

Steps for Obtaining Consent from Stakeholders to Share Home Visiting Data

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Introduction

Home visiting programs collect a wealth of data from families and clients throughout their participation in home visiting services. This information is critical to inform eligibility, tailor services provided, and identify needs for referrals. States may be interested in linking these types of data with data on the same families from other sources (e.g., child welfare system, child care subsidy system, or social service programs). As states begin to integrate home visiting data on families, they will need to first identify which regulations, data sharing agreements, or requirements exist that protect the privacy of families' data when integrating data from different sources. This information will help states determine whether and when family consent is needed to use and share data.¹

Once states identify the requirement(s) for family consent, they will need to develop a process for obtaining this consent. For this purpose, consent is permission provided by a parent or legal guardian to collect, document, access, use, or share data collected from, or about, the child or family. Often, families participating in home visiting or other early childhood programs are already providing consent for data to be collected and used for other purposes. When a parent provides consent, they are acknowledging that they allow for their information to be used or shared by whomever collects it. The consent may also clarify the purpose of data collected, and under what circumstances a program may be required (or plan) to disclose a family's information. When families choose not to provide consent, their information cannot be used or shared, with some exceptions per state or federal law. These exceptions can also be due to particular funder requirements.

The purpose of this resource is to outline suggested steps that data integration leaders can take to determine when and how family consent is needed when integrating home visiting data with other early childhood data. This resource will discuss 1) how to determine when family consent is required, 2) what consent revisions to consider when integrating home visiting data, and 3) the importance of providing consistent information to all parents whose data are integrated across programs.

Step 1. Determine whether consent is required.

There may be a variety of situations in which states may need to seek consent from home visiting stakeholders in order to use and share home visiting data. Sometimes, multiple authorities may require

¹ For more information on the types of authorities and entities states should consult to determine whether individual family consents are necessary for data integration, see *Privacy and Security Considerations When Integrating Home Visiting Data* at <https://www.childtrends.org/publications/privacy-security-considerations-when-integrating-home-visiting-data>.

The State-level Home Visiting Integration with Early Childhood Data Systems (SHINE) project aims to support states in integrating their home visiting data with other early childhood data. SHINE is a project of the Early Childhood Data Collaborative (ECDC), which focuses on the development and use of coordinated state early care and education data systems. This resource was funded by the Heising-Simons Foundation.



that family consent be obtained, so it is important that the consent obtained meets the privacy and security requirements of all of these regulating authorities. The following scenarios may result in the need to obtain consent from families:

- When current consent forms do not allow for the sharing of families' data between programs or agencies
- When an institutional review board (IRB) or data governance body requires that family consents are necessary before integrating their data
- When federal, state, or local regulations stipulate that family consents are required
- When home visiting programs, model developers, or data vendors require family consent

Regardless of the reason consent may be required, it should be obtained from the identified parties as soon as possible. Data on these parties should not be used or shared until consent has been obtained.

Step 2. Determine who must be consented and who will obtain consent.

State leaders will need to identify who needs to be consented in order to use and share home visiting data, as well as who will be responsible for obtaining consent from these individuals. The following stakeholder groups may act as data providers or those who obtain consent:

- **Families:** For the most part, home visiting clients are parents or grandparents of young children. These adults are often the primary client and thus the individual who will be able to provide consent. Many home visiting programs already ask families to sign a consent form upon enrollment with home visiting services. Thus, families that participate in home visiting services are often familiar with the process of consenting to the use of their data. If families are to be consented to use and share their data, home visitors or those who collect intake forms from families upon enrollment may be best suited for obtaining consent because they are familiar with the process. It is important that families fully understand what they are consenting to and how it differs from the consent needed for enrollment and receipt of services.
- **Home visiting models:** When home visiting programs use a specific home visiting model, the model developers may require families in that program to provide consent to share data with the model developer. In this case, the model developer becomes the owner of the data that are collected on families and must be consented to use these data. The model developer subsequently determines how and when to share data with other organizations. If home visiting model developers must provide consent, the state may be responsible for drafting the consent language and corresponding documents such as a data sharing agreement to allow for this data integration between programs.
- **Home visiting programs or local implementing agencies:** Upon enrollment with a specific home visiting program or home visiting services overseen by a local implementing agencies (LIA), families may have consented to allow these programs or agencies to use and share their data. Therefore, it is up to the home visiting program or LIA to determine whether they will consent to sharing their data with other early childhood organizations. Again, the state agencies in charge of integrating home visiting data with other early childhood data may be responsible for obtaining consent from home visiting programs or LIAs either through a consent form or a data-sharing agreement with data security and protection language.

Step 3. Review existing documentation and make revisions as necessary.

State leaders will want to review all existing consent forms or data sharing agreements to determine what data are able to be shared and what information must be communicated to data providers upon the sharing of their data. The following questions may help state leaders understand what should be included in a consent form or data sharing agreement for home visiting data providers²:

- What information will be used for matching purposes? What information will be made publicly available (e.g., in reports or through a data request)?
- Who will have access to the data? Who will not be able to access data? How is access granted?
- How will data be stored and secured? What processes are set up to ensure the security of data or the reporting of breaches of data security?

If the current set of legal documents does not adequately or clearly provide permission for data sharing, state leaders should ask whether and how the documents can be edited or adapted. It is also necessary to consider the level at which the changes or modifications to the legal documents or the process itself can be made. For instance, can the changes be made at the LIA level, or will it be necessary to modify a state-level memorandum of understanding? Modifying a legal document will involve working closely with the state's legal department or entity to ensure that all changes are allowable by law.

In the case that the documents cannot be changed to allow for data integration, state leaders will have to determine what new process will be required to get permission to integrate data. Some possible scenarios include designing and implementing new consent forms, reaching out to individual families enrolled in home visiting programs to ask for permission, or re-designing data sharing platforms that are hosted within agencies and thus able to facilitate sharing (see State Highlight). Many of these options are likely time-consuming and costly and therefore it is important to build in time and resources for this work.

State Highlight

Minnesota integrated one county's family home visiting data into their statewide early childhood longitudinal data system (ECLDS). As they examined the consent language, they found that they would need to revise consent forms to offer families the opportunity to consent to sharing their data with the ECLDS. Saint Paul-Ramsey County home visiting leaders decided to move forward by consenting families newly enrolled in home visiting with the revised form. They trained their home visitors with a new consent form and have seen success in obtaining families' consent to share their data.



² For more information about which components should be included in a data sharing agreement, see Shaw, S.H., Lin, V., & Maxwell, K. L. (2018). Guidelines for Developing Data Sharing Agreements to Use State Administrative Data for Early Care and Education Research. OPRE Research Brief #2018-67. Washington, DC: Office of Planning, Research and Evaluation, Administration for Children and Families, U.S. Department of Health and Human Services. Retrieved at https://www.acf.hhs.gov/sites/default/files/opre/guidelines_for_developing_data_sharing_agreements_508_7_16_18_508.pdf

Step 4. Communicate clearly and consistently to all stakeholders.

State leaders should also plan for how they can clearly and consistently communicate to all relevant stakeholders about how their data will be collected, used, and shared with other entities irrespective of whether consent is required. In other words, even if existing consent forms do not require that data providers are notified about the use of their data, state data integration leaders and data owners should consider how they can communicate when data are being used. Being transparent with stakeholders about the use of their data is an effective way to build and maintain trust and support for integrating stakeholder data. Thus, state leaders should set up a process by which these stakeholders are notified that their data will be shared with other entities. By doing so, stakeholders also have an opportunity to withdraw consent they previously provided, which is their right.

State leaders can use a variety of methods to communicate to data providers about data integration, even if their consent is not required. For instance, to answer data providers' questions, leaders can provide informational fact sheets to all participating home visiting programs or set up in-person informational sessions when data integration begins. State leaders can also communicate via email listservs or other social media platforms to reach a wider audience. Although these communication activities may take some time and effort for data integration leaders to plan and implement, they will be vital to ensuring that data providers are able to participate in the data integration process.³

Conclusion

States must understand whether data providers must be consented before integrating home visiting data with other early childhood data. We recommend that states first determine whether consent is required for home visiting data integration. Then, they must determine who needs to provide consent and who will obtain it, as well as what and how information should be communicated to data providers. States can use the steps detailed in this resource as a guide for obtaining consent to use and share home visiting data; however, states will likely need to tailor each step to their specific state context and unique regulatory needs in consultation with their legal and compliance teams.

³For more information about how to communicate to home visiting stakeholders about the data integration process, see *Engaging Stakeholders in Home Visiting Data Integration Efforts* at <https://www.childtrends.org/publications/engaging-stakeholders-in-home-visiting-data-integration-efforts>.

Example Consent Form

The following is an example of the language that can be used to obtain consent from families to share their data with other organizations.⁴

Authorization to Share Information

Description of [Insert Name of Home Visiting Organization and Program]

[Insert Name of Home Visiting Organization and Program] voluntarily matches families, either before their child's birth or in their child's first year of life, with trained home visitors who provide information and support related to the healthy development of the family's child, the parent-child relationship, and importance of early learning in the home. [Insert Name of Home Visiting Organization & Program] is supported by both state and federal funding.

Description of [PROPOSED WORK BY ORGANIZATION SEEKING DATA]

For the purpose of [Insert Purpose of Proposed Work], it is necessary for [Insert Name of Home Visiting Organization and Program] to share your family and child's health and social information with [Insert Name of Organization Seeking Data].

Description of Information Released with Authorization

Any medical, social, or economic information about me or my family members that is shared with the [Insert Name of Organization Seeking Data] will be kept confidential under both state and federal law. Your authorization will allow information such as [Insert data elements that will be shared, such as parent name, child's name, date of birth, and address] be shared with the agencies listed above. The names and addresses will allow [Insert Name of Organization Seeking Data] to link home visiting data with other service data to better understand the array of services a family is receiving or not receiving compared to other similar families to better plan for future services.

Acknowledgement and Authorization

I understand that [Insert Name of Home Visiting Organization and Program] provides home visiting services to my family and is being asked to submit information on the services and assessments my family received or did not receive to [Insert Name of Organization Seeking Data].

I approve / I do not approve (circle one) including [Insert data elements that will be shared, such as parent name, child's name, date of birth, and address] in addition to other information described above. I acknowledge that I may revoke my approval at any time during participation in home visiting services and may continue participation. I have read this consent form and understand its contents. I understand that I have a right to receive a copy of this form upon my request.

If I have any questions in the future about any aspect of the program or how the information I provide may be used, I can contact my home visitor or their supervisor [Insert Contact Information of Home Visiting Organization and Program]. If I feel my information is not being used within the authority described here, I can contact the [Insert Name of Organization Seeking Data] to request a grievance hearing by emailing [Insert Contact Information of Organization Seeking Data].

Participant's Printed Name

Signature

Date

Parent/Legal Guardian's Printed Name

Signature

Date

(Only applicable if participant is under age 18)

⁴ The sample consent form was adapted from the Home Visiting Service Account administered by the Washington Department of Children, Youth, and Families and Thrive Washington.