Early Identification and Referral Systems Change: Exploration and Building Partnerships

This document is intended as a guide for state deaf-blind projects as they engage in systems technical assistance (TA) planning and delivery related to early identification and referral (EI&R).

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. The guidance is also closely aligned with NCDB’s Early Identification and Referral Toolbox, which contains additional information, resources, and suggestions for working with early intervention systems.

There are two main sections:

- **Exploration** – Gathering information about EI&R needs in your state, getting to know your state systems, 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 EI&R

“System” refers to a collection of agencies and individuals and the regulatory structures and processes that guide how they function. Systems TA to improve identification and referral of infants and toddlers with deaf-blindness typically involves addressing issues in one of the following systems:

**Part C of IDEA.** Part C is a federal grant program established in 1986 to assist states in providing a comprehensive, coordinated state-wide system of early intervention services for infants and toddlers with or at risk for (at the state’s discretion) disabilities and their families.
**Early hearing detection and intervention (EHDI) programs and Hands & Voices.**
EHDI programs in every state are responsible for newborn hearing screening. Hands & Voices is a non-profit, parent-driven organization dedicated to supporting children who are deaf or hard of hearing. It has a cooperative agreement to support EHDI programs through family involvement.

**Health Care System.** The term “health care system” has a variety of meanings. For the purposes of this guide, it includes hospitals (particularly NICUs), medical centers, clinics, and medical homes serving young children.

As you go through this guide, you will find overlap between these three systems as well as with other community agencies and organizations.

Note: The [Early Identification and Referral Toolbox](#) has additional information and resources about each of these systems.

**EXPLORATION**

**Initial Needs and Resources Assessment**

You likely already have a significant amount of existing data about EI&R 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 committee to obtain a broad perspective on what they mean.

If your project has not already completed the [Early Identification and Referral Self-Assessment Guide (SAG)](#), you should do so before getting started (NCDB can assist you with this). It takes state deaf-blind projects through a data-based decision-making process to analyze current early identification efforts and determine strategies to improve EI&R at local and state levels.

The following data sources supplement and in some instances overlap with the SAG. You should have a good idea of the system you plan to target before going through the rest of this guide.
Technical Assistance Data

Documentation from previous TA (e.g., completed intake forms, evaluations) from your work with teams and families can be analyzed to identify factors that may impact early identification and referral. For example:

- Characteristics of children and families associated with early or late referral to your project
- Training and information needs of early intervention providers

It is also helpful to reflect on and document barriers or challenges you have faced, such as frequent turnover of early intervention providers who are responsible for making referrals.

State Child Count Data and Referral Patterns

Examine factors associated with referral to your project of children prior to age three. This information can be found in your child count, records you keep on how children were referred, and your completed SAG. The following questions can help guide your analysis. Not all will be relevant to each state, so pick the ones that are most useful to you.

- What percentage of children on your project’s child count are less than age three? How does this compare with the national percentage for this age group on the National Deaf-Blind Child Count?
- Over the past three years, how many infants and toddlers were identified annually?
- How many are in each of the following age groups: <1, 1 to 2, > 2 but < 3?
- At what age are most infants and toddlers referred?
- What are your referral sources for this age group?
- Are there any patterns associated with early (or late) referrals, such as geographic region, race/ethnicity, severity of vision and hearing loss, etiology, and presence (or not) of additional disabilities?
Other Data Sources

PART C

What data does your state’s Part C agency collect that may help you estimate the number of children served by Part C who are deaf-blind. For example:

- Number of children with hearing loss
- Number with visual impairments
- Number who have conditions associated with deaf-blindness

What other information do they collect that may help your EI&R efforts? If data is not publicly available, you may be able to obtain it from Part C personnel.

EHDI/HANDS & VOICES

What data does your state’s EHDI program collect that could help you estimate the number of children who are deaf-blind? For example:

- Number of children in state with hearing loss
- Number who have conditions associated with deaf-blindness

This information may be publicly available from Centers for Disease Control and Prevention EHDI data or from state EHDI personnel.

HEALTH CARE SYSTEM

Health care agencies and organizations may have data about:

- How medical conditions are diagnosed and reported in your state
- The numbers of infants and toddlers with conditions associated with deaf-blindness such as prematurity, cytomegalovirus, and CHARGE syndrome

Examples of health care data include:

- Public health statistics on birth defects
- NICU data (diagnoses or conditions associated with deaf-blindness)
- Other hospital data on diagnoses or conditions associated with deaf-blindness
State Systems

This section provides information to help you learn more about the specific system you plan to target—Part C, EHDI/Hands & Voices, or health care. Areas to consider for each system are provided below. As you research a system, also keep the following overarching questions in mind:

- What are the strengths of the system with respect to identification and referral of infants and toddlers with deaf-blindness?
- What does it need in order to improve?
- Are personnel aware of your project and your TA and training services?
- Are they aware of common risk factors and etiologies associated with deaf-blindness?
- Have there been prior efforts to increase the identification of infants and toddlers with deaf-blindness in your state related to this system? If so, what was done, who participated, what did and did not work, and why?

Note: The “Get to Know . . .” sections of the Early Identification and Referral Toolbox provide links to resources and suggestions for who to contact.

PART C

Research how Part C functions in your state in the following areas:

- Procedures for identifying hearing and vision loss
- Early intervention service guidelines for infants and toddlers with vision or hearing loss
- How infants and toddlers are identified and referred for early intervention services
- How Part C collaborates with additional state systems to identify infants and toddlers with disabilities

EHDI/HANDS & VOICES

Research how EHDI functions in your state in the following areas:

- EHDI screening and reporting guidelines
- Processes for coordination between EHDI and the state Hands & Voices chapter
- Processes for coordination between EHDI and Part C
HEALTH CARE SYSTEM

Find out how the health care system functions in your state in the following areas:

- State vision screening policies
- State hearing screening policies
- How EHDI screening and reporting guidelines relate to follow up with health care providers

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)?
- 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, while detailed information about how a particular system works may require interviews 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 as well as change related to the system you are targeting.

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?

**Early Identification & Referral Systems Capacity**

How confident are you of your knowledge of the following aspects of the targeted system?

● Purpose and function (e.g., services, policies)
● Personnel and their roles and responsibilities (see “Building Partnerships” below for more information)
● Personnel training
● Whether current training includes content that could be relevant to early identification and referral of infants and toddlers with deaf-blindness (e.g., vision loss, hearing loss, multiple disabilities)
● Processes for screening and identification of vision and hearing loss
● Processes for referring children to other relevant agencies and organizations
● Personnel responsible for making referrals
● Processes (if any) for referring children to your state deaf-blind project
● Current state and national systems-change efforts to improve early identification and referral

**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 early identification and referral?
Problem Statement 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 related to early identification and referral 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. Lack of or inadequate referral processes by the targeted system to the state deaf-blind project
2. Lack of awareness within the targeted system of the state deaf-blind project and its services
3. Limited understanding within the targeted system of the importance of identifying deaf-blindness as a distinct disability
4. Limited understanding of the importance of referring children to the state deaf-blind project as soon as possible
5. Personnel responsible for referrals within the targeted system have insufficient knowledge of deaf-blindness and its etiologies and risk factors
6. The system does not have sufficient personnel to do the screening and assessment that would identify infants and toddlers with deaf-blindness
7. High turnover of staff who conduct screening and assessment creates the need for repeated training
8. Issues relevant for children with deaf-blindness are not incorporated into the targeted system’s initiatives

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.

Example solutions that could apply to any of the three systems:

- Establish a formal referral agreement between the targeted system and your project that outlines eligibility guidelines and the referral process. Ideally, this will be incorporated into the targeted system’s existing referral processes.
- Embed screening for deaf-blindness into existing hearing and vision screening programs (existing programs might currently be sponsored by Part C, ELDI, schools for the deaf or the blind outreach programs, Lions Clubs, or regional or state-wide low vision clinics).
- Embed information about deaf-blindness as a distinct disability and its associated etiologies and risk factors into the targeted system’s training materials for personnel responsible for or in a position to refer children with known or suspected deaf-blindness to your project.
● Embed information about the importance of screening for vision loss in children who are deaf or hard of hearing, and screening for hearing loss in children with vision loss, into the targeted system’s procedures.
● Collaborate with the targeted system to embed information about deaf-blindness into their resources for personnel and families. This should become part of their system rather than disseminated on behalf of the state deaf-blind project.
● Collaborate with the targeted system to develop awareness-level information for families from culturally diverse or underserved populations on the importance of screening for and diagnosing hearing and vision loss as early as possible.
● Serve or have families familiar with your project serve on committees or boards working on initiatives to improve the targeted system’s identification and referral processes.

Examples for specific systems:

● Develop a presentation for NICU staff, ophthalmologists, and audiologists/ENTs that includes information about common risk factors for deaf-blindness, and the positive impact a referral to your state deaf-blind project can have on child and family outcomes. Work with NICUs, clinics, and medical centers to use it for grand rounds, new staff orientation, and other training events. *(Health Care System)*
● Partner with health care providers (e.g., ophthalmologists) to develop a CVI screening program for infants and toddlers with risk factors commonly associated with deaf-blindness. *(Health Care System)*
● Embed information about deaf-blindness into resource guides created by family organizations. This will increase your project’s visibility to a larger population of families who either have children with deaf-blindness or are able to pass information along to other families who may be interested in learning more about your project’s services. *(Parent Centers/Hands & Voices)*

**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).

Example outcomes:

- Targeted agency personnel have increased knowledge of deaf-blindness as a distinct disability *(short)*
- Targeted agency personnel have increased knowledge of your state deaf-blind project and its services *(short)*
- Families who receive services from the targeted system and have children who are potentially eligible for state deaf-blind project services have increased awareness of the state deaf-blind project *(short)*
- Targeted agency personnel responsible for identification and referral have an increased understanding of the etiologies and risk factors associated with deaf-blindness *(medium)*
- Targeted agency personnel have a clear understanding of the process for referring infants and toddlers to your project *(medium)*
- An increased number of infants are referred to your state deaf-blind project by the targeted system as soon as deaf-blindness is suspected or diagnosed *(long)*
- The race/ethnicity identification for children aged birth through 2 on the state deaf-blind child count is consistent with race/ethnicity data for children served by Part C or EHDI *(long)*

Note: The Early Identification and Referral Toolbox has a summary of the needs, solutions, and outcomes for each system described above. It also has separate “Take Action” sections containing materials and resources you can use to begin to address needs.

BUILDING PARTNERSHIPS

Existing Partnerships/Relationships

Use existing relationships to gain access to a system or connect you to other entities in that system. What existing relationships do you have within systems, agencies, or programs that support identification and referral efforts for infants and toddlers with deaf-blindness? Use them to gain or improve access to the system you are targeting.
These might be individuals who already work within the system or who work outside of it but have solid contacts and influence. For example, does your project have an advisory board? If so, are there individuals on the board who can help you connect to people and agencies within the systems you need to access?

For each, capture:

- Who they are (name, role, agency)
- Opportunities they offer
- Whether they possess enough authority to support systems change efforts
- What your ask of them 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) involved in EI&R?

You will also want to establish relationships with personnel in your targeted system who are responsible for identifying infants and toddlers with combined vision and hearing loss and referring them to your project. The following are lists of personnel likely to serve in this role for each system.

**Part C Personnel Responsible for EI&R**

- Evaluation coordinators
• Part C providers (e.g., service coordinators, educators, physical and occupational therapists, speech-language pathologists)
• Family resource consultants
• Infant/toddler vision and hearing providers
• Regional Part C early intervention office staff
• Interagency Coordinating Council members

**EHDI/Hands & Voices Personnel Responsible for EI&R**

• Audiologists who provide 3-month follow-up evaluations for infants who failed newborn hearing screening
• EHDI Chapter Champion pediatricians
• Hands & Voices state coordinators
• Hands & Voices parent advocates
• Guide By Your Side parent guides
• EHDI advisory board members

**Health Care System Personnel Responsible for EI&R**

• Developmental pediatricians
• American Academy of Pediatrics state presidents
• Medical home personnel
• NICU personnel, including individuals who administer hearing and vision screenings
• NICU follow-up clinic personnel including social workers
• Hospital specialty clinic personnel
• Ophthalmologists
• ENTs
• Audiologists
• Personnel at hospitals and regional medical centers in neighboring states that may be accessed by families and providers

**Note:** The *Early Identification and Referral Toolbox* has additional suggestions for how to build partnerships within each system.
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

Implementation teams should collaborate with low-incidence groups and structures 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 that are responsible for meeting the needs of individuals with low-incidence disabilities. They are not necessarily specific to special education but should 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 or 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 change and improvement. While it is critical to have representation for deaf-blindness inside existing structures, external entities are also critical 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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