends.
Data System Model Planning		
Brief (7 pages)	Provides an overview of three models (centralized, federated, hybrid) including each models' strengths, weaknesses, and structure as well as tips for having a successful ECIDS conversation in your state.	Duarte, S., Sellers, J., Cochenour, M. (n.d.). Which ECIDS system model is best for our State ECIDS? Institute of Education Sciences, Statewide Longitudinal Data Systems.
Article (35 pages)	Overview of three data integration approaches (need-based, periodic, and continuous) as well as detailed information on the "how-to" of data architecture, data linkage, data retrieval, available technologies and tools, and cost considerations.	Kumar, P. (2017) ^e . An overview of architectures and techniques for Integrated Data Systems (IDS) implementation . Children's Data Network.
Diversity, Equity, and Inclusion		
Toolkit (76 pages)	Modules to direct the centering of racial equity throughout the data lifecycle with application to integrated data systems using a framework to "normalize, organize, and operationalize" at each step of the process.	Hawn Nelson, A., Jenkins, D., Zanti, S., Katz, M., Berkowitz, E., Burnett, T.C., Culhane, D. (2020). A toolkit for centering racial equity throughout data integration . Actionable Intelligence for Social Policy. University of Pennsylvania.
Brief (4 pages)	Highlights North Dakota's work to include family voice as an engaged party while developing their state's ECIDS strategic plan, as well as brief descriptions of family engagement work in California, Florida, and Minnesota.	Morrison, H., Reeve, A. (2022). Empower families with data . Office of Early Childhood Development, Administration for Children & Families.
<p>^b Despite this document being slightly older, it presents a process that is still highly relevant and easy to use to build a list of essential questions that can be answered by statewide data systems.</p> <p>^c Memorandum of Understanding, Data Sharing Agreement/Data Use Agreement</p> <p>^d This document is produced by the state of Connecticut and includes some state-specific information. In addition, some laws may change and should be checked for updates before any decisions are made. However, the document provides a good overview of unique considerations for each type of program data as well as examples of use cases from the state.</p> <p>^e Despite this document being slightly older, it includes a useful overview of data integration approaches in a way that is relatively accessible to non-technical personnel. In addition, it provides clear advantages and disadvantages to different approaches and an overview of techniques that should remain relevant even as technologies evolve.</p>		

The **Acquire** stage includes:

- Establishing standards for data exchange.
- Obtaining data from engaged parties and relevant programs.
- Conducting an inventory of data.

Table 3. Acquire

Format (length)	Description	Citation
Establishing Data Exchange Standards		
Toolkit (25 pages)	Includes steps needed to establish a common set of definitions and the structure and format of key variables as the foundation for sharing home visiting data. This resource presents information with the goal of achieving interoperability. However, establishing data exchange standards is useful across all types of data exchange activities. Steps include developing organizational capacity, engaging interested parties, establishing/enhancing data governance, addressing data privacy and security, aligning data, and accounting for the state’s contextual factors.	Health Resources and Services Administration. (2020). Implementing data exchange standards: A toolkit for MIECHV awardees . U.S. Department of Health and Human Services.
Data Inventory		
Brief (7 pages)	Discussion of steps to identify data that can be linked with other early childhood programs and provides a template to conduct an inventory of home visiting data.	Bui Lin, V.K. (2019). Identifying home visiting data to integrate with other early childhood data . Early Childhood Data Collaborative, Child Trends.
Module (7 pages)	A module including a guide to data mapping and a data map template.	Tribal Evaluation Institute. (2018). Data system improvement toolkit: Module 2 documenting and improving data system processes .
Toolkit (26 pages)	Includes steps to building a data inventory including planning, determining data attributes to collect, and populating the inventory. Also includes a template of example metadata.	Open Data Institute, CABI. (2021). Data sharing toolkit: How to create a data inventory . Gates Open Research 5:56.

The **Process or Analyze** stage includes:

- Intake and processing of administrative data to make it usable to answer policy and program questions.
- Linking and analyzing administrative data.

This stage includes significant input from technical personnel and relies heavily on the planning stage, especially in relation to the inclusion of DEI principles.

Table 4. Process or Analyze

Format (length)	Description	Citation
Data Linkage		
Brief (7 pages)	Overview of technical solutions and processes for linking cross-agency data. Includes case studies with a description of infrastructure, matching process, assigning unique identifiers, and governance.	Gosa, K., Sellers, J., Fergus, M., Murphy, C., Norris, T., Petrosky, C. (2020). Interagency data linking and common identifiers . Institute of Education Sciences.
Brief (5 pages)	Presents options for integrating home visiting data by geographic location, funding source, and model with another early childhood program or with specific data elements to answer a specific research or policy question.	Steber, K., Epstein Richards, D. (2019). One step at a time: The benefits of an incremental approach to the integration of home visiting and other early childhood data . Early Childhood Data Collaborative, Child Trends.
Analysis		
Toolkit (68 pages)	A detailed overview of enhancing agency data analysis through recruiting, retaining, and training analytic staff, building strong external partnerships to increase analytic capacity, fostering a strong internal data culture, improving documentation and management of institutional knowledge, and securing funding for analytic efforts.	Wiegand, E.R., Monahan, E.K., Goeghegan, R., Wavelet, M., Goerge, R.M. (2023). Strengthening analytics in government agencies: A toolkit for sustainable data use . OPRE Report 2023-148. Washington, DC: Office of Planning, Research, and Evaluation, Administration for Children and Families, U.S. Department of Health and Human Services.
Brief (3 pages)	Presents tips for the creation of an analysis plan, understanding data quality and collection, and understanding and explaining data context to various audiences.	Bloom-Weltman, J., Coffey, M. (2018). SLDS data analysis tip sheet . Institute for Education Sciences.

The **Share, Use, and Reuse** stage includes:

- Dissemination of findings for use and reuse to answer relevant policy, program, and research questions.

Establishing strong feedback loops for the interpretation and dissemination of findings supports this stage.

Table 5. Share, Use, and Reuse

Format (length)	Description	Citation
Sharing Findings		
Toolkit (webpages)	This toolkit provides an in-depth introduction to data visualization. It covers topics like accessibility, use of color, and equity. It also presents types of visualizations and ways to enhance engagement through animations and interactivity.	Nelson, R., Ortiz, N., Jackson, L. (2022). Data visualization toolkit . The Center for IDEA Early Childhood Data Systems.
Brief (7 pages)	Description of seven steps to produce a series of data visualizations that are focused on answering a specific question by inviting interested parties into the process of producing a data story. This process can help break down institutional silos, build participant technical expertise, and expand dissemination of the product.	Gold, A., Hendey, L. (2017). Seven steps to creating better data stories . National Neighborhood Indicators Partnership.
Brief (webpage)	This resource presents steps to create a feedback loop, discussion of positive and negative feedback loops, the benefits of feedback loops, and best practices.	Listen for Good. (2022). What is a feedback loop: Creating feedback from nonprofit supporters .
Brief (webpage)	This resource discusses examples of feedback loops to support community engagement. This is an important equity consideration and provides a way to incorporate feedback from data users and contributors throughout the data-sharing process.	Jackson, K. T., Burgess, S., Toms, F., & Cuthbertson, E. L. (2018). How to use feedback loops to engage your community . Community Psychology.

The **Preserve or Discard** stage:

- Delineates how the data are managed, archived, or disposed of in accordance with governance guidelines established in the planning stage.

Table 6. Preserve or Discard

Format (length)	Description	Citation
Data Disposition		
Brief (10 pages)	An overview of methods for disposing of electronic data and how those methods relate to legal requirements and best practices for protecting data.	Privacy Technical Assistance Center. (2019). Best practices for data destruction . U.S. Department of Education.
Report (64 pages)	A guide to making sanitization decisions based on data types and privacy level.	Kissel, R., Regenscheid, A., Scholl, M., Stine, K. (2014). Guidelines for media sanitization . National Institute of Standards and Technology (NIST), SP 800-88 Rev. 1
Brief (12 pages)	Highlights current practices for publishing research data that is collected and prepared as part of a federal project and making data available for reuse.	Gordon, H., O’Callahan, C., Hunter, K., Inanc, H., Grider, M., Zaveri, H. (2023). Guide to publishing research data for secondary analysis . ACF Evidence Capacity Support. OPRE Report #2023-227.

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