



Case Study #2: The Learning Center for Families' Use of Data to Support Children's Healthy Development

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The Learning Center for Families provides health, family support, and school readiness services in a rural community. This case study describes how the program accesses and matches health data from a variety of other agencies in the community to link important information to better serve children and families. This case study highlights an example of linking data that involves staff from multiple different agencies sharing data on children and families with staff at another agency.

The mission of The Learning Center for Families (TLC) is to “promote the success of children one family at a time.”¹ Since 1993, they have provided comprehensive health, family support, and school readiness services for rural communities in Washington County, Utah, and a rural part of northern Arizona known as the Arizona Strip. TLC works in partnership with families, state agencies, and health professionals to support the healthy development of infants and toddlers by fostering children’s cognitive, emotional, social, language, and physical development from birth. In order to support this cross-cutting work, TLC link their program data with health data from multiple sources in order to provide more comprehensive support to the families in their programs.²

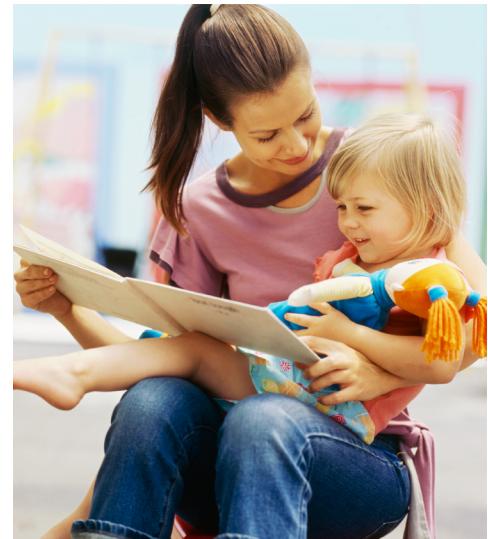
¹ A description of The Learning Center is available at <https://tlc4families.org/about/>

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.

Last year, TLC served approximately 600 children and their families through home visiting, early intervention services, and parenting classes. TLC serves children with and without developmental delays, and provides home-based services to parents who are low-income and experiencing high levels of stress. Focusing on pregnant mothers and children birth through 36 months, TLC offers the following four core services:

1. Early intervention (EI) home-based services for infants and toddlers with developmental delays,
2. Early Head Start (EHS) home-based program to support the health and learning needs of pregnant mothers and children under 3 years of age through home visits,
3. Parents as Teachers (PAT), a program targeted to low-income, high-risk pregnant mothers and families of young children that includes home visits and group parenting supports, and
4. Kindermusik, a series of parent-child classes that infuse early learning with music and movement to promote children's early development.

Some children and families may be eligible for more than one TLC program. For example, a family enrolled in EHS or PAT may also receive early intervention services if a child is identified as having a developmental delay. Program staff work closely with other programs both internally and externally to identify families who qualify for their services and connect children to needed health and developmental care services. Information from other organizations is shared with TLC to reduce the burden on families who use multiple government-funded services.³ TLC and the agencies developed memorandums of understanding to outline the responsibilities of each party to collaboratively provide services and share information. They also agreed to coordinate family referrals, staff training, and data reporting processes. This coordination is intended to create a smooth and timely transition for families accessing multiple services in the community. For example, if a family enrolled in EHS or PAT has a child suspected to have a disability or delay, the family, with consent, is immediately referred to EI to determine if additional services are needed. The EHS or PAT program then shares developmental screening, health and nutrition history, and family service plan data with EI program staff, as needed, to support this transition. This case study focuses on the tools TLC uses to link their program health data with data from other programs and agencies to determine family eligibility, support family goals, and coordinate services.



Cross-Training Staff Supports Data Collection and Service Delivery

One way that TLC coordinates their EI, EHS, and PAT programs is through cross-training program staff to gather required reporting information and provide services across all the TLC programs. This cross-training enables staff to immediately address and appropriately communicate the needs of the family to other service providers to arrange for additional services as needed. Program and administrative staff are responsible for collecting, entering, and managing data about children and families served. The administrative personnel are responsible for conducting intake calls to enroll families and entering information into the EI and EHS databases. The data administrator aggregates, analyzes, and develops reports using program data. PAT data are managed by program staff and shared with EI and EHS with parental consent as needed. Two registered nurses, a Health Services Assistant, and a Medical Records Clerk are in charge of requesting and releasing health records and entering the information into the EI, EHS, and PAT databases. TLC maintains these data in four separate databases:

1. Early Intervention: Baby Toddler Online Tracking System (BTOTS) in Utah
2. Early Intervention: Infant-Toddler Electronic Administration and Monitoring System (ITEAMS) in Arizona

³TLC has *memorandums of understanding* to share information and coordinate services with groups such as: Medicaid, Southwest Behavioral Center, Utah Dept. of Health, Utah Dept. of Health and Human Services Division of Child and Family Services, Utah Statewide Immunization Information System, and the Special Supplemental Nutrition Program for Women, Infants, and Children.

3. Parents as Teachers: Office of Home Visiting Case Management System in Utah
4. Early Head Start: ChildPlus in Arizona and Utah

For each visit, program staff⁴ complete a form called a *contact sheet* to collect child health and development data as well as some family data. The contact sheet includes the date, type of service, duration, activities, and goal setting for each visit. A copy of the sheet is given to the family for their records, and the original form is returned to the office for data entry. The information is then given to the appropriate staff person trained on reporting requirements for each program, who enters the data into the proper database on the secure server. The next section provides more information on TLC's processes for obtaining parental consent as well as the collection, sharing, and use of health data gathered by TLC and other health organizations (i.e., medical homes, state health department, or Medicaid).

Process for Accessing, Linking, and Using Child Health Data

Obtaining Parent Consent

Before accessing any information about children served through their programs from within or outside the agency, TLC first obtains parental permission to access medical or family services data from EI, EHS, PAT or external agencies. Families sign a consent form to give permission for TLC staff to receive their family's information from other agencies, hospitals, and programs. Table 1 describes examples of health data requested, the source of the information, type of consent requested, and how TLC uses the data. Families can choose to provide consent for TLC to access none, all, or some of the data by completing a release/request form. In some cases, TLC is already authorized to access some data for certain families because of their status as a Part C early intervention provider; however, a family is still notified of this access by TLC and can decide to not share their data.

Table 1: Health data linked to plan and coordinate services

Health Data	Data Source(s)	Type of Consent	Use of the Data
EI family service plan	BTOTS (UT), ITEAMs (AZ), ChildPlus	Data only released to non-early intervention staff per parent signature	Staff coordinated family plans and transition services for children who are dually enrolled in EI and EHS or EI and PAT.
Medical records	Dental Home, Medical Home	Parent Release/Request Form	Staff linked dental, medical, and mental health records with home visiting data to monitor child's health status, need for follow up care, and/or diagnosis for eligibility for early intervention.
Immunization records	Utah Statewide Immunization Information System	Accessed through state agreement for authorized users ⁵	Staff linked state immunization records with program databases to verify that a child has received immunizations for EHS and PAT program enrollment, and conduct follow-up with families as needed.
Birth history, height, weight, occipital-frontal circumference	State WIC/ Medical Home, Hospital	Parent Release/Request Form	Staff linked health data with home visiting data to develop service plans based on a child's developmental needs and to monitor children for health conditions.
Medicaid number	Utah Health Department	Interdepartmental agreement with state health department authorizes access for early intervention programs	Staff requested Medicaid status to determine if child has access to health insurance. It is also used to bill for early intervention services.

⁴ Program staff includes nurses, teachers, assistants, social workers, and home visitors who provide direct services to children and families.

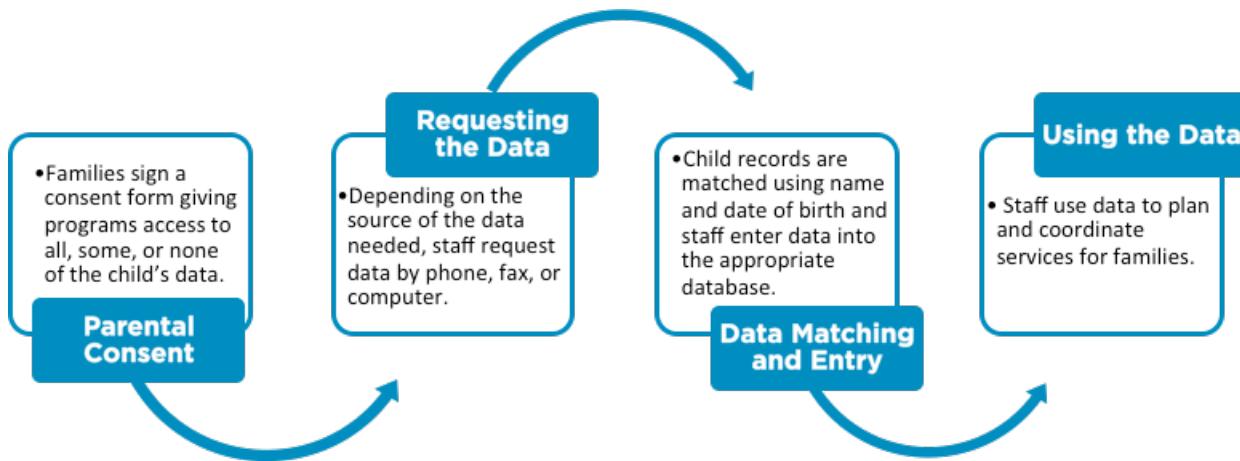
⁵ Authorized users include health department programs (i.e. early intervention), medical homes and community health providers.

Requesting and Matching Data

TLC staff access information in various ways. After TLC has received parental consent, child records from EI, EHS, PAT, or other health organizations are matched using the child's name and date of birth. Depending on the source of the data needed, staff may request data by phone, fax, or computer. Once the data are received, it is then entered into the EI, EHS, and/or PAT databases to be used by program staff (see Figure 1). For example, all programs must certify that families have access to health insurance to appropriately monitor and support children's health development. To verify whether a child has current Medicaid coverage, TLC staff access information from the Utah Department of Health Medicaid Eligibility Lookup tool on a secure network. Staff log into a password-protected website accessible only to authorized users. The child's Medicaid number and status are then entered into the EI, EHS, and PAT databases to verify coverage.

Because TLC's early intervention and PAT home visiting programs are considered health department programs, their data are part of the Child Health Advanced Records Management (CHARM system). CHARM, managed by the Utah Department of Health, links data from early intervention, newborn hearing screening, home visiting, and the Utah State Immunization Information system. These data are entered by TLC staff into the child's record in ChildPlus to record if the child has an individual family service plan and the effective dates of the plan. Linking these data helps TLC easily access information for treatment purposes about the services a child has already received and any follow-up care that is still needed. TLC shares family contact and health information from their EI program with CHARM if a parent or guardian has completed TLC's consent form granting permission. Access to CHARM is password protected to ensure the security of the information and to control access. Families provide written permission to share their child's contact and health information through CHARM.

Figure 1: Process for accessing, linking, and using health data



Using the Data

TLC staff use data from the local and state data sources listed above to better serve children and families. In particular, they:

- Link past child vision and hearing screening data with EI, EHS, and PAT records to reduce the need for multiple assessments and burden on families.
- Link physical, dental, and mental health diagnoses from medical records with information collected by home visiting staff to work with families to develop strategies for keeping their child in good health.
- Link immunization records, doctor visits, and medical insurance to verify program requirements and reduce paperwork for families.
- Link data on Medicaid coverage to EI, EHS, and PAT records to ensure children have access to medical services and help families re-establish eligibility if they lose coverage. TLC staff sends reminders to families to avoid loss of coverage and helps families re-establish eligibility, if needed, by helping them complete the Medicaid forms and gather the necessary documents.

Linked data are used to develop early intervention plans based on infants' and toddlers' developmental delay areas and recommended medical interventions. For example, a child diagnosed with recurrent otitis media (a middle ear infection) would be referred to an ear, nose, and throat specialist. The diagnosis information from the medical home data file is linked to the family's TLC record so a home visiting specialist can have easy access to the medical information to help her talk with the parent about the effects of ear infections on children's development, discuss treatment plans, and, if needed, help set up future medical appointments.

Linking health data also can reduce the burden on children and families. For example, if a child enrolled in EHS is referred to the Early Intervention program, the parent can give permission for EI program staff to access the EHS assessment data to determine eligibility rather than having their child retested. As another example, EHS families can give staff permission to access medical information so that the program staff can verify that a child has received immunizations, attended well-child check-ups, and has a medical home. TLC's access to these records reduces the burden on both families and staff to gather the information needed to maintain up-to-date child records.

Summary

TLC works in partnership with families, state agencies, and health professionals to ensure each child has a healthy start. By linking health data from multiple sources, TLC has been able to provide more comprehensive support to families through home visits, early intervention services, and parenting classes. In the future, TLC is interested in automating some of their data sharing across program databases and with other agencies to improve the efficiency of this process. Strengthening these relationships and linking data across programs and agencies will help staff have the information they need to support families with young children during these critical early years.

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