

# Family Services Systems Change: Exploration and Building Partnerships

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This document is intended as a guide for state deaf-blind projects as they engage in systems TA planning and delivery related to family services. It is part of a broader resource called [Changing Systems: Moving Beyond Child-Specific Technical Assistance](#), which is where you will find specific systems-change activities.

There are two main sections:

- **Exploration** – Gathering information about family needs in your state, learning about agencies and organizations that assist families, and determining where your project can have the most influence and impact
- **Building Partnerships** – Developing partnerships with individuals and organizations that share your goals for improving services to families

“System” refers to a collection of agencies and individuals and the regulatory structures and processes that guide how they function. Systems-change TA related to family services is a little different than that of other national initiatives. This is because there aren’t large systems in most states that exist specifically to meet the needs of families of children with disabilities. Instead, family services are a part of larger systems (e.g., a state department of education) or are handled by smaller agencies (e.g., Parent Centers). This provides many opportunities to impact services.

A useful approach to systems change in this area is to look first at the services you are and are not able to offer to meet the needs of families on your child count. Then, for the services you do not provide or that could be provided better by another agency if their capacity to serve families of children with deaf-blindness were improved, identify the most important agencies or organizations to work with to enact change.

## EXPLORATION

### Needs and Resources Assessment

You likely already have a significant amount of existing data about family services in your state, but may also need to collect new information. This section provides

recommendations about useful data sources and the types of information that can be obtained from each.

Be sure to discuss your findings with other staff members (if you have them) and possibly even your advisory board to obtain a broad perspective on what they mean.

Consider organizing the results into the following categories to help you identify gaps in services.

- Knowledge and skills (e.g., deaf-blindness, high-quality instructional practices, ability to advocate for services)
- Connections to other families and family organizations
- Quality of life of all family members (includes self-care)
- Quality of services (e.g., transportation, respite/child care, waivers)

## Family Needs Assessments

The most important assessment you can conduct is an annual family needs assessment to learn directly from families what they need in terms of knowledge, skills, services, and other supports. This can be done via a survey (mail or email), interviews, or focus groups. Helpful topics include:

- Families' success securing services from agencies and organizations (i.e., services they have accessed and their usefulness)
- Responsiveness of agencies and the professionals who work at them
- Current family training opportunities
- Children's needs and how they vary by age and etiology

This [Example Family Needs Assessment Survey](#) can be adapted (e.g., shorten or change elements) to meet the needs of your project.

## State Child Count

Your state deaf-blind child count includes data that can help you think about how to focus your efforts. Here are some questions to consider:

- Where are families geographically located and what are the implications (e.g., lack of reliable internet access, limited access to other families with children who are deaf-blind)?
- What are the most common etiologies of deaf-blindness?
- Which age groups have the most children?
- What is the breakdown by race/ethnicity?

What are the characteristics of families that typically receive the most attention from your project (e.g., live in particular regions or have children in specific age groups or whose deaf-blindness is caused by similar conditions)?

## Technical Assistance Data

Documentation from previous TA provided to families and service providers can be used to identify common family needs. Documentation includes individualized TA documents (e.g., intake and planning forms, program and classroom evaluations, service provider assessments, student assessments) and evaluations from workshops and other training events. In addition to analyzing this information for patterns of need, be sure to consider how things like geographic location, age of child, and cultural background are related to the needs you identify.

## Information about Agencies and Organizations that Serve or Support Families

Now look at current and potential resources for families. What programs in your state support families of children with disabilities or specific types of disabilities (e.g., deaf-blindness, other sensory disabilities)? These might be state, regional, or local programs (e.g., a school district that serves a large number of children with deaf-blindness). Identify all that could be beneficial for families on your child count either as they are or with changes. Programs to explore include but are not limited to:

- [Parent Training and Information Centers and Community Parent Resource Centers](#)
- State department of education
- [State program for children with special health care needs](#)
- Developmental disabilities services
- Organizations that work with culturally and linguistically diverse populations (e.g., interpreting and translation services, refugee support agencies)
- Relevant organizations or agencies in neighboring states—for example, a medical center across a state line that has a neonatal intensive care unit or other medical specialty services accessed by families on your child count
- [National Family Association for Deaf-Blind](#) (including Affiliates)
- [CHARGE Syndrome Foundation](#) (including State Liaisons)
- Other etiology-specific organizations, if you have a significant number of children on your child count with the conditions they represent (e.g., Usher Coalition, Cornelia de Lange syndrome, Global Foundation for Peroxisomal Disorders)
- [University Centers for Excellence in Developmental Disabilities Education, Research, and Service](#) (UCEDDs)
- Other

Capture information for the programs you research, including:

- Location
- Key contacts

- Services (e.g., training, coaching, consultation, financial aid, counseling)
- Level of support (e.g., do they offer individualized support?)
- How well they meet your families' needs

## Ongoing Needs Assessment

At times, during systems-change activities, you may find that you need to gather additional information in order to move forward. When this happens, it's good to pause and ask yourself the following questions:

- What additional information do we need?
- From whom (audience)? Are there stakeholders not represented in our existing data?
- What tools or processes will it require?
- How in depth should the data collection be (e.g., general information can be collected through a survey, detailed information about how a particular system works may require interviewing or possibly conducting a focus group with stakeholders)?

## Project Capacity

An essential part of making decisions about how to approach systems-change TA is to evaluate your project's experience with systems change in general and with the specific family services you might target. The knowledge and experience of your project's personnel can inform your decision-making in two ways:

1. You may decide to target services with which you already have significant expertise
2. You may decide to target services where your expertise is limited and will therefore need to identify specific topics and issues to learn more about

The following questions can help you evaluate your staff's current knowledge and expertise.

## Overall Systems-Change Capacity

- Are you familiar with systems-change implementation strategies?
- Have you worked on developing or revising policies or regulations?
- Have you participated in advocacy efforts?
- Do you have experience influencing training systems?
- Have you had experience locating funding resources?
- Have you negotiated collaborative agreements or memorandums of understanding?

What support might you need from NCDB or other state deaf-blind project colleagues?

## Family Services Capacity

The first step in evaluating your family services capacity is to review your current family TA processes and procedures. As noted at the beginning of this document, family systems TA often involves improving the ability of other agencies to serve families in areas that your own project doesn't or can't provide. In order to make decisions about where to focus your external efforts, you need to have clear internal processes. [Providing Technical Assistance to Families: A Guide for State Deaf-Blind Projects](#) can help you evaluate and, if indicated, make changes to your project's family TA. This is essential before taking on systems-change activities.

In addition to reviewing your project's processes and procedures, evaluate your current understanding of family systems change:

- What is your level of knowledge about family supports and services? Was this covered sufficiently during your needs and resources assessment or do you need additional information and training?
- What is your level of knowledge of current state and national systems-change efforts to improve family supports and services?
- Do you have project goals (e.g., in your grant application) related to family systems-change efforts?

## Your Project's Location

Where your project is located (state education department, university/UCEDD, school or other agency) can influence your ability to carry out different types of systems work. Being at a state department of education may give you access to regulatory processes that allow you to inform and propose change. Being at a university may give you the freedom to organize grassroots efforts and build model programs.

What limitations and opportunities are associated with your project's home agency with respect to the work you would like to conduct related to families?

## Problem Statements and Prioritizing Needs

Writing a global needs or problem statement provides a clear definition of the problem you want to address, not only for yourself but for partners you would like to recruit and stakeholders you hope to influence. Based on your needs assessment, what are the main areas of difficulty for families in your state? What isn't working? Do you have hypotheses for why something isn't working? Clarity is critical for building engagement.

Example problem statements:

1. Families have a need for mental health counseling that the state deaf-blind project does not provide

2. Families have a need for social service case management (e.g., rent, food, respite, financial planning) that the state deaf-blind project does not provide
3. Families need assistance accessing Medicaid waiver supports
4. Families need legal rights and conflict resolution training that the state deaf-blind project does not provide
5. Families need training on child development (or other topics that are not deaf-blind specific) that the project does not provide

Typically, systemic issues involve multiple needs that must be addressed to bring about desired change. Ultimately, it may be necessary to address all the needs, but determining the order in which you address them is important. Prioritize needs in an order that seems logical. This may involve putting the most pressing issues first, but more likely will be an order that makes internal sense.

## **Solutions and Outcomes**

There is overlap between solutions and outcomes, but in general, solutions are what you are proposing should be done and outcomes are what you hope will be achieved as a result.

### **Solutions**

Systemic solutions for your problems/needs should be actions likely to create lasting change in entities external to your project. They typically fall into the following categories (a single solution may fit more than one category):

- Policies/regulations
- Programs (e.g., sustainable training program, community of practice)
- Activities/materials to change an agency or organization's culture or norms (e.g., shift provider attitudes about children with deaf-blindness)
- Processes (e.g., referral or shared training agreements)
- Funding

As you identify potential solutions, it's helpful to think about how they fit with the existing priorities and values of current and potential partners. This is essential for obtaining buy-in. Keeping in mind that your goals must align in some way with potential partner organizations' goals will guide your thinking about with whom to seek partnerships.

For example, if your solution to a need for legal rights and conflict resolution training is to integrate support for families of children who are deaf-blind into PTI activities and services, you would need to ensure that this solution was consistent with the PTI's priorities. Do their organizational goals include extending outreach and services to specific populations? If not, it is unlikely you will be successful.

The following are examples of potential solutions to common family services problems. Due to variations among family systems and services, not all examples apply to every state:

- Embed questions and information about deaf-blindness into the targeted agency's (e.g., PTIs, social service agencies) intake procedures
- Establish a formal process for [agency] to refer families of children with known or suspected deaf-blindness to your project
- Embed information on the unique needs of children with deaf-blindness—and their capacity to learn and thrive with appropriate intervention—into training materials for [agency] staff
- Establish a formal agreement and processes (e.g., planning, dissemination, shared calendar) with [agency] to include families of children who are deaf-blind in their training
- Create a program (e.g., training materials, coaching process) on the needs of families of children who are deaf-blind that could be adopted by [agency] to build their staff's capacity to serve these families
- Embed information about children with deaf-blindness and their families into existing parent training programs offered by universities (often conducted by UCEDDs)

## Outcomes

Outcomes should align with your grant objectives and include desired short-, medium-, and long-term versions. Those that focus on immediate changes you would like to see are as important as medium- and long-term ones because they help you evaluate ongoing progress. You will likely have multiple outcomes, depending on the desired scope of change. As you set outcomes, make initial determinations about how you'll measure them (e.g., surveys, interviews, focus groups).

Examples:

- Targeted agencies' staff members report increased willingness to serve families of children who are deaf-blind (**short**)
- Targeted agencies' staff members report increased confidence to serve families of children who are deaf-blind (**short**)
- Increased referrals of families from targeted agencies (**medium**)
- Staff members at targeted agencies have increased knowledge of deaf-blindness (**medium**)
- Parents report improved services from targeted agencies (**medium**)
- An increased number of families of children with deaf-blindness are served by targeted agencies (**long**)

- The quality of targeted agencies' services to families reflect an increased understanding of deaf-blindness and the capacity of children with deaf-blindness to learn (*long*)

## BUILDING PARTNERSHIPS

### Existing Partners/Relationships

Many of your current partnerships may be with agencies or organizations listed in the "Needs and Resources" section above that provide services or support to families.

Here is the list again:

- [Parent Training and Information Centers and Community Parent Resource Centers](#)
- State department of education
- [State program for children with special health care needs](#)
- Developmental disabilities services
- Organizations that work with culturally or linguistically diverse populations
- Relevant organizations or agencies in neighboring states (e.g., a medical center)
- [National Family Association for Deaf-Blind](#)
- [CHARGE Syndrome Foundation](#)
- Other etiology-specific organizations (e.g., Usher Coalition, Cornelia de Lange syndrome, Global Foundation for Peroxisomal Disorders)
- [University Centers for Excellence in Developmental Disabilities Education, Research, and Service](#) (UCEDDs)

Use these and other existing relationships to gain access to a system or help you get connected with individuals in that system. Ask families on your child count about organizations they are involved with such as state parent organizations, national family associations, and school boards. If you have an advisory board or parent council reach out to the members for their input.

For each partner, capture:

- Who they are (name, role, agency)
- Opportunities they offer to families
- Whether they possess enough authority to support systems change efforts
- What your ask of them is and how it relates to your problem statement and potential solutions
- What you can you offer them

## Potential Partners/Relationships

Look for gaps in your current partnerships. Who else do you need to recruit? They might be people with power and influence in the system you are targeting or who have knowledge, skills, and resources your current partners do not have. Consider including individuals or agencies with expertise working with non-English-speaking families and families from a variety of cultural backgrounds.

Guiding questions:

- Who works on the issue nationally? What type of support can they offer?
- What task forces, councils, interagency groups, or other decision-making/advisory bodies are likely to be interested?
- Is there a low-incidence infrastructure in your state (e.g., low-incidence advisory or interagency group, disability-specific consultants in your department of education)?

Whether drawing on existing relationships or pursuing new ones, be mindful of what you ask for and what you can give back in terms of time, resources, and expertise.

## Developing Agreements

Because systems-change efforts involve collaboration among agencies or organizations, written [memorandums of understanding \(MoUs\) or collaborative agreements](#) are essential. They outline what the work will entail and how responsibilities and resources will be shared. They are co-written between the entities involved.

## Low-Incidence Infrastructures and Advisory Groups

These groups and structures should be coordinated with implementation teams as they plan, organize, and implement systems-change strategies and activities.

### Low-Incidence Infrastructures

Low-incidence infrastructures refer to programs or groups within a state or region responsible for meeting the needs of individuals with low-incidence disabilities. They are not just specific to special education, but actually have a clear low-incidence focus (e.g., deafness, visual impairment, deaf-blindness). Examples include:

- A state department of education's regional service delivery system with specialized low-incidence disability consultants and services
- Statewide advisory or interagency groups
- Other advisory groups
- Schools for the deaf or blind outreach programs

- Commissions for the blind that provide services across the lifespan

Partnerships with individuals and agencies that operate within low-incidence infrastructures are essential for many systems-change efforts. Without them, it's difficult to influence existing state and regional agencies, programs, and initiatives. Some type of low-incidence infrastructure at the state or regional level will be needed (or developed if it does not exist) to engage in the exploration and planning phases of systems-change projects in order to clarify the problem and identify solutions. If you have these types of groups in your state you need to understand who they are and partner with them.

## **Advisory Groups**

Many states lack low-incidence infrastructures, have ones that don't adequately represent the interests of children with deaf-blindness and their families, or are restricted in their ability to advocate for needed change and improvement. While it is critical to have representation for deaf-blindness inside existing infrastructures, external entities are also essential because they can increase the visibility of children with deaf-blindness and their families. Groups such as deaf-blind task forces or advisory councils bring together stakeholders in a common cause to do just that.

Like infrastructure entities, task forces and advisory councils are not responsible for the implementation of solutions within systems. They serve a larger adaptive function of building an understanding of the needs of children and youth with deaf-blindness, pointing out systemic shortcomings, and suggesting systemic changes. In being tasked with exploration and planning, these advisory structures frequently employ facilitative processes that lead to the development of consensus on needs and solutions.

The following are examples of processes and tools that could be used with groups to support this type of work:

- [Leading By Convening](#)
- [University of Kansas Community Tool Box – Chapter 16: Group Facilitation and Problem-Solving](#)
- [NCDB Facilitation Factsheet](#)

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