



COORDINATING DATA SHARING ACROSS AGENCIES

Strategies to Address Common Challenges

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INTRODUCTION

In 2018, the Maternal, Infant, and Early Childhood Home Visiting (MIECHV) Program was extended through the Bipartisan Budget Act of 2018 (Pub. L. 115-123) (BBA). Part of the legislation directed MIECHV awardees to establish standards for the exchange of data between home visiting and other state programs and with federal agencies. Data interoperability occurs when there is a mechanism by which data are shared automatically between two or more sources or programs without needing human intervention. Sharing data across agencies allows awardees and their state partners to increase the efficiency of data collection to support service coordination and answer critical questions about the children and families they serve. For example, when interoperable data are available, state administrators can answer questions about the number, characteristics, and location of children and families served across multiple programs. However, coordinating data sharing efforts between state agencies can sometimes be challenging, especially if there is not already an established data sharing agreement or process in place.

This resource identifies five common challenges that occur when sharing data across agencies to make data interoperable. For each identified challenge, there are strategies that MIECHV awardees can use for articulating data sharing goals, obtaining commitment from agency partners, developing a data sharing agreement, and establishing processes to facilitate the security and use of shared data. Awardees can use these strategies and resources to conduct ongoing outreach and facilitate conversations to coordinate data sharing across agencies.

CHALLENGES WHEN COORDINATING DATA SHARING WITH OTHER AGENCIES

Awardees often collect a wealth of data about the families they serve but may still lack information about other services families may need, are receiving while enrolled in home visiting, or could benefit from during or after leaving the program. One way to learn more about the children and families awardees serve, without needing to collect more data, is to share data with other agencies serving the same families. Establishing a process with other state agencies to make data interoperable can help fill current knowledge gaps about access to services, improve coordination with other agencies that offer additional services, and increase the use of data to improve program outcomes. However, when coordinating this process across agencies, awardees may encounter issues or barriers that slow progress. The following section describes common challenges awardees may encounter when working to make data interoperable, and recommended strategies for overcoming these issues to increase opportunities for data sharing.

CHALLENGE #1: OBTAINING COMMITMENT FROM LEADERSHIP

Securing commitment from and across agency leadership to dedicate staff time and resources to making data interoperable can be a challenge. Agency leadership may express reservations about sharing data that become a barrier to coordination, particularly when sharing data for the first time. These reservations may be related to uncertainty about the relevance of data sharing to agency goals, lack of resources, apprehensions about data privacy, or concerns about how data will be used. Awardees will first want to ensure commitment from their own agency. Commitment from the awardee's agency will signal confidence in the value of interoperability and data sharing plans to other agency leadership

considering participation. To secure commitment from agency leadership, MIECHV awardees can use the following strategies:

- ▲ **Clearly articulate goals and rationale for data sharing in a written statement.** Before reaching out to an external agency, meet internally to develop a written statement that clearly outlines reasons for making data interoperable across agencies and planned uses of the data. Having a clear sense of the scope and purpose of data interoperability requests will help to build trust with a potential partner. Often, there are uncertainties associated with data sharing due to the lack of clarity on exactly how an agency's data will be used or shared, and how it will be protected. It is important to note that not all data programs collect are permissible or appropriate to share with outside agencies. For this reason, it is important to clearly state what type of data are needed, why they are of interest, and how they will be used by participating agencies. With a clear plan and rationale for establishing a data sharing partnership, barriers caused by lack of transparency and trust can be addressed early.
- ▲ **Set up an initial meeting to discuss data sharing goals.** Setting up an initial meeting creates an opportunity to articulate how the establishment of a data sharing relationship is mutually beneficial, and to learn about any concerns from the partner agency. Concerns may include costs associated with making data interoperable, staff capacity to participate, and potential violations of privacy laws. Awardees should identify internal staff or engage external partners with expertise in these areas to respond to these types of questions, and to demonstrate awareness of potential challenges and plans to address them (see Challenge #5 for details on building staff capacity). During this meeting, it is also important to ask partners what they hope to achieve through this collaboration across agencies, so that this work is viewed as meeting everyone's needs. Communications with partner agencies can occur through one-on-one conversations or as part of a broader stakeholder committee discussion, cross-departmental meeting, or governing board session. During these conversations, awardees should be prepared to share their statement describing the data sharing goals and disclose the names of any other agencies that may be involved. These meetings are also an opportunity to meet with agency representatives separately and allow them flexibility to include opinions of additional staff, as needed.
- ▲ **Prioritize mutually beneficial data sharing goals.** During meetings with agency partners, it is important to prioritize goals that would be viewed as mutually beneficial for agencies contributing data. Mutually beneficial goals are uses of shared data that are helpful for all programs contributing data. One way to do this is to develop shared use cases for the data. A use case is a detailed description of an instance when data sharing is needed for a specific purpose, and includes what data are needed, and how those data would be shared and used. For example, an awardee may want to use interoperable data to understand the effectiveness of specific programs. It is important to articulate how the uses of these data will benefit both partners who are sharing data as well as those who are receiving data. A use case could be developed which describes the use of interoperable data to track follow-up and receipt of services based on a referral from a home visitor. These data would be used to assess the referral process and inform training and policies within both organizations or agencies to improve coordination and receipt of additional services. Findings could then be shared back with partner organizations who contributed data to inform their internal efforts to support receipt of services for families.
- ▲ **Be open to feedback from partners.** In discussions with partners, awardees should be open to feedback and willing to include additional goals important to external partners. The initial written statement of data sharing goals should be viewed as a starting point that will be revised as awardees gain more information from potential partners. Goals may shrink, shift, or expand based on conversations. For example, an awardee may learn through conversations with external

partners that a current policy or regulation prohibits the sharing of certain data. In contrast, awardees may learn that data thought to be unavailable can be accessed if a data sharing agreement is put in place. Further, awardees may learn that other agencies are interested in using home visiting data to meet additional needs and choose to add new goals to the data sharing process. For these reasons, it is important to use conversations as an opportunity to revise and clarify the stated goals of the partnership and be flexible in making changes to those goals as the need arises.

CHALLENGE #2: REACHING AGREEMENT ON DECISIONS

After agencies have committed to developing a plan for coordinating data, all participating agencies will need to reach consensus on how best to move forward and establish a decision-making process. The process for reaching consensus will vary depending on the number of agencies and stakeholders that need to be involved in decision-making. It is recommended to establish an implementation team that is assigned to work on making data interoperable.¹ To reach agreement on data sharing goals, MIECHV awardees can use the following strategies:

- ▲ **Identify agency representatives to facilitate decision-making.** Before developing a process for finalizing data sharing goals, each agency contributing data should identify a representative with decision-making powers. For example, this person should have the authority to approve changes to data exchange standards to make data interoperable and share data with external agencies. Another representative should serve as a main contact for ongoing communication and be responsible for coordinating feedback from their agency's program, legal, and information technology staff to respond to questions and reconcile any conflicting feedback. This person should have knowledge about data management and their agency's capacity to share data.
- ▲ **Develop a transparent process for decision-making.** A decision-making process should address how issues are raised for consideration, reviewed, and resolved. The process would also determine the composition of a decision-making body, and outline how public input is incorporated. For example, a governance body which typically consists of agency leadership and experts can serve a decision-making function in states. It will be important to make decisions about circumstances for data sharing, how the data are used, and how to ensure adherence to state and federal regulations. For example, North Carolina and Utah each have established Early Childhood Integrated Data System (ECIDS) governance bodies that have authority to make decisions about how data are collected, shared, and used within their ECIDS. Representatives from agencies/programs contributing data have voting rights and clear decision-making processes described in a charter or governance manual.¹

CHALLENGE #3: SETTING UP A DATA SHARING AGREEMENT

Setting up a data sharing agreement can be a lengthy process. A data sharing agreement is a written document specifying under what conditions data will be shared and how data will be used between agencies.ⁱⁱ Having clear guidance and agreement about what data are needed for a data sharing and requirements for making data interoperable helps reduce delays. Awardees can work with agency partners and legal staff to determine what type of agreement is needed to share data. To set up a data sharing agreement, MIECHV awardees can use the following strategies:

- ▲ **Identify use cases based on data sharing goals.** To develop a data sharing agreement, partner

¹ For more information on the roles and responsibilities of an Implementation Team, please see [Implementing data exchange standards: A toolkit for MIECHV awardees](#).

agencies and stakeholders can translate mutually beneficial data sharing goals into specific use cases. These use cases then guide decisions around which data elements need to be part of a data interoperability process. It is important to note that not all data from a particular program or service need to be included when making data interoperable; instead, it is often just a subset of data that need to be shared. For example, if the overarching goal is to assess the effectiveness of agency referrals, partners would next identify the specific research questions to address in support of this goal. Specifically, how many families that were issued referrals received additional services based on those referrals? There will likely be several questions developed for each goal.

- ▲ **Identify data available to address use cases.** Use cases will help determine the type of data and necessary data sources. For example, a use case developed to answer questions about which combination of services families are enrolled in might require data from multiple agency databases (e.g., Medicaid, Supplemental Nutrition Assistance Program, Temporary Assistance for Needy Families). Agency staff who work closely with the data from each program of interest can then help the team learn more about how the data are collected and stored and who has authority over its management.ⁱⁱⁱ After identifying the use cases, data sources, and data elements, awardees can document or map programs and databases within agencies.
- ▲ **Determine agency roles and expectations.** Amongst the implementation team and partners, it is important to clearly articulate each partner agency's roles and responsibilities to make sure expectations are known and can be met. Specify which agencies will be contributing data, participating in committees, or responsible for making data interoperable. Expectations may include using common definitions, data formats, and transmission processes to support data interoperability. For example, to meet data security requirements partners may need to de-identify data and transmit it using a secure data transmission process. Data privacy and security requirements regarding the data destruction, de-identification, and breaches should also be specified.
- ▲ **Consult legal counsel.** For each agency, involve legal staff and those in charge of contracts early to inform the data sharing process and development of a data sharing agreement. Legal staff can help awardees draft an agreement and identify legal considerations during the planning process. They can also help respond to questions and identify any legal restrictions to data sharing early.
- ▲ **Use existing data sharing agreements as a template when applicable.** Using an existing data sharing template can help jump start the development of an agreement. Data sharing agreements can take different forms. For example, a data use agreement could include legally binding terms, while a memorandum of understanding outlines responsibilities and roles that are not legally binding. Awardees should work with agency leadership, legal counsel, and contracts staff to determine if the agency has experience developing data sharing agreements and examples that would be relevant and could be used as a starting point. A benefit of starting with an existing template is that the agreement reflects language previously reviewed by agency legal and program staff which may help reduce the amount revisions by state agency partners. The type of agreement developed will depend on the agency's data use requirements.

CHALLENGE #4: ALIGNMENT OF DATA PRIVACY AND SECURITY REQUIREMENTS

Efforts to coordinate data across agencies can be challenging when different data privacy and security standards requirements are not aligned.^{iv} Data privacy and security policies regulate how data are safeguarded, used, and shared. These policies address issues of data ownership and when consent for data sharing is required and by whom. Before moving forward with a data sharing agreement, awardees will need to understand the laws and regulations governing the management of data they are interested

in sharing. To align data privacy and security requirements, MIECHV awardees can use the following strategies:

- ▲ **Identify data sharing processes that meet the highest level of privacy and security requirements.** Because data are governed by multiple entities, laws, and regulations, there may be a variety of data privacy and security standards that need to be met when making data interoperable. Determine which federal, state, local, and program requirements apply to data sharing goals. For example, the Family Education Rights and Privacy Act (FERPA) is applicable to educational entities that receive funds from the U.S. Department of Education. Entities that transmit protected health information must adhere to processes for sharing data specified through the Health Insurance Portability and Accountability Act (HIPAA). Prior to sharing data, partners must identify all relevant federal, state, local, and program requirements. To identify and interpret these requirements, awardees may want to consult with their state or agency legal counsel, chief information officer, or HIPAA compliance officer for guidance. One strategy to ensure the data sharing process meets all privacy and security requirements is to apply the strictest regulations across all data regardless of individual variations in regulations across data sources. That way, when making data interoperable, agencies are abiding to that strictest regulation and can confirm that all requirements are met.
- ▲ **Establish or join a governance body with representatives from external partners to manage data privacy and security requirements.** One function of a data governance body is to facilitate ongoing cross-agency data sharing efforts by overseeing the alignment of data privacy and security guidelines.^v Data governance bodies have the responsibility and authority to determine the appropriate uses, confidentiality, and security of shared data. Typically, governance membership consists of partner agencies contributing data. This allows agency partners to have input on decisions about how their data are used. If there is not an existing governance body, then an awardee could propose to establish one. If there is an existing governance structure, it will be important to have representatives from home visiting and other agency partners. The awardee can also involve experts such as a chief data officer, a HIPAA compliance officer, a contracts person, or legal counsel to provide guidance to governance body members who make decisions.
- ▲ **Examine consent policies for sharing data.** For each use case, it will be essential to determine when family consent is required to access and use the data requested. Not all uses of data require consent, and in some cases, families may have already signed a consent form that covers a particular use case of data sharing. However, before engaging in any data sharing process with child or family data, awardees should review any data consent policies developed by the model, local implementing agency (LIA), state or federal government. Review of consent policies should examine if there are restrictions on how and when data can be shared and with what entities they are permitted to be shared. If these policies conflict with a data sharing goal or use case, then the governance body will need to work across partners to determine what revisions or additional consent process needs to be in place before data can be shared. Please see the Appendix for additional resources on data security and consent processes when sharing home visiting data.

CHALLENGE #5: STAFF CAPACITY TO MAKE DATA INTEROPERABLE

Awardees will also need to determine whether partner agencies have the internal capacity to make data interoperable. Agency capacity may vary and depend on staff expertise, funding, or technology available to meet interoperability requirements. To increase capacity to make data interoperable, MIECHV awardees can use the following strategies:

- ▲ **Determine capacity of partner agencies to support data interoperability.** Do not assume all agencies have similar levels of resources available. Ask and assess if agencies contributing data have necessary program and technological staff to implement data exchange standards and make data interoperable. For example, some agencies may not have expertise or resources needed to transform data into interoperable formats that meet cross-agency security requirements. An agency's capacity could then become a barrier to participation in the data sharing partnership. It will be important to conduct an assessment of each agency's capabilities to perform tasks needed to make data interoperable. Use information from this assessment to identify additional resources or partners needed. The assessment can help inform decisions about additional funding and assignment of roles across agencies. For example, an agency with greater staff capacity or expertise may be well situated to transform data to make it interoperable for multiple agencies. Or, additional funding may be needed to support agencies' capacity for making their data interoperable. Funding may also be needed for staff time or technology upgrades to meet new requirements for data sharing.
- ▲ **Establish an internal or external research partnership to make data interoperable.**^{vi} Establishing research partnerships with staff internal to agency partners or researchers from external organizations are strategies used to collect and share data when there is a lack of expertise or capacity within the agencies sharing information. Researchers offer specific expertise meeting data security standards for handling data and compiling data from multiple data sources to answer policy and research questions. Internal partnerships involve the use of program and research staff within a state agency. For example, an education research unit housed within the Department of Education that manages data generated across programs might be able to also serve as the lead for making data interoperable with another agency such as a Department of Health. Alternatively, an external partnership involves the use of an independent organization such as a university or non-government research organization. External research partners typically do not contribute data. They instead serve as an intermediary to coordinate the data sharing process and may also aggregate and analyze shared data for the agencies. For example, Iowa State University (ISU) serves as a research partner to integrate data across the Iowa state Departments of Public Health, Education, Human Services, Human Rights, and Workforce Development. ISU's expertise in data security requirements and management are leveraged to make data interoperable across departments.^{vii} Regardless of the type of partnership, strong relationships between program and research staff can be beneficial because of the expertise researchers have using data to answer policy and research questions. The decision to use an internal or external research partner should be discussed and agreed upon by all participating agencies.

CONCLUSION

Data sharing across agencies allows MIECHV awardees and their state partners to answer critical questions about the children and families they serve. Sharing of data across agencies can also reduce burden and increase the efficiency of data collection to support service coordination. However, establishing a process or agreement to allow for data sharing can be challenging. These strategies can be used to help address challenges as they arise and facilitate conversations to ensure successful data sharing across agencies.

APPENDIX: RESOURCES TO SUPPORT DATA COORDINATION ACROSS AGENCIES

1. [Implementing Data Exchange Standards: A Toolkit for MIECHV Awardees](#): This resource provides guidance on implementing data standard to increase the interoperability of home visiting data with other agencies.
2. [Developing Policy Questions to Guide Integration of Home Visiting and Other Early Childhood Data](#): This resource provides examples of policy questions that can be answered when data is shared across home visiting programs and other early childhood programs.
3. [Data Sharing Worksheet](#): This worksheet walks the user through answering questions needed to clarify goals and information to develop a data sharing agreement.
4. [Data Direction 4: Building a Data Sharing Partnership with Other Organizations](#): This resource provides a scenario and potential actions steps to develop a data sharing partnership.
5. [Engaging Stakeholders in Home Visiting Data Integration Efforts](#): This resource outlines strategies to engage stakeholders when sharing home visiting data with other programs.
6. [Identifying Home Visiting Data to Integrate with Other Early Childhood Data](#): This resource provides guidance on identifying and mapping home visiting data sources for data sharing purposes. A [sample data inventory worksheet](#) is available for users to enter information about their own state home visiting data sources.
7. [Privacy and Security Considerations When Integrating Home Visiting Data](#): This resource describes the difference types of privacy and security policies governing the sharing of home visiting data.
8. [Steps for Obtaining Consent from Stakeholders to Share Home Visiting Data](#): The resource outlines steps to determine when and how consent is needed when sharing home visiting data with other agencies.
9. [Including Home Visiting Programs in Early Childhood Data Governance Bodies](#): This resource provides examples and recommendations for including home visiting programs in early childhood governance structures.
10. [Guidelines for Developing Data Sharing Agreements to Use State Administrative Data for Early Care and Education Research](#): This resource provides guidance on developing a data sharing agreement for research purposes and outlines key components to include in a data sharing agreement. Sample data sharing agreements are included.
11. [Opportunities through State Agency Research Partnerships for Using Administrative Data to Support Early Care and Education](#): This resource describes types of research partnerships involving state agencies. Examples from Georgia, South Carolina, and Oregon are highlighted.

ⁱ Kane, M. & King, C. (2020). [Including home visiting programs in early childhood data governance bodies](#). MD: Child Trends.

ⁱⁱ Shaw, S.H., Lin, V., & Maxwell, K. L. (2018). [Guidelines for developing data sharing agreements to use state administrative data for early care and education research](#). OPRE Research Brief #2018-67. Office of Planning, Research and Evaluation, Administration for Children and Families, U.S. Department of Health and Human Services.

ⁱⁱⁱ Lin, V. (2019). [Identifying home visiting data to integrate with other early childhood data](#). Bethesda, MD: Child Trends.

^{iv} Lin, V. & Crowne, S. (2020). [Privacy and security considerations when integrating home visiting data](#). Bethesda, MD: Child Trends.

^v Kane, M. & King, C. (2020). [Including home visiting programs in early childhood data governance bodies](#). Bethesda, MD: Child Trends.

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- ^{vi} Lin, V., King, C., Maxwell, K., & Shaw, S. (2018). [*Opportunities through state agency research partnerships for using administrative data to support early care and education*](#). OPRE Research Brief # 2018-53. Office of Planning, Research and Evaluation, Administration for Children and Families, U.S. Department of Health and Human Services.
- ^{vii} Rouse, H., Dorius, C., Bruning, J., & Horras, J. (2020). *Data in action: A state-university partnership in evidence-based home visiting* [PowerPoint slides]. HRSA CoP on Security and Consent Considerations Webinar.