



COMMUNICATING EFFECTIVELY WITH FAMILIES ABOUT DATA SHARING

Recommendations and Strategies

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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 this bill directed the Health Services Resources Administration (HRSA) to establish standards for the exchange of data between home visiting, other state programs, and federal agencies. Data about families receiving home visiting services are often stored within each local implementing agency (LIA) or program, which are separate from other early childhood data often stored in another agency or organization. Therefore, it can be difficult for state leaders to exchange these data to better understand how families are served comprehensively across the broader early childhood system.

LIAs are local organizations or agencies that receive funding to implement home visiting services and work with home visitors to provide such services to families. In addition to delivery of services, home visitors are often required to collect data on the families with whom they work. The type and amount of data collected may differ depending on the specific home visiting model requirements, funding source, or agency overseeing the program, or may depend on a combination of all these things.

Sharing or exchanging data can help home visiting programs answer questions about the children and families they are serving that they may not currently be able to answer. For instance, when an LIA or home visiting program shares information with state administrators about the families they serve and the services they offer, state administrators can better measure short- and long-term child and family outcomes after participating in home visiting. Additionally, sharing data between home visiting and other state programs can reduce the amount of data collection required of local programs, as some data can be collected once and then shared across agencies in the state.

Sharing data on home visiting can happen in various ways. For instance, home visiting programs using the same model across the state may share data with one another, or home visiting programs within a county may share data with the same county's health department. Other times, home visiting programs across the state may provide their data to state-level administrators or agencies. It is important for home visitors to understand how data are and are not shared so that they can effectively communicate data sharing practices to the families they serve. LIAs need to clearly communicate with home visitors about why they collect data and how the data will be used. In turn, home visitors must effectively communicate with the families they serve about why they are collecting data, what information is being collected, and how the data will be used.

While home visitors are trained to ensure their effective and appropriate communication with families, their cultural values and perspectives may influence how they ask questions and interact with families. Discussions of data-sharing with families should be culturally competent. Those working directly with families must understand, learn, and appreciate the different beliefs, expectations, and experiences that families have about sharing personal data, and should understand that home visitors themselves hold their own beliefs and expectations about data sharing.

This resource focuses on the importance of effectively communicating with families and provides strategies for home visitors to enact this practice with the families they serve.

WHY COMMUNICATING ABOUT DATA SHARING WITH FAMILIES IS IMPORTANT

Sharing data about children and families between home visiting and other state programs can allow home visiting programs to better answer important questions that inform effective service delivery. Most home visiting programs and models ask families for a wealth of data that track important indicators and outcomes. Yet, families may not know why these data are being collected or how they are being used. Furthermore, home visitors might not have the skills and resources to effectively communicate with families about data collection and sharing.

Families should be active participants in the data sharing process, rather than passive recipients of information provided by programs about how their data will be shared. Historically, data collection and research has been done *on* people rather than *with* people, leading to potential distrust and fear about data sharing. This practice was and continues to be especially harmful for people of color and other marginalized or vulnerable populations. Involving families throughout the process of data sharing is one way to ensure they understand the importance of data sharing and how it may benefit them. It is important that home visitors are knowledgeable about how the data they collect are being shared and can speak with families about their rights regarding sharing of data.¹

Families can become active participants through routine and effective communication about the data sharing process. There are many reasons why this is important. For instance, families:

- ▲ Have a right to know how and why information collected about them is being used and shared
- ▲ Need to understand they have a choice in what they share about their children and themselves
- ▲ May have concerns or questions about why certain data are being shared
- ▲ May want to know how a home visitor, program, model, or agency is protecting the privacy of their data
- ▲ May want to know who has access to their data and what safeguards are in place to prevent data breaches or loss of privacy²
- ▲ Should be informed about why sharing their data can be beneficial, not only to them but also to others

WHAT EFFECTIVE COMMUNICATION LOOKS LIKE

Effective communication involves the ability to give and receive information clearly. It includes non-verbal and verbal forms of communication such as speaking, writing, listening, body language, and tone of voice.¹ Culturally competent communication is defined by HRSA as the “knowledge and skills necessary to communicate and interact effectively with people regardless of differences, helping to ensure that the needs of all people and communities are met in a respectful and responsive way.”ⁱⁱ In

¹ For more information on discussion data with families, please see, Lin, V., Maxwell, K. L., Epstein, D., Hutchison, L., & Burgess, K. (2016). [Data direction 2: Discussing data with families](#). Report #2016-32. Bethesda, MD: Child Trends.

² An exception to data privacy is the requirement of home visitors to divulge information on suspected abuse or neglect.

order to effectively communicate with families about data sharing, becoming culturally competent is a critical first step.

THREE DIMENSIONS OF ACHIEVING CULTURAL COMPETENCY

Cultural competency does not have a prescriptive approach because culture is not one size fits all. At the core of cultural competency is understanding that culture is ever-changing and has different meanings for people, and thus requires home visitors to readily adapt. This resource draws upon a model developed by Calzada and Suarez-Balcazarⁱⁱⁱ that describes three dimensions of achieving cultural competency. The dimensions are:

- ▲ Critical awareness/knowledge: being aware of one's own biases and being knowledgeable about others' cultural background, beliefs and historical contexts.
- ▲ Skills development: building the necessary skills to encourage trust and effectively communicate with children and families from diverse backgrounds.
- ▲ Organizational supports: policies and practices within an organization that enable staff to meet and be responsive to the diverse needs of children and families.

Drawing on the three dimensions of cultural competence, below are strategies home visitors can use to communicate effectively about data sharing with the children and families they serve.

UNDERSTAND WHY FAMILIES ARE BEING ASKED TO SHARE DATA

Home visitors need to have a clear understanding about why a program is asking families to share their data that they can effectively communicate to families. Typically, during or immediately after enrollment, home visiting programs ask families to complete consent forms that discuss data usage, sharing, privacy and confidentiality. A state may also have an additional consent form for families to sign that specifically seeks consent to share data between home visiting and other state programs. Home visitors may use the consent process as an opportunity to further engage families in discussions about data sharing, beyond simply explaining that consent is needed to share data. Further, home visitors might have their own perceptions about data sharing that may affect how they communicate with families. For instance, home visitors may perceive it to be rude or unwarranted to ask families to share data beyond that which is required for model or federal reporting purposes. LIAs should work with home visitors to be able to clearly answer the following questions:

- ▲ Why is the program asking families they serve to share their data?
- ▲ What types of data do home visitors need to collect from families to allow for data sharing?
- ▲ How will the data home visitors collect from families be used and shared, and with whom (if known)?
- ▲ How will sharing of data benefit families they are serving?

BE PREPARED FOR FAMILIES TO PERCEIVE DATA SHARING DIFFERENTLY

Home visitors need to be knowledgeable about the cultural contexts in which the family exists and experiences families may have with data. Historically, people of color and vulnerable populations, such as those who are incarcerated or pregnant, have been coerced or forced into participating in unethical research while receiving little to no benefit from participation. Both short- and long-term physical, psychological, and financial harm have resulted from this practice. Home visitors must learn about the culture and history of the communities they serve and how experiences with research and government institutions might influence community and individual perceptions of data sharing. Ways home visitors

can learn about perceptions, attitudes and beliefs about data sharing include:

- ▲ Speaking with families openly about their concerns. Home visitors can build trust with families by describing what data sharing is and listening to their apprehensions or fears around data sharing.
- ▲ Learning about the cultural backgrounds and histories of the families they serve. Home visitors can determine what common beliefs or values families have about data sharing. Home visitors need to be open and willing to learn about the families and communities they serve.
- ▲ Meeting families where they are in their understanding of data sharing. Some families may be more knowledgeable and comfortable with data sharing while other families may not. Home visitors can determine how much each family knows about data sharing as a way to open the conversation.

ENSURE ALL COMMUNICATION AND MATERIALS ARE EASILY UNDERSTOOD

LIAs can support home visitors in clearly communicating about data sharing through developing organizational supports such as training on assessing cultural and individual preferences about data or actively engaging families in conversations about data. In order to ensure clear communication around data sharing, there are a few key principles home visitors should follow:

- ▲ Information should be explained in the family's primary or preferred oral or written language, and written materials should be at an appropriate literacy level.
- ▲ Information should be presented in a way that is preferred by the family, considering cultural and individual preferences when discussing data.
- ▲ Information should be shared with families about why they are being asked to share their data, and how it will benefit themselves and others.
- ▲ Families should have opportunities to ask questions and seek more information, if needed.
- ▲ Families should be able to confirm their understanding of how data will be shared.
- ▲ Families should understand that they have the right to decide if they want to share their information, and that their decision will not impact their eligibility for or participation in services. This includes deciding to revoke consent at a later point in time, even if they originally gave consent.
- ▲ Families should be active, not passive, participants in conversations about data sharing through open, ongoing, and shared dialog about data.

DETERMINE THE BEST APPROACH TO DISCUSSING DATA SHARING

When discussing data sharing with families, home visitors need to think about a suitable approach. This includes determining when to have the conversation about data sharing and with whom, and how to talk about data sharing in a way that is respectful and understanding of the families' lived experiences, beliefs, and expectations. Recommendations include the following:

- ▲ Ensure there is enough time.
 - Schedule a visit when there is enough time to discuss data sharing. Be sure to confirm with the family that the time selected is still appropriate to discuss data sharing. For instance, home visitors should not broach the subject if they are leaving to go to another appointment, or if the family is distracted and worried about other things.

- Find a convenient time to raise the subject when the family member can focus on the conversation, such as when the children are napping or when there are other adults in the home who can watch the children.
- ▲ Determine which family members need to be present.
 - Speak with the primary contact in the family to learn who should be involved in the conversation on data collection and data sharing. Families may have preferences or cultural norms about who should be involved in these conversations. For instance, a family may require a specific family member to be present for the conversation.
- ▲ Ask the family what the best approach is.
 - Do not assume that all families of a particular racial and/or ethnic group share the same beliefs, values, and expectations. Work with each individual family to understand their preferences for these types of discussions. This will also help the home visitor to build trust with the family.

INCORPORATE FEEDBACK

Part of any effective communication strategy is ensuring there is an ongoing feedback loop that informs future communication. Supervisors or program managers should work with home visitors to understand their experiences when speaking with families about data sharing, so they can improve their home visitor trainings. This includes collecting their own data on how the process is working. For instance, LIAs may consider gathering staff input on how families responded to these conversations. Did families have a lot of questions that home visitors were not sure how to answer? Did families tend to be receptive to data sharing or did they express concern with data privacy? Ways to gather and incorporate feedback include the following:

- ▲ Seek out family input on the process. LIAs and MIECHV awardees can take this feedback to families serving on a data governance or home visiting committees or consortia and gather input on what worked well and how to improve the process going forward. LIAs could also develop a feedback form or survey for families to complete.
- ▲ Examine the data to identify any unwanted trends. For instance, do some home visitors have a 100% participation rate for data sharing among their clients? Alternatively, do some home visitors have very low participation rates? Either of these situations could indicate potential issues with how home visitors are communicating with families about data use and data sharing.

CONCLUSION

Data sharing is a critical component for home visitors, LIAs, MIECHV awardees, and their state and local partners to learn about the needs of the children and families they serve. A key step in this process is learning how to effectively communicate about data sharing with families. It is important for LIAs to help home visitors learn to effectively communicate about data sharing in a culturally competent way. LIAs could develop a plan for communicating with families about data sharing, both at the programmatic level and the individual level. This plan could then be used to train home visitors on effectively communicating about data sharing, while being responsive to the varied needs and beliefs of the diverse children and families home visitors serve.

APPENDIX: RESOURCES TO SUPPORT CULTURAL COMPETENCY AND EFFECTIVE COMMUNICATION

[Data Direction 2: Discussing Data with Families](#): This resource describes why it is important to discuss data sharing with families and tips for how an early care and education program could talk with families.

[Developing Culturally Responsive Approaches to Serving Diverse Populations: A Resource Guide for Community-Based Organizations](#): This resource reviews what it means to have a cultural competency approach for community-based organizations. It directs readers to tools and resources helpful for serving diverse populations including identifying needs, selecting interventions, budgeting, collaborating, and measuring impacts.

[Enhancing Cultural Competence in Social Service Agencies: A Promising Approach to Serving Diverse Children and Families](#): This resource provides information to support cultural competency for organizations that serve children and families from diverse backgrounds.

[Reaching and Engaging with Hispanic Communities: A Research-Informed Communication Guide for Nonprofits, Policymakers, and Funders](#): This resource provides a communication approach to help service providers who work with Hispanic families. It provides recommendations on how to reach intended audiences and communicate effectively.

ⁱ Maternal and Child Health Bureau. [MCH Leadership Competencies – Competency 5: Communication](#). Health Resource and Service Administration.

ⁱⁱ Maternal and Child Health Bureau. [MCH Leadership Competencies – Competency 7: Cultural Competency](#). Health Resource and Service Administration.

ⁱⁱⁱ Calzada, E. & Suarez-Balcazar, Y. (2014). [Enhancing cultural competence in social service agencies: A promising approach to serving diverse children and families](#). OPRE Report #2014-31, Office of Planning, Research and Evaluation, Administration for Children and Families, U.S. Department of Health and Human Services.