



Data Direction 2: **Discussing Data with Families**

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This is one of a set of five “Data Directions” that present issues ECE staff may encounter if they are interested in or attempting to share or link their data with other agencies. Each Data Direction presents a hypothetical scenario, and then outlines possible action steps programs could use to address the issues raised. This second Data Direction offers ideas about discussing data with families, including why to discuss data with families, what should be discussed, who could have these discussions, and when and where discussions could happen.

Mrs. Jones is the director of an early care and education (ECE) program that provides Head Start and pre-Kindergarten services. The program collects a range of *administrative data* on individual children, families, and staff.¹ A few parents recently asked her for more information about what data are collected, what the data are used for, and whether data are shared with any other agencies in the local community. As is required by her ECE program, Mrs. Jones shares information annually with parents about what data are collected on individual children and families, as well as to whom and why these data are shared. However, given the questions she is receiving from parents, she would like improve how her program works with families to ensure that they are informed about data use. She recognizes that it is important to talk with families about data and that they have a right to know and understand what information the program is collecting and sharing or linking with other organizations, especially when it includes information about them and their children.

¹ *Administrative data* refers to any information programs routinely collect about individual children, families, and staff to deliver program services and meet program, funding, or legal requirements. This could include, but is not limited to, demographic information (e.g., race/ethnicity, date of birth), child attendance, and results of screenings.

Mrs. Jones also recently began exploring *linking*² data with the local public health agency to improve comprehensive services for families. She knows that families can help identify important questions to answer with the data, and that linking data might reduce burden on families or help them better navigate complex systems. However, she has not yet talked with families about this potential data linking project. She would like to support her staff in talking with families about this potential project and also about data more broadly, especially considering that the collection and use of data can sometimes raise concerns among both staff and families. As she thinks through how to improve communication around data, how should she do this? She may want to consider five basic questions: *Why, What, Who, When, and Where*.

WHY should a program discuss data linking and use with families?

Families have a right to know and understand the information programs are collecting about them and their children, as well as what data are shared or linked with other programs or agencies. Families may also help identify ways to make the most out of a data linking project, including identifying questions that the linked data can help answer. Some families may have concerns or questions about how a program is using their data. Involving families in data decisions and addressing their questions and concerns can help families understand their rights to privacy of personal information, how programs will protect their data, and the many benefits that come from sharing and linking data. The following questions or concerns may come up as programs and families discuss data:

- Families may have questions or be concerned about what data are collected and for what purposes.** Notifying families about the data the program typically collects and why the data are collected (e.g., to determine eligibility for services, to examine progress children are making, to help the program better meet the needs of families) can help ease these concerns and build understanding with families. Staff may discuss this as part of the enrollment process, and suggested topics to discuss can be found in the *WHAT should staff and families discuss about data* section of this document below. Families may feel more comfortable with the information the program collects and with giving permission to link this data with another organization if they know how it will (and will not) be used. For example, Mrs. Jones would like to know which children in the program are up to date on their well-child visits and immunizations. If she linked data with the local health department, she could access this information more easily. She could include parent representatives in a meeting with ECE staff to explain that by linking data from the two organizations, the program can quickly identify which children need follow-up visits to get the health services they need. She could also send a letter to all families to let them know about this opportunity. See *ECE Program Tip #1* for additional information about the reasons or purposes for which programs collect data.



² In this resource, data are considered linked when information from two or more separate data systems or databases are shared, connected, combined, or merged. These data systems or databases may be housed in the same program or in multiple programs or agencies. Linking can occur in various ways ranging from simple, (e.g., sharing a spreadsheet) to more complex (e.g., merging two databases into a single file), to very complex (e.g., fully integrating data across multiple agencies). However, all linked data have the potential to provide useful information to support ECE program improvement.

ECE Program Tip #1: Discuss with Families Why Administrative Data are Collected

Possible question from a family: What data do you want to collect about my child and family and why do you want it?

Possible staff discussion points:

Our program collects different kinds of data for different purposes, such as:

- To determine child/family eligibility for an array of services (e.g., TANF, WIC) and ensure that services are provided to the population most in need of services
 - These data might include, for example, family income or employment status, documentation of a child's developmental delay, or a family's housing status
 - The program may need data to document services it or a community partner provides and ensure children and families are receiving needed services for which they have been referred
 - These data might include, for example, the number of times a home visitor meets with a family or the date the Health Department staff completed a developmental screening of a child as well as the findings from the screening.
 - To track progress children are making (e.g., recording child assessments) and support their continued development
 - Teachers might take notes on what the children in their classroom know and can do. They might also collect child assessment data on children's progress in different areas, such as language and early math skills. Teachers use these data to guide instruction and to discuss child progress with a family during parent conferences.
 - To include in required reports for funding agencies and ensure compliance or continue to grow and develop the program
 - This information might include, for example, the number of days a child attended the program each month or the age of children served.
 - To listen to families and improve the program to better meet their needs
 - This information might include an annual survey of families about how well the program meets their needs or observations of classroom quality to help the director provide useful professional development for staff.
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- ***Families have a choice about the sharing of their personal information.*** Individuals have a right to decide what personal information to share and programs have a responsibility to protect the privacy of the children and families served. Generally, families have a choice in whether the program shares their data with outside organizations. In these instances, programs may ask a parent or legal guardian for permission (or *consent*) to use and share data about their child or family. Providing information to families and engaging families in a conversation about data will help them make an informed decision about whether to give consent to share certain information. There could be exceptions to consent, and program staff should understand program and funder requirements about required versus optional data collection and sharing activities, as well as required data protection policies. This will enable staff to have informed conversations with families and answer any questions about data (see Program Tip #2 for more information). For instance, in the example scenario above, Mrs. Jones might consider asking a small team of teachers and families to help her review and update the program's parental consent forms to ensure that relevant and helpful information is included; that it makes sense to families; and that it is up-to-date with new information about the data that will be linked with the public health organization, once that data linking partnership is further developed.

- **Families may want to know how the program will protect their privacy.** Data collected by the program will often contain sensitive or identifying information about children or families. Ideally, any data the program shares and links with data from another organization will *not* contain identifying information; however, this may not always be the case. Therefore, it is important to protect this information, both that which is stored by the program and linked with another organization. Families may feel better about the collection and linking of sensitive information once they understand how programs protect this information in their own program as well as when they share or link it with another organization. Describing protections in place, such as confidentiality agreements, data sharing agreements, secure storage of data with personally identifiable information, and using unique identifiers (UIDs) to match and link data records can help families understand how their privacy is protected. The section below, *WHAT should staff and families discuss about data*, provides additional information on what a unique identifier is and how to protect sensitive information.

ECE Program Tip #2: Find Out about Policies, Guidelines, and Considerations in Protecting the Confidentiality of Child and Family Data

ECE programs that receive state or federal funds may have to follow particular rules or regulations about when and how to obtain parental consent when collecting data or linking data with another organization. For example, the current Head Start Performance Standards describe the circumstances for which a Head Start program must obtain parental permission or consent (e.g., determining eligibility). The Head Start Program Performance Standards were under review at the time of this publication, and the proposed new standards include additional requirements for protecting the privacy of data on children and families, when parental consent is needed to share data, parents' rights related to data, and appropriate maintenance of child records. When finalized, the revised Head Start Program Performance Standards will be available on this website: <https://eclkc.ohs.acf.hhs.gov/hslc>. Depending on the funding source and type of early childhood program, additional federal regulations about protecting children's privacy may also be relevant.¹

To find out more information about these policies and the need for parental consent, programs can reach out to a local technical assistance (TA) provider, a Head Start Collaboration Office, or resources provided by the [Privacy Technical Assistance Center \(PTAC\)](#).²

Here are a few additional resources with more information about these issues:

- [Family Educational Rights and Privacy Act \(FERPA\)](#)
- [Children's Online Privacy Protection Rule \(COPPA\)](#)
- [Health Insurance Portability and Accountability Act \(HIPAA\)](#)

¹ For instance, depending on how an ECE program is funded and what type of agency they are, the program may be subject to requirements under FERPA or IDEA Part B or C for protecting the privacy of children's information.

² The Privacy Technical Assistance Center is funded by the U.S. Department of Education and serves as a resource on data privacy, confidentiality, and security practices for student data.

- **Families may be concerned about how and why others may be using their data.** If a program decides to link data about individual children and families with data from other organizations, discussing this decision with families, and sharing what data will be linked and the reason(s) to link those data can improve the effectiveness of the data linking project. For instance, Mrs. Jones may also be interested in linking data with the local agency that administers the Temporary Assistance for Needy Families program, so she could identify families that may not be receiving services they are eligible for, and help them complete the application form.³ Mrs. Jones could invite the public health or TANF

³ Refer to another resource in this series, *Case Study #3: Telamon North Carolina Corporation's Collaboration with a County Agency*, to learn more about how a Head Start program linked family data with TANF data from a community agency to improve service coordination and program enrollment.

agency director to attend the next parent meeting so that families can meet the team involved, and everyone can talk together about the possibility of this data linking project. Families may feel more comfortable if they understand which specific pieces of information will be linked (e.g., child age, family income), and the reasons for wanting to link the data (such as how the linked data would benefit the program, child, or family). It will also be important to explain the choices families have about linking (or deciding not to link) their information with other organizations.

WHAT should staff and families discuss about data?

Mrs. Jones will want to address the following important *What* question with families in her program: **“What rights and protections do I have to maintain the confidentiality of my family’s data?”** Whenever data are being collected and linked, it is important to let families know the steps a program takes to protect their data. Program staff can also discuss and share the policies, rules and regulations a program follows (See ECE Program Tip #2 for more information about these regulations). Below are example questions that families in Mrs. Jones’ program might ask or concerns they might express, as well as possible strategies for addressing these concerns.



- **“I’m concerned that staff might talk about the private information I provide, like our family income, with other people in the community.”**
 - *Confidentiality forms:* Programs may require staff members who have access to data about a child or family to sign a confidentiality form. By signing a confidentiality form, the person agrees not to share any personally identifiable or sensitive information about individual children and families and to follow program procedures about data use and data security. It may be helpful to explain these forms to families and any other ways a program protects information about individual children and families. Additionally, families should know which staff members will have access to their information (this may be part of a parental consent form or parent handbook).
- **“Where do you keep the data you collect and how do you keep it safe and confidential?”**
 - *Secure data storage:* *Personally identifiable information* (i.e., information that could be used to identify a person such as a child’s address, name, date of birth or social security number) should be stored so that only individuals who have permission to see the data have access to it. For example, electronic data can be stored on a secure electronic drive or on one computer that is locked in an office, accessible only to those with permission. Paper documents with personally identifiable information can be stored in locked filing cabinets. It is important to talk with families about the precautions a program uses to maintain the safety and confidentiality of the data collected.
- **“How will you protect data on my child and family that you share or link with another organization?”**
 - *Data-sharing agreements:* When data are linked between a program and another organization, creating a data sharing agreement (often called a Memorandum of Understanding or MOU) can ensure that both groups know exactly what data will be linked, how the data will be used, and the shared standards for privacy and confidentiality of the data. Data sharing agreements often include policies and procedures for the destruction of data after it is no longer needed. These agreements can also describe what each organization or program hopes to learn from using the data. If a program has this kind of data sharing agreement in place, staff can explain the document to families and discuss what policies are included to protect their family’s information.

- “When you share my data with these outside organizations, will they know it is my data?”
 - *Unique Identifier:* A unique identifier is a single, unduplicated number that is assigned to an individual and can be used to match child and family data that are stored in different datasets or programs. It can also be used *instead of* providing personally identifiable information about a person, like their name or social security number. For instance, staff may assign a child the unique identifier of 2117. They can then use this number, 2117, in databases or on paper forms instead of including personally identifying information like the child’s name. Thus, a unique identifier helps protect the confidentiality of data that a program collects by minimizing the use of information that could identify a person.

ECE Program Tip #3: Learn More about Creating Data Sharing Agreements or Memoranda of Understanding

Creating a data-sharing agreement can involve drafting legal and technical language to ensure that data are kept confidential and private. Partner organizations can assist programs in developing these agreements, or they may already have templates that the program could modify and use for their purposes. The following resources are a starting point to help your program develop a data-sharing agreement:

- The Administration for Children and Families (ACF) in the U.S. Department of Health and Human Services has a [Confidentiality Toolkit](#) that provides examples of a Memorandum of Understanding and a data-sharing agreement. Specifically, Appendix B of the Toolkit provides examples of data-sharing agreements in Kentucky, New York, and Colorado that your program could use.
- The Privacy Technical Assistance Center (PTAC), funded by the U.S. Department of Education, has a [data-sharing agreement checklist](#) to help programs integrate federal policies into data-sharing agreements. The checklist also provides other resources your program can use to create data-sharing agreements.

WHO should discuss data use with families?

Depending on the structure of an ECE program, and how that program typically communicates with families, there are many different ECE staff who may potentially need to be prepared for discussions with families about data use. Program directors such as Mrs. Jones may want to consider questions like: Who would be the best person to discuss with families how the program uses and links data? Should the first person that the family meets share some information? Should the person who has the closest relationship with the family be the primary person who discusses data use? If there is someone who speaks the same language as the family, would they be the best person to communicate this information? Below are examples of ECE program staff Mrs. Jones may consider asking to communicate with families about data collection and data use:

- **Family service workers:** In Head Start programs, a family service worker often helps families complete forms and sign up for the program. This person could also discuss with families how the program uses and links data and explain any forms or policies the program has related to data use and linking.
- **Teachers:** Families frequently interact with their child’s teacher. Because data can be confusing, having a close relationship with a program staff member may help the family feel comfortable asking questions about data. Even if teachers are not the primary person to explain the program’s policies and procedures about data to families, it is important that teachers are knowledgeable about their program’s data practices so that they can answer any questions families may have.

- **Directors:** Directors are key in promoting open, respectful discussions among staff and families about data. Directors can also invite families to join advisory boards, a data governance entity (if the program has one),⁴ or other groups to talk about data issues. Programs benefit from proactively involving families in data discussions *before* data are collected, linked, or used as well as *after* data are analyzed. For instance, before data are shared with another organization, program directors may want to talk with families to decide what child and family data the program will link, as well as how programs might use those data. After data are linked and analyzed, the director or staff could discuss the results with families and what the data might mean for improving services. Working with families to understand what the data mean can be particularly important if the program would like to help parents understand the benefits of sharing and linking data with outside organizations.

If programs do not have a staff member who speaks the family's native language, programs should use other resources to translate information related to data use and linking into families' native language for ease of communication and transparency of data practices.

WHEN and WHERE should staff talk with families about data?

Programs should identify the best time, location, and frequency for discussions with families about the data they collect and use in their program, and possibly share with other organizations. For instance, although staff in Mrs. Jones' program might communicate with families about data on a regular basis (e.g., annually, through program handouts), it may be helpful to set aside specific times to discuss with families the program's policies and practices about data use and linking. Additionally, involving family representatives in program leadership groups or committees can help ensure that parents have a voice when issues related to data linking and use are discussed. Mrs. Jones could also choose to host an open meeting to provide an opportunity for families who are interested in participating in a conversation around data, particularly if there are interesting findings to share from analyses Mrs. Jones' staff (or a partner organization) conducted with the data. For example, by linking data with the local public health agency, Mrs. Jones may be able to identify many children in her program who had already received immunizations. This would reduce burden on family service workers, as they would not have as many families to follow-up with regarding immunization records. Mrs. Jones or her staff could communicate this benefit of data linking to families. They could also discuss whether there are additional areas of interest that might be possible to learn more about with linked data. Below are a few options that might work well for when and where Mrs. Jones or her staff could discuss data policies, data use, data sharing, and/or any interesting findings from analyses with families:



- **During a pre-enrollment visit:** Programs may offer a pre-enrollment meeting or visit to families before enrolling in the program. If the program requires particular data from all enrolled children and families, it will be especially important to explain this so that families have the information before choosing to enroll. A pre-enrollment visit can happen either one-on-one or in a large group.
- **During the enrollment process:** In many Head Start and other early childhood programs, consent to collect and use a child or family's data is obtained during the enrollment process. If a staff member meets with families to review the enrollment packet, then this could be a good time to talk about data use and policies. Programs may also want to give families a handout about the data a program collects and potentially shares with other organizations, as well as a copy of the policies that guide their use of the data. ECE Program Tip #4 provides an example of a data handout that a program might provide to families.
- **At an open house or family meeting:** Many programs have open houses or family meetings throughout the year. These events could provide opportunities to talk together about data issues, review data policies and discuss

⁴ For more information on data governance, see *Data Direction 1: Creating and Managing a Data Governance Entity*, another resource in this series.

needed revisions, describe any new or existing data collection activities or uses, share findings from a data linking project, and answer questions families have. It is important to recognize, though, that not all families attend these events.

- **During a parent-teacher conference:** Parent-teacher conferences are a great venue for discussing data issues one-on-one with families. Especially for child assessment data, teachers may want to use a parent-teacher conference as a time to remind the family how the teacher or program is using (and protecting) the data, as well as how their child is progressing in various developmental domains.
- **At a family resource center:** Programs may want to include in their family resource center or parent library a document that describes the program’s policies and procedures related to data collection, use, linking, and security. This may be a helpful reference for families who would like to review additional information on data policies.
- **During an advisory board or parent group meeting.** Families often serve on advisory or leadership boards for ECE programs. Program staff can talk about data use and engage the group in setting policies and identifying priorities in how best to use data to improve program quality and better serve children and families.

ECE Program Tip #4: Share Information Related to Data Use with Families

To help summarize information for families, programs can develop a handout about the data a program collects and/or plans to link with other organizations, including when data are collected, who will collect it, and how it will be used. We provide an example of a handout below that could be used in Mrs. Jones program. Note that the types of data a program collects and/or links with other organizations may not be the same as below; this is only meant to serve as an example that programs can modify.

Type of data collected	When data are collected	Who will collect the data	How will the data be used and/or linked
Child assessment data (e.g. Teaching Strategies GOLD)	On a specified timeline (e.g., in the fall and spring; or three times a year)	The child’s teacher	<ul style="list-style-type: none"> • Used by program to help teachers tailor activities to the individual needs of the child. • Linked with the local public schools to inform transition to school.
Family survey data	Once a year	Program staff	<ul style="list-style-type: none"> • Used by program to learn more about the children and families in the program and help determine eligibility for services. • Linked with local social service agencies to learn about the kinds of services families might already be receiving from community partners, and what additional services they might be eligible for.
Child attendance data	Every day	The child’s teacher	<ul style="list-style-type: none"> • Used by program to help record attendance rates and understand patterns for individual children. • Linked with the local public schools to understand how ECE attendance might relate to kindergarten readiness.
Child health information	Twice a year	Family service worker	<ul style="list-style-type: none"> • Used by program to help plan for any additional health services that children might need that the program could provide • Linked with the local health department or clinics to identify additional services or supports children might need and provide any needed referrals

Summary

It is important that ECE program staff and families have regular communications about the data collected on children and families, how the data are used, and whether data are linked. Programs can use the *Why, What, Who, Where, and When* questions to develop a plan to engage families meaningfully in the process of collecting, using, and linking data. Knowing *why* a family might have concerns about data collection and sharing helps prepare programs to address potential questions. Programs can develop an inventory of data to help them accurately communicate with families about *what* data they collect and how they will use those data. The plan could also include guidance about *who* should be prepared to communicate with families about data, and options for *where* and *when* these communications could take place.

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