

Developing Data Exchange Standards for MIECHV Home Visiting Programs

Summary of Discussions from Five Regional
Listening Sessions held June-July 2019

OPRE Report #2020-127
September 2020



Developing Data Exchange Standards for MIECHV Home Visiting Programs: Summary of Discussions from Five Regional Listening Sessions held June-July 2019

OPRE Report #2020-127

September 2020

SUBMITTED TO

Nancy Geyelin Margie, Project Officer
Office of Planning, Research, and Evaluation
Administration for Children and Families
U.S. Department of Health and Human Services

Heather Swope Pinaud and Kyle Peplinski
Maternal and Child Health Bureau
Health Resources and Services Administration
U.S. Department of Health and Human Services

Contract Number/Subcontract Number: HHSP233201500071I/18JJSK0271

SUBMITTED BY

Ivy Pool, Paul Wormeli, and Daniel Stein
Stewards of Change Institute
100 Centershore Road
Centerport, NY 11721

This report is in the public domain. Permission to reproduce is not necessary. Suggested citation: Pool, Ivy, Paul Wormeli, and Daniel Stein. 2020. *Developing Data Exchange Standards for MIECHV Home Visiting Programs: Summary of Discussions from Five Regional Listening Sessions held June-July 2019*. OPRE Report #2020-127. Washington, DC: Office of Planning, Research, and Evaluation, Administration for Children and Families, U.S. Department of Health and Human Services.

DISCLAIMER

The views expressed in this publication do not necessarily reflect the views or policies of the Office of Planning, Research, and Evaluation, the Administration for Children and Families, or the U.S. Department of Health and Human Services.

This report and other reports sponsored by the Office of Planning, Research, and Evaluation are available at www.acf.hhs.gov/opre.



Follow OPRE on
Twitter
[@OPRE_ACF](https://twitter.com/OPRE_ACF)



[Sign-up for the OPRE Newsletter](#)



Like OPRE on Facebook
facebook.com/OPRE.ACF



Follow OPRE on Instagram
[@opre_acf](https://www.instagram.com/opre_acf)



Stewards of Change
INSTITUTE

Contents

Overview	1
Introduction	4
Methodology.....	5
Overview of Current State of State Data Sharing and Interoperability.....	5
Summary of Feedback on Potential Data Sharing Scenarios.....	7
1. REFERRALS	11
2. OUTCOMES AND LONGITUDINAL DATA	14
3. PROGRAM AND ADMINISTRATIVE DATA.....	17
4. SCREENING.....	19
Foundational Projects	21
Establish a Governance Process.....	21
Create a Policy and Legal Framework	23
Managing the consent process.....	23
Sample or model MOUs and/or other data sharing agreements	23
Explore Technology Solutions	23
Master Client Index	24
Information Safeguarding.....	24
Role-Based Access Controls.....	25
Information Systems Architecture	25
Establish a Funding Source.....	26
Create a Minimum Data Set.....	26
Conclusions	27
APPENDIX A: Agenda from MIECHV Data Exchange Standards Regional Listening Sessions.....	28
APPENDIX B: List of Attendees from MIECHV Data Exchange Standards Regional Listening Sessions.....	29
APPENDIX C: Potential Use Cases for Data Exchange Standards for MIECHV Home Visiting Programs (<i>Draft from Regional Listening Sessions</i>).....	36

Overview

The Maternal, Infant, and Early Childhood Home Visiting (MIECHV) Program, administered by the Health Resources and Services Administration (HRSA) in collaboration with the Administration for Children and Families (ACF), supports voluntary, evidence-based home visiting services for at-risk pregnant women and parents with young children up to kindergarten entry. In February 2018, the MIECHV Program was allocated \$400 million per year through fiscal year (FY) 2022 through the Bipartisan Budget Act of 2018 (BBA). The BBA also provided new authority to the MIECHV program to designate data exchange standards for information required to be electronically exchanged between the MIECHV state/territory agency and other agencies within the state/territory.

In order to determine state/territory and local program views regarding the data exchange standards that would be helpful in improving interoperability and information sharing between state/territory agencies, HRSA and ACF conducted five (5) regional listening sessions over June and July 2019. The purpose of these listening sessions was to engage the home visiting field in a conversation about how data exchange standards can help achieve long-standing goals of state/territory and local programs, such as better integration of data from home visiting programs with broader early childhood strategies and programs, improved interoperability among service delivery partners, and reduced data collection and reporting burdens. Listening session attendees included MIECHV state/territory administrators, representatives from state/territory agencies they partner with, staff from local home visiting programs, and representatives from home visiting models. The following report is a summary of the input from the field gathered at the listening sessions.

Key Findings and Highlights

At each meeting, attendees shared what data exchange and interoperability efforts they were currently involved in. Overall:

- More than half of the states/territories represented at the listening sessions reported being at the very beginning of thinking about how to exchange data, and many noted that they do not have any formal data sharing agreements in place. The one exception to this general observation is for the MIECHV annual reporting requirement related to child maltreatment data.
- The agency the MIECHV Program is housed in at the state/territory level impacts the Program's level of integration with related agencies.
- The most common data integration project at the state/territory level is the Early Childhood Integrated Data Systems (ECIDS). A few states/territories also talked about pilot programs to access health information, and some states/territories discussed

initiatives to create a Master Client Index (MCI) to enable merging records by leveraging a centralized set of demographic data.

- Preschool Development and Race-to-the-Top grants have been an important source of funding for data exchange efforts for many states. In addition, a legislative or political mandate can be a powerful catalyst for information sharing.
- While there were different interpretations among states/territories as to what data sharing requires consent, there was a consistent theme around the need to inform clients and gain their consent prior to sharing data.

In addition, attendees discussed and prioritized scenarios in which they would find it useful to have data exchange standards:

1. **Referrals**: Home visitors' referrals of children and families to other health and human services providers, and other service providers' referrals of children and families to the home visiting programs.
2. **Outcomes and Longitudinal Data**: The measurement of common outcomes across home visiting programs to support longitudinal studies of program effectiveness and value.
3. **Program and Administrative Data**: Standards for defining how home visitors can gain access to data repositories in other health and human service agencies that will help the home visitor fully understand the needs of the child and family and improve services accordingly.
4. **Screening**: Standards for exchanging screening data previously recorded for children and families who are clients of home visitors with other providers that collect and/or could benefit from knowing the results of the screening measures.

Methods

At the beginning of each meeting, state/territory representatives were asked to provide an overview of the current state of data sharing in their respective state/territory. Specifically:

- How does your state/territory currently share data as it relates to your MIECHV Program?
- What structures or systems are in place to support data sharing in your state/territory (e.g., integrated data systems, preschool development grants, MOUs, data governance bodies, etc.)?
- Briefly describe any data sharing agreements you have in place.

The second key objective of the listening sessions was to understand what standards the states and territories would find helpful in promoting information sharing across programs and agencies within their state/territory. A roundtable of data exchange and home visiting experts

was convened in March 2019 and identified an initial set of twenty (20) data sharing scenarios that became a starting point for the discussions at the regional meetings. Regional meeting participants were then presented with these scenarios, and were asked to prioritize among these and to select 3-4 scenarios for further exploration, as well as suggest additional data sharing scenarios that would be helpful.

Glossary

ACF: Administration for Children and Families

HRSA: Health Resources and Services Administration

MIECHV: Maternal, Infant, and Early Childhood Home Visiting Program

Introduction

The Maternal, Infant, and Early Childhood Home Visiting (MIECHV) Program supports voluntary, evidence-based home visiting services for at-risk pregnant women and parents with young children up to kindergarten entry. The MIECHV Program builds upon decades of scientific research showing that home visits by a nurse, social worker, early childhood educator, or other trained professional during pregnancy and in the first years of a child's life improve the well-being of children and families by preventing child abuse and neglect, supporting positive parenting, improving maternal and child health, and promoting child development and school readiness.

States, territories, and tribal entities receive funding through the MIECHV Program, and have the flexibility to select evidence-based or promising approach home visiting service delivery models that best meet state and local needs. The MIECHV Program is administered by the Health Resources and Services Administration (HRSA) in partnership with the Administration for Children and Families (ACF). In February 2018, the MIECHV Program was allocated \$400 million per year through fiscal year (FY) 2022 through the Bipartisan Budget Act of 2018 (BBA).

The BBA also provided new authority to the MIECHV program to designate data exchange standards for information required to be electronically exchanged between the MIECHV state agency and other agencies within the state.¹

The following are the statutory requirements for data exchange standards for the MIECHV program:

“The head of the department or agency responsible for administering a program funded under this section shall, in consultation with an interagency work group established by the Office of Management and Budget and considering State government perspectives, designate data exchange standards for necessary categories of information that a State agency operating the program is required to electronically exchange with another State agency under applicable Federal law.”

“The head of the department or agency responsible for administering a program referred to in this section shall, in consultation with an interagency work group established by the Office of Management and Budget, and considering State government perspectives, designate data exchange standards to govern Federal reporting and exchange requirements under applicable Federal law.”

¹ The term “state” is inclusive of states and territories that receive MIECHV funding.

The BBA included similar, although not identical, statutory requirements for other HHS programs, including Temporary Assistance for Needy Families (TANF), child welfare and foster care, and child support. Since these federal programs and MIECHV programs may work with some of the same families, efforts to address these statutory requirements are being coordinated and streamlined across federal programs to the extent practicable.²

Methodology

In order to determine state and program views regarding the data exchange standards that would be helpful in improving interoperability and information sharing between state agencies, HRSA and ACF conducted five regional listening sessions. The purpose of these listening sessions was to engage the home visiting field in a conversation about how data exchange standards can help achieve long-standing goals of state and local programs, such as better integration of data from home visiting programs with broader early childhood strategies and programs, improved interoperability among service delivery partners, and reduced data collection and reporting burdens.³ Listening session attendees included MIECHV state administrators, representatives from state agencies they partner with, staff from local home visiting programs, and representatives from home visiting models.⁴ This report is a summary of the input from the field gathered at the listening sessions.

Overview of Current State of State Data Sharing and Interoperability

As described above, in June and July 2019, HRSA and ACF invited stakeholders to a series of data exchange standards regional listening sessions. At these sessions, HRSA and ACF learned about current data exchange efforts and gained a better understanding of how they can support MIECHV awardees and their partners in identifying and improving interoperability strategies, including leveraging any existing work.

At the beginning of each meeting, states representatives were asked to provide an overview of the current state of data sharing in their respective states. States were asked the following questions:

- How does your state currently share data as it relates to your MIECHV program?

² <https://mchb.hrsa.gov/sites/default/files/mchb/MaternalChildHealthInitiatives/HomeVisiting/data-exchange-standards-miechv.pdf>. For additional information regarding the background for this project, an overview of data exchange standards, and challenges and opportunities for creating standards in the home visiting field, please see “Developing Data Exchange Standards for MIECHV Home Visiting Programs - Conceptual Brief” from May 2019.

³ See Appendix A for a sample agenda from the MIECHV Data Exchange Standards Regional Listening Sessions.

⁴ See Appendix B for a list of attendees from the MIECHV Data Exchange Standards Regional Listening Sessions.

- What structures or systems are in place to support data sharing in your state (e.g., integrated data systems, preschool development grants, MOUs, data governance bodies, etc.)?
- Briefly describe any data sharing agreements you have in place.

The following is an overview of the key themes that emerged from the responses provided.

“We are at the very beginning...”

More than half of the states represented at the listening session reported being at the very beginning of thinking about how to exchange data. Many noted that they do not have any formal data sharing agreements in place.

Child Maltreatment is One Area Where Many States are Sharing Data

The one exception to the general observation that many states do not have formal data sharing agreements is for the MIECHV annual reporting requirement related to child maltreatment data. For many states, this is the only formal agreement or current data match that MIECHV awardees have with another state agency. States described sending a file with social security numbers, or other demographic data, to the child welfare agency, which performs the match and returns aggregate data for MIECHV annual reporting purposes.

The Administering Agency Varies Among States

There are marked differences among states in terms of where the MIECHV program is situated, which impacts their level of integration with related agencies. For example, in states in which MIECHV is run out of the same agency as child welfare, a data sharing agreement may not be needed to access child maltreatment data. By comparison, states where MIECHV is administered by the Department of Public Health or the Health Department, a formal agreement typically is needed.

Access to Health Data is an Area Where Some States Reported Promising Approaches

While several states discussed an absence of and/or a desire for health data, a few states talked about pilot programs to access health information. For example, one state discussed a pilot program to match Medicaid Managed Care Organization (MCO) and home visiting data for care coordination. Other states talked about accessing vital records data to be able to identify potentially eligible families for enrollment.

The Most Common Data Integration Project is ECIDS

Many states reported that they have already or are in the process of adding home visiting data into their state’s Early Childhood Integrated Data Systems (ECIDS). This was the most commonly discussed program that supports integration among related programs. However, it was noted

that these systems are integrating de-identified data for aggregate level reporting and program evaluation. Few states reported true integrated systems including case or client data.

Some States are Developing a Master Client Index to Support Data Sharing

Some states discussed initiatives to create a Master Client Index (MCI) to enable “merging records” by leveraging a centralized set of demographic data. It was often unclear whether the MCI would be used to share case-level data, or if it was primarily to support the state’s ECIDS. Various different algorithms can be used to link case records for an MCI.

Preschool Development Grants have been an Important Source of Funding for Many States

Federal grants, such as the Preschool Development grants⁵ and the Race to the Top grants⁶, have been used by states to fund data matching technologies, such as Master Client Indices, as well as systems development. Later in this report we highlight the challenges states raised of identifying sustainable funding sources.

Several States Reported Challenges with Managing Informed Consent

While there were different interpretations among states as to what data sharing requires consent, there was a consistent theme around the need to inform clients and gain their consent prior to sharing data. At least one state called for the development of consent management standards that would cover HIPAA and other statutes.

A Legislative or Political Mandate Can Be a Powerful Catalyst for Information Sharing

Where such mandates exist, states found it easier to begin projects involving collaboration and information sharing across agency boundaries. Conversely, states reported that it was challenging to advance data sharing and interoperability programs when there was political turnover or lack of sustained political will.

Summary of Feedback on Potential Data Sharing Scenarios⁷

In addition to eliciting summaries of the state of information sharing within each state, a key objective of the listening sessions was to understand what standards the states would find helpful in promoting information sharing across programs and agencies within their state. In order to frame the question in such a way as to solicit very specific descriptions of information sharing that might be helpful, a roundtable of data exchange and home visiting experts was convened to identify an initial set of data sharing scenarios that could become a starting point for the discussions at the regional meetings. The roundtable discussion resulted in the

⁵ For more information about the Preschool Development Grants:

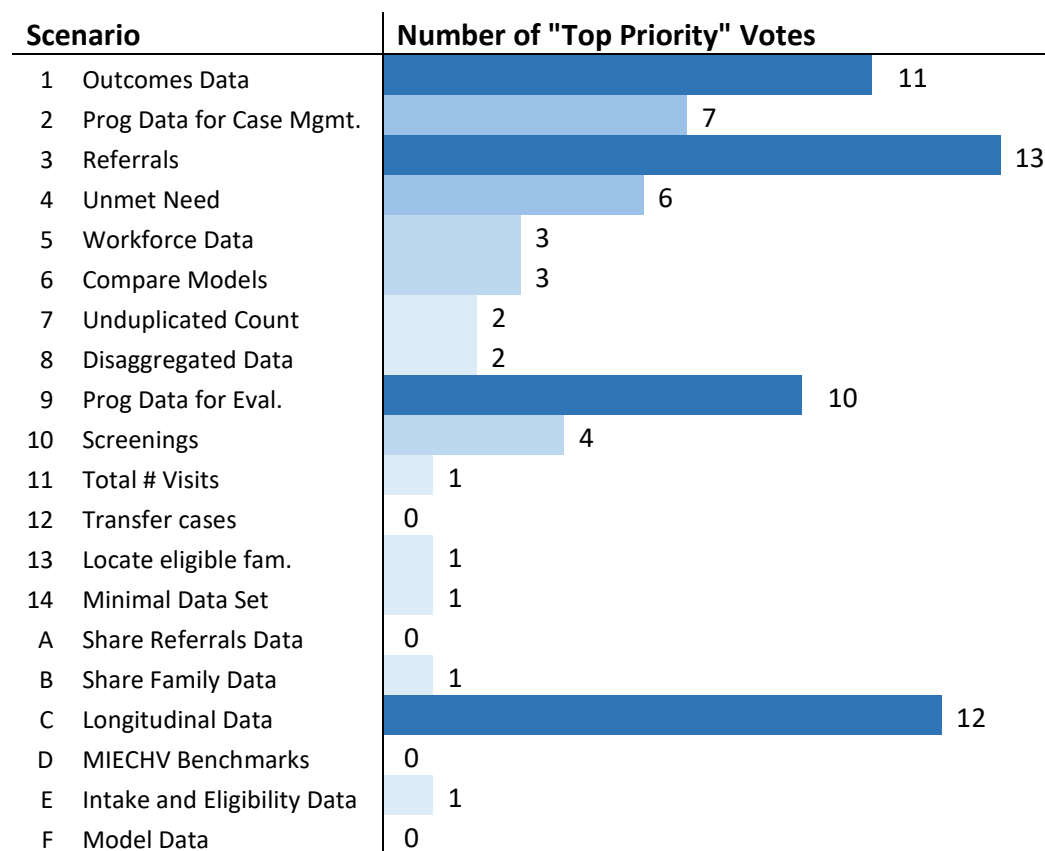
<https://www2.ed.gov/programs/preschooldevelopmentgrants>

⁶ For more information about Race to the Top: <https://www2.ed.gov/programs/racetothetop/>

⁷ We started out describing these as “high-level use cases”, but over the course of the regional listening sessions found that they are more accurately described as “data sharing scenarios” from which use cases can be developed.

identification of twenty potential data sharing scenarios that the roundtable participants thought would add value and improve service delivery. Regional meeting participants were then presented with these scenarios, and were asked to select 3-4 scenarios for further exploration.⁸ The participants were also invited to create additional data sharing scenarios where standards might be helpful beyond the 20 originally identified.

Data Sharing Scenarios Selected as Top Priorities by Participants in Regional Listening Session Breakout Groups⁹



Based on the active engagement of the participants in the regional meetings, their prioritization discussions, and their expressed views on specific potential scenarios, a clearer picture emerged regarding the kinds of standards that would be valuable for state programs. Based on

⁸ See Appendix C for the list of Potential Use Cases for Data Exchange Standards for MIECHV Home Visiting Programs used in the Regional Listening Sessions. This list represents the scenarios that were identified by the roundtable participants and was used to spark the conversations at the regional listening sessions.

⁹ This table shows the number of times each Data Sharing Scenario was chosen as a "top 5" priority by attendees at the regional listening sessions. There were 4-5 breakout groups per regional listening session, and each breakout group had 5 "top 5 votes," so the maximum score would be approximately 20.

feedback from the regional meetings, and in particular the small group discussions that focused on the data sharing scenarios that were identified by the participants as being of the highest priority, additional detail and refinement of the most important scenarios was developed. While all of the potential scenarios had some level of support from participants in the regional listening sessions, and none was believed to be superfluous, participants acknowledged that prioritization would be necessary due to the complexity of the home visiting field, with its multiple stakeholders, as well as the relative lack of data sharing currently underway. In this context, the feedback on the data sharing scenarios gathered in the regional listening sessions enabled the further definition of detail and content that can be used to start the standards development process for state-to-state exchanges in the home visiting field.

Four topics emerged through the listening sessions as candidates for further work to develop data standards:

1. **Referrals**: Home visitors' referrals of children and families to other health and human services providers, and other service providers' referrals of children and families to the home visiting programs.
2. **Outcomes and Longitudinal Data**: The measurement of common outcomes across home visiting programs to support longitudinal studies of program effectiveness and value.
3. **Program and Administrative Data**: Standards for defining how home visitors can gain access to data repositories in other health and human service agencies that will help the home visitor fully understand the needs of the child and family and improve services accordingly.
4. **Screening**: Standards for exchanging screening data previously recorded for children and families who are clients of home visitors with other providers that collect and/or could benefit from knowing the results of the screening measures.

Some of these topic areas (e.g., Outcomes and Longitudinal Data) were created by merging data sharing scenarios presented at the regional listening sessions. This was suggested due to similarities identified among scenarios and specific feedback from the participants at the sessions. In addition, some of the scenarios that were originally prioritized are not included in this list of topics (e.g., Unmet Need), because when participants attempted to elaborate upon and create more detailed descriptions of them, they determined that these scenarios were not the best candidates for data exchange standards since specific data exchanges could not be articulated for those scenarios.

The four topics above are discussed in more detail in the next section. These data sharing scenarios are described at a high level, and will require additional exploration to be transformed into formal use cases. However, the scenario descriptions include the key fields that are required for a use case: **overview, objectives, benefits, participants, data sharing process, and frequency**. Also included are additional issues for consideration, that is, key questions or issues that should be resolved during the formal use case development process. Lastly, it is important to note that not all fields are complete for each of the scenarios. This is because the regional listening session participants did not provide feedback in that area, or simply because this requires further exploration in the next stage of the process.

1. REFERRALS

Overview: *What information is or would be exchanged and for what purpose?*

- A goal of home visiting is to connect families with other health, education, and social service programs in their communities. In addition, families are often referred to home visiting from other health and human services programs. There is currently no standard process by which referrals are made, and there is a knowledge gap in terms of understanding the care continuum for the family. This scenario has two parts:
 - A: Information about referrals into home visiting programs, including the source of the referral and information about the reason for the referral.
 - B: Referrals from home visitors to other programs, as well as information about whether the family followed up on the referral, and the outcome or service provided.
- Exchanging standardized data on referrals will help local programs and home visitors to understand whether services for which they provided a referral were received by the family.

Objectives: *What are the specific objectives of this data exchange?*

- To initiate a referral after identifying a need, and with consent from the family, and to receive confirmation from the referral agency as to whether the referral was accepted or rejected.
- To exchange data that will close the feedback loop by providing information on whether services occur.
- To improve and maintain communication with the referral agency, until such a time as the family is discharged.

Benefits: *What are the benefits to the home visiting field of exchanging data as described above?*

- + CARE COORDINATION: By standardizing referrals data, there would be greater coordination and continuity of care for families between and among service providers. A more holistic picture of the services received by a family will deepen home visitors' knowledge and understanding of the complexities and needs of the families they serve.
- + DATA QUALITY: Today, many home visiting programs rely on "self-reported" data from the family as to whether a service was received. By automating data on referrals, there will be better quality and more reliable information.
- + AVAILABILITY OF SERVICES: Creating a direct connection between home visiting programs and other service providers would enable home visitors to know whether there was availability in the program, whether there was a wait list, the timeliness of the services provided, and the reasons for denial, when applicable.

- + **REDUCE DUPLICATE REFERRALS:** Centralized information about referrals would eliminate the problem of duplicate referrals.
- + **MAKE BETTER REFERRALS:** By understanding whether services were received and the outcome of the referral, home visitors would be able to better target where to send families, and state and local administering agencies would be able to evaluate and improve partnerships with other programs.
- + **REDUCE SERVICE GAPS:** By understanding what referrals were made, and which referrals were successful/completed, the home visiting field can identify where stronger partnerships are needed and potentially solicit for funding to provide additional support services. Ultimately, stronger partnerships will help to address the unmet needs of the families served by home visiting.
- + **CLIENT ENGAGEMENT:** More effective and targeted referrals will result in more positive engagement and rapport between families and home visitors.

Participants: *Who are the key stakeholders in this data sharing scenario and what roles would they play?*

- **Referring agencies:** Provides the referral to home visiting services
- **LIA administrative staff:** Receives and processes referral (possibly automated by data exchange?)
- **Home visitor:** Identifies the need, educates the family, and makes the referrals to other agencies/programs
- **Service providers:** Receives the referral from home visitor, confirms status and eligibility, provides services, sends data back after service delivery to confirm the family received the service
- **Families:** Consents to data collection and exchange, approves referrals, receives services
- **Models:** Models collect some referral data, but role in data sharing process for referral information is uncertain

Data Sharing Process: *What triggers the start of this data exchange, and when does it end?*

- **When Does the Scenario Start?**
 - A: N/A – Requires further exploration during the use case development process.
 - B: The process starts when the home visitor screens the family for services. A referral can result from a formal trigger (e.g., a high score on a screening tool), or a referral can be for potential services (e.g., “you may qualify...”). The referral occurs when the home visitor and the family agree to a service plan. The data exchange occurs when the family is referred for services.
- **When Does it End?**
 - A: N/A – Requires further exploration during the use case development process.
 - B: The exchange ends with a disposition: the client follows-up or declines the referral; they are found ineligible; they are placed on a wait list; or they enroll in

services. Sometimes home visitors cannot find families and the case is closed after a period of time. For case management purposes, the home visitor wants to receive data back on whether the client accessed the service, the outcome, and whether the client was referred onto another set of services.

Frequency: *How frequently does this data exchange occur?*

- The exchange is ongoing for programs and agencies, who would be continuously checking for updated information.
- The frequency of the exchange also depends on the type of service provided. For example, mental health services would need to be monitored on an ongoing basis, whereas a referral to a food bank might be a one-time occurrence.
- For specific clients and families, the exchange would be episodic.

Issues for Further Consideration:

- In order to make this scenario of data exchange possible, the consent and release process would need to be standardized.
- Information security is a key concern and must be addressed.
- The further exploration of this scenario should include a review of information and referral solutions and open referral data standards.

2. OUTCOMES AND LONGITUDINAL DATA

Overview: *What information is or would be exchanged and for what purpose?*

- Home visiting programs are required to report data for a variety of mandatory reports.
- Program administrators and evaluators want access to home visiting data for purposes of quality improvement.
- In describing this scenario it is important to note the meaning of “outcomes and longitudinal data” must be further defined.
 - The first step would be to select and define the specific outcomes and metrics for which data exchange standards would improve access to data; for example, some states expressed an interest in school readiness outcomes.
 - Once metrics are identified, the next step is to come up with common definitions for each of the key performance indicators (KPI). For example, a metric about school readiness would require consensus about how to measure school readiness, and possibly standardization of the standard assessment that is used to measure the same.
- One promising approach to consider is the data exchanges that have been created to share child maltreatment data.

Objectives: *What are the specific objectives of this data exchange?*

- To validate the effects of home visiting services by accessing outcomes data from other administrative sources and measuring the impact over time.
- To support performance-based funding and measurement.
- To produce cost/benefit analyses with data collected and assessed over time.
- To assess the efficacy of services provided and to drive development of ongoing program and service improvements.

Benefits: *What are the benefits to the home visiting field of exchanging data as described above?*

- + UNDERSTANDING THE TRUE IMPACT OF THE WORK: Data related to outcomes for children and families served would enable the home visiting field to better understand and communicate the true impact of the work. State and local administrators would like to know where and how home visiting services are impacting outcomes for families served. Longitudinal data would provide “proof” of the long-term changes and impacts of home visiting.
- + STREAMLINED REPORTING PROCESSES: By creating data exchange standards, there is the possibility of streamlining the data reporting process across all levels, and to ensure better quality data.
- + UNDERSTANDING WHAT WORKS: Outcomes and longitudinal data would improve the ability of service providers to deliver holistic services, and enable them to provide the

right “mix” of services that is most likely to improve outcomes for families. Conversely, outcomes data reveals what does not work, which can inform prevention efforts upstream. These data would allow the home visiting field to revise and improve the theory of change.

- + CONTINUOUS QUALITY IMPROVEMENT: Outcomes and longitudinal data would improve program evaluation and continuous quality improvement (CQI).
- + STORYTELLING: By focusing on longitudinal data, the home visiting field would be able to tell a more complete story of the children and families served, rather than focusing on point-in-time numbers served.
- + AVAILABILITY AND SUSTAINABILITY OF FUNDING: This allows funders to invest in proven solutions. Funders are focused on outcomes data. Access to better, longitudinal data may diversify and increase available funding sources.
- + PROGRAM EVALUATION: Access to outcomes data would allow for more sophisticated research and analysis, e.g., replicating findings from different studies, creating different samples, etc.

Participants: *Who are the key stakeholders in this data sharing scenario and what roles would they play?*

- **State agencies/programs**¹⁰: Potential data sources and data sharing partners
- **Local home visiting programs**: Collect and share home visiting data
- **Program evaluation and research**: Uses available data for program evaluation and research purposes
- **Families**: Provides consent for data collection and sharing
- **Funders**: Uses available data, as well as the results of research and analysis, to inform future funding decisions
- **Legislators**: Provides support and/or mandates to facilitate data sharing
- **HRSA/ACF**: Provides guidance on key performance indicators – definitions, measurement, and reporting frequency
- **State administrators**: Gathers data and makes it available to stakeholders

Data Sharing Process: *What are the preconditions necessary to advance this data sharing opportunity?*¹¹

- Agreement on what data is being collected and how metrics are defined and analyzed.

¹⁰ For example: Pre-k and Head Start, School districts, Health and mental health (e.g., vital statistics, Medicaid claims, hospital data, morbidity, immunizations), Child Protective Services, Other EC programs, Criminal Justice, Workforce data, Wages, State longitudinal system, Integrated Eligibility System.

¹¹ Because this data sharing opportunity will include several use cases based on the KPIs selected for data exchange and standardization, we are describing the preconditions needed to advance this work, as opposed to describing the starting and ending point for a particular use case or process.

- Knowledge of reporting deadlines for each defined metric, as well as agreement about the length of time for which you will continue to track/measure outcomes for families.
- Data sharing agreements with necessary partners for related outcomes data.
- Political will and/or legislation can be an important driver to successfully advancing data sharing around outcomes.
- Agreement among home visiting models and other early childhood agencies that the goal of sharing outcomes data is to be “comprehensive, instead of competing.” This means shifting to a mindset that sees clients as “our families.”
- A plan for advocacy and sustainability must be determined from the outset to ensure that this work is able to continue long-term (which is essential for longitudinal data).

Frequency: *How frequently does this data exchange occur?*

- No feedback was provided in this area.

Issues for Further Consideration:

- For the identified outcome metrics for which home visiting would like to create data exchange standards, it will be important to consider what data standards already exist in related domains. Returning to the example of school readiness data, is there a common education data standard that can be leveraged?

3. PROGRAM AND ADMINISTRATIVE DATA

Overview: *What information is or would be exchanged and for what purpose?*

- From a service delivery perspective, home visitors want access to other sources of administrative and program data (e.g., Medicaid, Education, Early Intervention, etc.) to more easily understand household characteristics such as how many people are in the household, their ages, and the programs and services in which they are enrolled.
- The information is needed at and before the point of intake, and on an ongoing basis during the home visiting engagement, to help home visitors provide more tailored and effective services and referrals.

Objectives: *What are the specific objectives of this data exchange?*

- To establish a more comprehensive family profile to inform service delivery.

Benefits: *What are the benefits to the home visiting field of exchanging data as described above?*

- + **IMPROVE SERVICE DELIVERY:** By accessing household data and information about the other benefits or services provided to a family, the home visitor can improve service delivery through a greater understanding of the family.
- + **CARE COORDINATION:** Information about programs and services in which a family is currently enrolled would assist home visitors in identifying a family's needs and coordinating and communicating about services with other service providers.
- + **REDUCE DATA COLLECTION BURDEN:** Home visitors and families would spend less time on administrative paperwork and more time on the direct service delivery aspects of the home visit. This would result in more productive relationships, less burnout among home visitors, and more engagement from families.
- + **IMPROVE DATA QUALITY:** Data would be more complete and accurate since the family profile will be compiled from across programs and would not be self-reported. Families and home visitors can verify data, rather than collecting from scratch.

Participants: *Who are the key stakeholders in this data sharing scenario and what roles would they play?*

- **Families:** Provide data to home visitors
- **Home Visitors:** Access program and administrative data; collect new data from families
- **Local home visiting Program Directors:** Review data from home visitors; ensure that data are entered into system; share data as appropriate with State and others
- **Other agencies** (e.g., family services organizations): Collect data from families
- **State administering agency or third-party organization** (e.g., university research center): Stores data and shares as appropriate

Data Sharing Process: *What triggers the start of this data exchange, and when does it end?*

- **When Does the Use Case Start?**

- Data sharing begins at intake or the first home visit, but data collection is an iterative process. New information is obtained at each home visit or subsequent point of entry for other services.
- Sometimes data collection begins prior to the first home visit, for example when a referral is received from another agency.

- **When Does it End?**

- Data exchange ends when service delivery ends for a family with a particular agency at a specific point in time.

Frequency: *How frequently does this data exchange occur?*

No feedback was provided in this area.

Issues for Further Consideration:

No issues for further consideration were identified for this scenario.

4. SCREENING

Overview: *What information is or would be exchanged and for what purpose?*

- Home visitors want to understand what screenings have been performed already (e.g., ASQ developmental screenings, etc.) and the results of those screenings.
- This will help deliver better services and ensure that any additional screenings are appropriate and needed (thereby reducing burden on families and home visitors).
- Regional meeting participants recommended focusing on the ASQ as a starting point, because it is a widely used tool and one that participants and families are likely to agree to share the results.

Objectives: *What are the specific objectives of this data exchange?*

- To gain information about screenings that have been performed by other service providers, including doctors, other home visitors, child care, child welfare, etc.

Benefits: *What are the benefits to the home visiting field of exchanging data as described above?*

- + IDENTIFY SERVICE GAPS: Sharing screening data would help home visitors to identify gaps in services in order to understand where additional services and referrals are needed.
- + IMPROVE SERVICE DELIVERY: Understanding the results of screenings would be beneficial to home visitors in terms of identifying the children and families that need services and making connections via referrals.
- + REDUCE DATA COLLECTION BURDEN: Sharing screening data for previously provided screenings would reduce the data collection burden for home visitors. It would also ensure that families and children are not subjected to unnecessary, repetitive screenings.

Participants: *Who are the key stakeholders in this data sharing scenario and what roles would they play?*

- **Home visitors:** Receive results of screenings from other agencies and programs
- **Families:** Participate in screenings; agree to share screening results with other providers
- **Other providers** (e.g., pediatricians, child care providers, Head Starts): Conduct screenings and share results
- **Local home visiting programs:** Collect screening data; assess data to identify service gaps; partner with other agencies to access data

Data Sharing Process: *What triggers the start of this data exchange, and when does it end?*

- **When Does the Use Case Start?**
 - This use case would begin when the child/family started to receive home visiting services.
- **When Does it End?**
 - Data exchange would end when the child/family was no longer receiving home visiting services.

Frequency: *How frequently does this data exchange occur?*

- Programs would be perpetually engaged in sharing screening data.
- From the point of view of a child/family, screenings would be episodic.
- There would need to be consensus on what screens are required and when.

Issues for Further Consideration:

- It is important to note that the ASQ is a proprietary tool, developed by Brookes Publishing. ASQ Online includes an API that can connect the online survey results with an agency's system. Assuming that there is a data model used by the online ASQ, this would be a good starting place for data standards.

Foundational Projects

Feedback from the regional listening sessions led to an understanding that there was a set of foundational projects that would help to facilitate the development of data exchange standards in the home visiting field prior to beginning work on the development of formal use cases. The following is a list of these foundational projects.

Establish a Governance Process

A first step in creating data exchange standards for home visiting is to establish a governance process. In other words, the field will need to determine who is managing the project, who is approving key decisions, who is being consulted and included in the project, and what is the decision-making process that will be used to drive change. In addressing governance, the following are some of the key questions to be considered:

- *Who is leading this effort?*
Regional listening session participants requested clarification from HRSA and ACF as to who will be the champion for creating data exchange standards and who will be responsible for driving the process. It will be important for there to be an organizational unit that is the “owner” of the standards that emerge from this effort, and that this owner will be responsible for engaging the stakeholders in a long-term effort to develop, vet, and implement standards. Roles and responsibilities should be clearly delineated in a governance structure.
- *What are the goals and objectives for data interoperability?*
Different actors in the home visiting service delivery system have different goals and objectives for sharing data. For example, State administrators said they want access to integrated early childhood data and long-term outcomes data in order to justify and sustain funders’ investments in home visiting, but this could be different from the goals of local programs, the home visitors, or the families themselves. As such, it would be helpful for the governance body (as identified in the governance structure) to address this question early on: “Whose needs are we prioritizing in this effort?” It is essential to consider who is going to benefit from this work, and who *should* benefit from it.
- *Who is at the table?*
Not all stakeholders need to be involved in the detailed governance process – they can be consulted or informed as the work proceeds, but it is useful to map out all stakeholders and to think about how and when they will be included. Regional listening session participants indicated that, in addition to Federal and State representation, the following stakeholders should be included:

- Local implementing agencies (LIAs): One of the themes we heard repeatedly in our regional listening sessions was that the LIAs should have increased representation going forward. The perspective of the LIAs is different from State administering agencies; LIAs are focused more on care coordination and reducing data entry burdens. Their perspectives on the process of entering and re-entering data in systems that do not speak to each other would be highly valuable. Overall, we heard feedback that the data sharing scenarios that were presented at the regional meetings did a good job of capturing the program evaluation needs, but service delivery needs may require further definition. Increasing LIA participation would deepen our understanding of the needs for home visitors on the ground.
- Other Early Childhood Programs: Several of the data sharing scenarios pertain to sharing data with other early childhood programs. As such, they should be involved in the governance process to set reasonable expectations and create buy-in for data sharing. Moreover, as home visiting seeks to establish itself as a known entity in the early childhood ecosystem of programs and services, there was an acknowledgement among some regional meeting participants that it is essential to align and share data as a way of establishing legitimacy.
- Home Visiting Models: A challenge for the field in the effort to create data exchange standards is how to address that there are a variety of home visiting models with different data and reporting requirements. Regional meeting participants recognized the challenge and the importance of creating standardized definitions for home visiting data, particularly across the models. There was a strong desire for a cohesive way to demonstrate the collective impact of home visiting across models and programs. Buy-in and participation from the models is essential to the success of data exchange standards for home visiting.
- Families: Perhaps the most frequently discussed topic at the regional meetings was the role that the families themselves could and should play in the process of creating data exchange standards. It was widely agreed that the starting point for data sharing should be improving service delivery and outcomes for families and children. As such, regional meeting participants argued that scenarios for data sharing should be focused foremost on what will best help families, and consideration should be given to managing and explaining consent for data sharing. Some suggested that an equal amount of attention should be given to protecting family information, ensuring a balance between privacy and increased data sharing capabilities. There was broad agreement that the paramount goal must be maintaining the trust of clients (families).

Create a Policy and Legal Framework

Perhaps because there is not already extensive data sharing across the home visiting field with other organizations and agencies, many regional listening session participants expressed skepticism about the legality of sharing information, and noted few examples that could be held up as best practices. A number of State administrators said they would welcome leadership from HRSA and ACF to provide the rationale and guidance to facilitate data sharing. Specifically, states are looking for information on how to share data legally, what consents are required, and how to create privacy and confidentiality agreements. Both federal law and state laws are potential obstacles or opportunities to affect information sharing.

Managing the consent process

Gathering consent can be challenging. Consent requirements vary by state, and requirements are interpreted differently by different states' attorneys general. Generally speaking, there are two approaches that MIECHV could take to dealing with consent management. One approach would be to launch a workstream to create a universal consent management process. This would entail determining, upfront, the data that might be shared, and creating a standardized, and potentially automated, process to gather consent from families. Another approach would be to deal with issues of consent on a use case by use case basis, by determining for each use case what data elements would be shared and the consent requirements for those data. Regardless of the approach that is taken, it will be essential to tackle issues of consent management to advance data exchange.

Sample or model MOUs and/or other data sharing agreements

One of the requests from State administrators was for the MIECHV program to provide sample MOUs, data sharing agreements, or legislation that states could use to advance data exchange. Federal guidance can be powerful in advancing states' respective abilities to share data. We suggest working with ACF to leverage guidance and samples developed as a part of their confidentiality toolkit. Similarly, some states specifically requested federal guidance on how to legally share data (i.e., how to be compliant with both FERPA and HIPAA).

Explore Technology Solutions

For standards related to interoperability to be helpful, it is important to take into account the technology that is available to implement such standards. Some home visiting programs have implemented the use of tablets and web-based software to make it easier for home visitors to capture and access information about clients and services. It is likely that increasing numbers of applications will migrate to cloud computing in the foreseeable future. Mobile devices can help home visitors more efficiently discover resources and make referrals on site for clients. Given

this clear trend in the use of mobile digital devices, it would make sense to develop standards that at the very least encouraged the use of such devices.

Varying technologies are in use throughout the country for implementing the protocols required for automated exchanges in standards that may be developed, and the choice of the middleware components will affect the way standards are implemented. It would be useful to identify the technologies in use and forthcoming that states and individual models are adopting for information exchanges. Consideration should be given to developing communications standards that are associated with human services interoperability standards in general.¹²

Master Client Index

In order to create holistic data records of the clients and services provided across programs, even beyond home visiting, many states have turned to the intuitively attractive idea of creating a master person or client index to link records from multiple services and systems. Indeed, as noted in the “Overview of Current State of State Data Sharing and Interoperability” summary, several States have tackled this project and included home visiting programs in the design for the index. Early childhood integrated data systems depend on this construct to make links between programs and services to consolidate a service record for clients. For such an index to be useful, there must be appropriate algorithms to match client records by person. While there are variations in how to do this, current technologies including artificial intelligence are rapidly improving this capability, although there remain considerable challenges to identity resolution in linking records about children. A reference guideline, provided to states by HRSA and ACF, on best practices for identity resolution in home visiting or in child-centric systems in general would be helpful to states and programs beginning to build interoperability platforms.

Information Safeguarding

Participants in the regional discussions were quick to point out that one of the biggest challenges in moving forward with information sharing across programs and systems is the need to safeguard the data and preserve the privacy of clients. Often-heard statements such as the following were prevalent in every discussion:

- “We are challenged to walk a fine line between serving families and not violating privacy.”
- “An equal amount of attention should be given to protecting family information, ensuring a balance between privacy and increased data sharing capabilities. We need to maintain the trust of our clients (families).”

¹² For Federal guidance and information about the standards used by HHS agencies, as well as the technology components that are most widely implemented today, one starting place is the ACF data interoperability project: <https://www.acf.hhs.gov/opre/research/topic/overview/interoperability-and-data-sharing>

The issues cited above regarding consent management and the legal authorities are important components of assuring that the privacy of clients is upheld in ways that make the information exchange helpful.

Role-Based Access Controls

Another element of information safeguarding is the definition of standards for limiting access to shared data in accordance with explicit roles that justify the access. Such role-based access controls are important components of providing any access to shared data. It would be helpful to develop a standardized set of role definitions that might be broadly used to establish access rights and privileges.

Information Systems Architecture

A number of states have either already done so or are contemplating creating an integrated information system for data related to early childhood development that serves multiple agencies in the state including home visiting. These systems tend to be homogenous systems with a warehouse of data gathered by multiple agencies, preserving the original contributor's control over the data while providing privacy protections in accordance with federal and state laws.

The data elements in integrated systems are normally well defined and have singular meanings as defined by the system operator, and singular values and representations for those elements that have particular allowable values (using edits to limit entries). In a typical implementation of this concept, the collection of agencies participating are defined as an enterprise, and the system is designed to serve its participants. The role of data standards is less important when the enterprise is well defined, as the participants are mostly focused on the development of data structures to support their own missions rather than the work of external agencies.

However, while these integrated information systems can help improve access to data for the entities participating in them, they are not necessarily supportive of interoperability more broadly. Data exchange standards are still necessary if integrated data systems need to interact with external data systems. Building integrated enterprise information systems to handle the most commonly affiliated missions and functions makes practical sense, saving time and money in development and operation as well as maintenance. However, designers and developers of such systems would be wise to pay attention to what might happen at the edge of their enterprise, and to explore the availability of national standards for interoperability that can be included more easily when systems are built than by retrofitting systems after the fact.

For home visiting programs, this consideration implies being aware of the potential requirement for interoperability between home visiting programs and other programs that touch upon the same clients or services. It also means anticipating the need for interoperability

by including the capability for data element creation or translation into standards-based exchange formats and representations.

Establish a Funding Source

To move forward with developing data exchange standards, it will be important to consider the source of funding for this effort. In the regional listening sessions, states shared that the perceived cost of data integration makes data sharing seem impossible. This is particularly troublesome because some service providers feel that their funding for home visiting service delivery is in and of itself already uncertain. While MIECHV funding may be stable for the next several years, MIECHV only funds a portion of all home visiting programs. It should be noted that data exchange standards could be expected to apply across both MIECHV and non-MIECHV funded programs, and would be beneficial to both.

Regional listening session participants also shared that they were unsure whether this project would create additional work for the MIECHV grantees, and how they will adjust to and pay for the implementation of data exchange standards for MIECHV home visiting programs. One way to build project buy-in and ensure its long-term viability is to establish a dedicated funding source.

Create a Minimum Data Set

Currently, home visiting programs and models do not have consistent definitions for even the most basic case information. Regional listening session participants recommended establishing a minimum data set that cuts across all home visiting programs, including both evidence-based and non-evidence-based models.

The benefits to the home visiting field of creating a minimum data set include:

- **ABILITY TO MAKE COMPARISONS:** By establishing a minimum data set, it would be possible to make comparisons across programs and models.
- **FACILITATE DATA SHARING:** A minimum data set of the most common client data elements that was standardized across programs and models would facilitate current and future data sharing.
- **IMPROVE SERVICE DELIVERY:** In the long-run, the minimum data set would potentially help place families in the models or programs best suited to their needs.
- **ESTABLISH ROI AND COLLECTIVE IMPACT:** By establishing a standard data set, there is also the potential to describe the collective impact of all home visiting models.
- **REDUCE DUPLICATE DATA ENTRY:** If all programs and models were to require the same core set of data elements, there would be a reduction in duplicate data entry.

- **DATA FOR FUNDERS:** Funders would appreciate consistent information across programs and models, which would enable them to better target financial resource in accordance with their respective missions and “what works.”

Creating a minimum data set as a foundational project could accelerate the effort to create the other data exchange scenarios discussed in this document.

Conclusion

The regional discussions of data standards for home visiting clearly established that the delivery of home visiting services and the management of home visiting programs in association with other early childhood education and developmental efforts could greatly benefit from the development of data exchange standards. In these discussions, there was consistent and pervasive support for developing standards, particularly if the process involved all relevant stakeholders (i.e., LIAs, families, states, other state health and human services programs).

While it was clear from the listening sessions that data exchange standards will improve service delivery, it was also apparent that technology and/or the lack of standards was not the only obstacle to information sharing. In fact, robust change management and business process improvements will be required, along with data exchange standards, to facilitate better information sharing.

The general sense from across these meetings was that it would be useful and helpful for the federal government to support the effort to develop standards and to then create grant opportunities and other avenues to promote adoption of the standards in system development.

Clearly, states are very widely in their readiness, ability, and progress toward information sharing between related programs of human service affecting children and families. Capacity building is a particularly worthwhile effort, working toward bringing the states to a more robust national capability to make home visiting most effective throughout the nation.

Given the diversity of models, programs, objectives, and processes, it is essential that the full range of stakeholders be involved with the development of data standards to achieve consensus on the standards in advance of implementation.

Finally, this model of holding regional listening sessions across the country is a very effective and useful approach to elicit input from the practitioners involved in delivering home visiting services. Heard repeatedly were comments that the listening session felt valuable to participants, who noted a “good representation of stakeholders” and appreciated the ability to “talk to other states and hear about similar thoughts and questions.”

APPENDIX A: Agenda from MIECHV Data Exchange Standards Regional Listening Sessions

Time	Topic/Objective
8:30 – 9:45	Welcome and Introductions <ul style="list-style-type: none"> Welcome & project background Introduce facilitators Each State lead to provide a brief (3 min.) overview of the current state of data sharing in their State
9:45 – 10:15	Data Exchange Standards for Home Visiting Programs <ul style="list-style-type: none"> Explanation of Statutory Requirements for MIECHV Data Exchange Standards Overview Data Standards for MIECHV: Challenges and Opportunities Process to create data standards, overview of use cases, and key terms
10:15-10:30	Break
10:30-11:30	Business Needs and Opportunities <ul style="list-style-type: none"> Presentation of the potential use cases previously identified Preliminary group discussion: What resonates for you and/or what might be missing from this list of use cases?
11:30 – 12:30	Prioritize Use Cases for Data Exchange Standards <ul style="list-style-type: none"> Small groups meet to discuss and prioritize potential use cases, adding new use cases as needed In plenary, each group presents their Top 5, and why they selected the use cases that they did
12:30 – 1:30	Lunch
1:30 -2:45	Small Group Activity: Use Case Definition <ul style="list-style-type: none"> Reveal the overall Top 5 use cases, based on the morning's activities Participants will choose the use case that they are most interested in and knowledgeable about In breakout sessions, participants will explore more deeply their chosen use case, and will complete the use case template
2:45 – 3:00	Break
3:00 – 3:40	Report out on Use Cases & Final Thoughts <ul style="list-style-type: none"> Breakout groups will briefly report out on the results of their work Participants reflect on the day's activities Opportunity for people to offer final thoughts
3:40 – 4:00	Conclusion & Wrap-Up <ul style="list-style-type: none"> Explain how the activities from today will inform the work going forward Remind participants of the path forward from developing use cases to creating data standards Thank you!

APPENDIX B: List of Attendees from MIECHV Data Exchange Standards Regional Listening Sessions

PARTICIPANTS

Kansas City, MO:

Jared Barton

Assistant Director
Center for Public Partnerships and Research

Abigail Eskenazi

Home Visiting Evaluation Coordinator
Wisconsin Department of Children and Families

Karen Harbert

Senior Epidemiology Specialist
Missouri Department of Health and Senior Services

Latonya Hicks

State Project Specialist
Parents as Teachers National Center

Bala Mutyala

Research Scientist
Center for Prevention Research and Development

Rob Reid

Data Warehouse Manager
Prevent Child Abuse America

Sommer Rose

Research Program Manager
Promise 1000 Home Visiting Collaborative

Cynthia Smith

Prevention Services Manager
Indiana Department of Child Services

Oneta Templeton

Manager, Community Programs
Children's Mercy Hospital

Virginia Zawistowski

FHV Evaluation Supervisor
Minnesota Department of Health

Lisa Bender

Program Manager
Iowa Department of Human Services

Cathy Gagne

RN, BSN, PHN, LHIT
St. Paul Ramsey County Public Health

Heather Herring

MIECHV Coordinator
Indiana State Department of Health

Stephen Martin

Programmer/Analyst
Promise 1000 Home Visiting Collaborative

Anne Plagge

MIECHV Applied Research Coordinator
Iowa Department of Public Health

Emily van Schenkhoof

Executive Director
Children's Trust Fund

Lesley Schwartz

MIECHV Project Director
Illinois Governor's Office of Early Childhood
Development

Michael Sophir

Evaluation and MIECHV Data Analyst
Parents as Teachers National Center

Jenny Taylor

Program Manager
Kansas Department of Health and Environment

Atlanta, GA:**Ellen Agho**

Program Director
Mississippi Dept. of Human Services

Matthew Bellew

Director of Development and Outreach
HIPPI USA

Hector Colon

Assistant Professor
University of Puerto Rico

Colleen Ehatt

Data Manager, Children & Youth Branch
NC Division of Public Health

Mark Ervin

Project Manager
Department of Public Health

Heather Johnson

Program Manager
University of Alabama at Birmingham

Sherry McGee

Director of Partnerships & Development
National SafeCare Training and Research Center

Bradley Planey

Family Health Branch Chief
Arkansas Dept. of Health

Carla Snodgrass

Section Chief, Early Childhood Initiatives
Tennessee Department of Health

Kimberly Vuong

MIECHV CQI/Data Coordinator
NC DHHS-Division of Public Health

Icelynn Baldwin

Quality Improvement Manager
Children's Trust of South Carolina

Anita Brown

Associate Director, Center for Family Research
University of Georgia

Jessica Diedling

MIECHV Data and Quality Manager
Louisiana Office of Public Health

Tonya Elkins

MIHOW Director
Vanderbilt School of Nursing

Emily Ferrell

Epidemiologist
Kentucky Department for Public Health

Roddey Jones

Senior Training Specialist
National SafeCare Training and Research Center

Lorraine McKelvey

Associate Professor
University of Arkansas for Medical Sciences

Davida Singleton

Epidemiologist
Tennessee Department of Health

Dianna Tullier

First Teacher Home Visiting Director, MIECHV Project
Director
Alabama Department of Early Childhood Education

Seattle, WA:**Laura Alfani**

Strengthening Families Administrator
Washington State Department of Children, Youth,
and Families

Dawn Bonder

Senior Director
CedarBridge Group

Margarita Gay

Project Director
Guam DPHSS

Kasondra Kugler

Prevention Program and Data Specialist
Dept. of Children, Youth, and Families

Catriona Macdonald

Executive Director
Association of State and Tribal Home Visiting
Initiatives

Jon Reeves

Infant Toddler Specialist
Early Learning Division

Teresa Vollan

Epidemiologist Section Manager
Department of Health

Jerome Ballesteros

Data Specialist
CNMI HFA Home Visiting Program

Izumi Chihara

Home Visiting Epidemiologist
WA State Department of Health

Benjamin Hazelton

Home Visiting Policy & Systems Coordinator
Oregon Health Authority

Barbara Lucenko

Chief, Program Research and Evaluation Services
DSHS/RDA

Heather Peasley

Quality & Operations Director
Family Building Blocks

Audrey Topasna

Program Coordinator
Guam Department of Public Health and Social Services

Mack Wood

Research Analyst
State of Alaska DHSS DPH

Denver, CO:**Carsten Baumann**

Manager, MCH Epi & Eval
Colorado Department of Public Health & Environment

Sandina Begic

Assistant Research Professor
Boise State University

Carrie Churchill

Child and Family Services
SD Department of Health – Home Visiting

Jill Filene

Executive Vice President
James Bell Associates

Ashtin Glodt

MIECHV Program Specialist
Idaho MIECHV

Leslie Lee

MIECHV Project Director
State of Montana – DPHHS

Katrine Montano-White

Bureau Chief
NM CYFD – Office of Child Development

Molly O’Fallon

Executive Director Compliance and Quality
Nurse-Family Partnership

Alejandra Rebolledo-Rea

Early Childhood Division Director
NM Children, Youth & Families Department

Julie Becker

Home Visiting Director
Colorado Department of Human Services

Rachel Breck

Data & Evaluation Manager
Parent Possible

Juan Delara

Program Evaluator
Oklahoma State Department of Health

Kaci Gaub-Bruno

Lead Program Specialist
State of Montana – DPHHS

Melissa Kelley

Facilitator
National Home Visiting Network

Stephen Matherly

ECIDS Program Coordinator
Utah State Department of Health

Staci Morley-Young

Data Analyst
Invest In Kids

Elizabeth Pihlaja

Program Director
Prevent Child Abuse North Dakota

Kathryn Sibley-Horton

PEI Director of Research and Safety
Texas Dept of Family and Protective Services

Rockville, MD:**Ellen Amore**

KIDSNET Manager
RI Department of Health

Cate Bohn

Research Analyst
NYS Council on Children and Families

Kristine Campagna

Chief, Office of Home Visiting
RI Department of Health

Kim DiBella-Farber

National Data and Quality Officer
Child First, Inc.

Matthew Firestone

Family Support Program Analyst
PA Office of Child Development and Early Learning

Ben Goodman

Director of Research and Innovation
Family Connects International

Constance Heye

Epidemiologist
CT Office of Early Childhood

Erika Lichter

Associate Research Professor/MCH Epidemiologist
University of Southern Maine

Alexandra Loizias

Division Chief, Innovation and Delivery System Reform
Maryland Medicaid
MD Department of Health

Patty Marickovich

Senior Program Analyst, FM Talent Source
MIECHV Coordinator
Office of Head Start
Administration for Children and Families

Kelly Myles

Data Consultant
KTM Consulting, LLC

Goodwill Apiyo

Analyst
DC Department of Health

Memory Bowman

Public Health Analyst
DC Health

Natalie Craver

Program Manager
DC Child and Family Services Agency

Karin Downs

MCH Director for Title V
Director, Division of Pregnancy, Infancy and Early
Childhood
MA Department of Public Health

Vinetta Freeman

Early Childhood Health Division Chief
DC Child and Family Services Agency

Robin Griffin

Program Examiner
Office of Management & Budget
Executive Office of the President

Mary LaCasse

Chief of Home Visiting and Family Support
MD Department of Health

Brittany Little

Early Childhood Specialist, PDG
University of New Hampshire &
NH Department of Health and Human Services

Susan Manning

CDC Maternal and Child Health Epidemiology Program
Assignee
CDC/MA Department of Public Health

Kim Morrison

DC MIECHV Program Coordinator
DC Health Community Health Administration – Family
Health Bureau

Jackie Newson

Program Manager
West Virginia Home Visitation Program/DHHR

Josh Prosser

Policy Associate

Association of State and Tribal Home Visiting Initiatives

Jeffrey Quinn

National Director of Programs

Family Connects International

Gary Titus

Data Coordinator

MCH/MIECHV

NH Department of Health and Human Services

Tierah West

Applied Research Coordinator

Early Impact Virginia

Erin Whitham

Performance Management Coordinator

Maine Children's Trust

FEDERAL STAFF

Anne Bergan

Senior Policy Analyst
Administration for Children and Families

Aira Jae Etheridge

HRSA Region IV Project Officer
Health Resources and Services Administration

Alicia Heim

Public Health Analyst
Health Resources and Services Administration

Nancy Geyelin Margie

Home Visiting Research Team Lead &
Senior Social Science Research Analyst
Administration for Children and Families

Kyle Peplinski

Senior Data Analyst
Health Resources and Services Administration

Sandy Sheehy

ECCS Impact Project Officer
Health Resources and Services Administration

Chris Traver

Senior Advisor
Administration for Children and Families

Janis Dubno

Senior Policy Advisor
Health Resources and Services Administration

Jeffrey Fredericks

Special Assistant
Administration for Children and Families

Lisa King

Senior Public Health Analyst
Health Resources and Services Administration

Kelsey McCoy

Team Lead
Health Resources and Services Administration

Heather Swope Pinaud

Social Scientist
Health Resources and Services Administration

Sandra Springer

HRSA Project Officer
Health Resources and Services Administration

Joe Warren

Senior Business Interoperability Analyst
Administration for Children and Families

FACILITATORS

Ivy Pool

Senior Consultant
Stewards of Change

Paul Wormeli

Innovation Strategist
Stewards of Change

Daniel Stein

Managing Partner
Stewards of Change

APPENDIX C: Potential Use Cases for Data Exchange Standards for MIECHV Home Visiting Programs *(Draft from Regional Listening Sessions)*

Business Needs Use Case:	Objective:
1. I want access to outcomes data related to the families we serve and linked to MIECHV benchmarks and Pew indicators. This includes: a) aggregate data, and b) individual-level data.	To understand and measure the impact of services provided by linking records from local implementing agencies with outcome data held by other agencies. a) To access <u>aggregate</u> local, state, and national home visiting data linked to data outside of the field of home visiting to assess long-term outcomes for those served by home visiting for program evaluation purposes. b) To access <u>individual</u> level data for families and children served by home visiting to link to outcome data outside from outside of the home visiting field to measure the effectiveness of service delivery.
2. For service delivery, I want access to other administrative and program data sources to understand the characteristics of the families we serve.	From a service delivery perspective, we want access to other sources of administrative and program data (e.g., Medicaid, Education, Early Intervention, etc.) to know how many people are in the household, their ages, and the programs and services in which they are enrolled. This information will help home visitors to provide more tailored and effective services and referrals. The information is needed at and before the point of intake, and on an ongoing basis during the home visiting engagement.
3. I need to know about: a) referrals into home visiting programs, and b) referrals from home visitors to other programs and services (e.g., what referrals were made, did the family follow-up on the referral, what was the outcome or service provided?)	a) To understand information about referrals into home visiting programs from referring agencies. b) To understand what referrals were made from home visitors, whether the family followed-up on the referral, and the outcome or service provided. This will “close the loop” by helping local programs and home visitors to understand whether services for which they provided a referral were received by the family.
4. I need to understand the unmet need for home visiting services by comparing timely administrative and program enrollment data.	To understand the scope of services provided today, to advocate for additional resources and funding to support program expansion, to compare states and municipalities to target where services should be expanded. This use case may also measure the difference between MIECHV and non-MIECHV funded home visiting programs.
5. I want access to workforce data to understand the characteristics of home visitors and to measure workforce effectiveness.	To understand the characteristics of home visitors, including salary, tenure, and turnover, and to measure effectiveness and the impact of workers on outcomes for families.
6. I need to be able to compare home visiting models to understand which models are most effective for which families.	To understand which models are most effective for which families (i.e., what works best for whom?). Currently 18 evidence-based models are eligible for MIECHV funding; each has different goals and outcome metrics, which makes comparison across models difficult today.

Business Needs Use Case:	Objective:
7. I want to be able to calculate an unduplicated count of families served.	To accurately measure the number of families receiving home visiting services. This use case will quantify the saturation of home visiting as compared to the general population.
8. I want access to data disaggregated by county, model, zip code, etc.	To access data that is disaggregated by county, home visiting model, zip code, local implementing agency, etc. to be able to perform more granular program evaluation.
9. For program evaluation and quality improvement purposes, I want access to other sources of administrative and program data .	For program design, quality improvement, and research and evaluation purposes, stakeholders want access to administrative and program data, including Medicaid, education, child welfare, and early intervention data. This use case includes providing access to original source data.
10. I need access to information about screenings provided (e.g., ASQ developmental screenings) and the results of the screens.	Home visitors want to understand what screenings have been performed already (e.g., ASQ developmental screenings) and the results of those screenings. This will help deliver better services and ensure that any additional screenings are appropriate and needed (thereby reducing burden on families and home visitors).
11. I want access to data about the total number of home visits received by a family or individual.	To understand the scope of home visiting services provided to a family or individual across different program models.
12. I need a mechanism to more easily transfer case files between programs, both intra- and interstate.	As families relocate within a state and/or from one state to another, program administrators want a process to transfer the enrollment and case file from one home visiting program to another. This would also be used as a family switches from one model to another, as their needs shift over time.
13. I need data to help me locate eligible families for enrollment in home visiting services.	To identify and locate potentially eligible families for enrollment in home visiting services by leveraging other data sources, such as Medicaid claims data.
14. I need a minimum data set across home visiting programs to make comparisons possible.	To identify a standard set of case data that can be consistent across home visiting programs and models. A minimum data set would make possible comparisons across programs and models, would facilitate data sharing, and would potentially help place families in the models or programs best suited to their needs. By establishing a standard data set, there is also the potential to describe the collective impact of all home visiting models.

Opportunity Use Case:	Objective:
A. We can provide information on referrals made by home visiting to other providers.	Home visitors provide families with referrals to other service providers. The information on referrals provided can be shared with providers so that they know when a referral has been made, as well as information about the family, their case, and the reason for the referral. Other early care and education programs may also be interested in referral data.
B. We have family-level data (as opposed to child-specific), which can provide potentially useful information about a family or household.	Home visiting programs collect family data, whereas other programs may collect child-specific data. By sharing family data, home visiting providers may be able to provide other programs that work with these families potentially useful information about a family or household.
C. Combined with other early childhood data sources, home visiting data can be used to track longitudinal outcomes for families served.	Combined with other data sources, home visiting data can be used to track longitudinal outcomes for families served. Since home visiting is often one of many programs or services a family participates in, it is beneficial to view outcomes in relation to other programs, and to track longitudinal outcomes, as opposed to examining any single point in time.
D. The MIECHV benchmark data , including literacy data and child/developmental screenings, may be valuable to other programs.	Researchers and program evaluators may find the data associated with the MIECHV benchmarks useful in conducting their own research and evaluations. Data such as literacy and child developmental screens could be used, if external researchers understand that the benchmarks are very precise and not broad in their definition.
E. We generate family and individual intake and eligibility data that may be useful to other programs, depending on permissions to share data.	Depending upon sharing permissions, the data related to intake and eligibility for families, as collected by home visitors, may be useful for other programs to determine eligibility for other related programs and services.
F. Home visiting models request, analyze, and store a lot of data that could be valuable for State and Federal program administrators, as well as researchers.	The models themselves, as opposed to the LIAs or State Agencies, generate a lot of data that could be valuable for State and Federal program administrators, as well as researchers.