## Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>2</td>
</tr>
<tr>
<td>Purpose</td>
<td>2</td>
</tr>
<tr>
<td>Definitions</td>
<td>2</td>
</tr>
<tr>
<td>Document Organization</td>
<td>2</td>
</tr>
<tr>
<td><strong>A. Exploration</strong></td>
<td></td>
</tr>
<tr>
<td>A1. Assess Needs</td>
<td>3</td>
</tr>
<tr>
<td>A2. Evaluate Your Project’s Capacity</td>
<td>5</td>
</tr>
<tr>
<td>A3. Prioritize Needs and Define the Problem</td>
<td>6</td>
</tr>
<tr>
<td>A4. Identify Systems to Target</td>
<td>6</td>
</tr>
<tr>
<td>A5. Propose Solutions and Define Desired Outcomes</td>
<td>6</td>
</tr>
<tr>
<td><strong>B. Building Partnerships</strong></td>
<td></td>
</tr>
<tr>
<td>B1. Take advantage of existing relationships</td>
<td>8</td>
</tr>
<tr>
<td>B2. Identify potential partners</td>
<td>8</td>
</tr>
<tr>
<td><strong>C. System-Change Activities</strong></td>
<td></td>
</tr>
<tr>
<td>C1. Leading</td>
<td>9</td>
</tr>
<tr>
<td>C2. Infiltrating</td>
<td>10</td>
</tr>
<tr>
<td><strong>D. Developing a TA plan</strong></td>
<td>11</td>
</tr>
<tr>
<td><strong>E. Systems-Change Opportunities by Initiative Area</strong></td>
<td>11</td>
</tr>
<tr>
<td>E1. Transition</td>
<td>11</td>
</tr>
<tr>
<td>E2. Early Identification and Referral</td>
<td>11</td>
</tr>
<tr>
<td>E3. Interveners and Qualified Personnel</td>
<td>12</td>
</tr>
<tr>
<td>E4. Families</td>
<td>12</td>
</tr>
<tr>
<td>References</td>
<td>13</td>
</tr>
<tr>
<td>Appendix A: Managing Collaborative Activities</td>
<td>14</td>
</tr>
<tr>
<td>Appendix B: Facilitating Teams and Work Groups</td>
<td>17</td>
</tr>
</tbody>
</table>
Introduction

Purpose

The purpose of this guide is to support state deaf-blind projects in addressing the needs of children and families by developing and implementing systems-change activities. Every project faces broad systemic challenges and, given limited resources, must make difficult choices about the direction their systems work will take.

This document will help you:
- Explore systems change opportunities by gathering information about needs in your state
- Locate and develop partnerships with individuals and organizations with common goals
- Make decisions about activities that can help you achieve your systems-change goals

Definitions

"System” refers to a collection of agencies and individuals and the regulatory structure and processes that guide how they function. Examples include Part C, school-age special education, developmental disabilities services, and vocational rehabilitation services.

In this document, “systems change” is a bit of a catch-all term for activities conducted by state deaf-blind projects that go beyond child-specific TA and are intended to address the needs of numerous children and families and create more sustainable deaf-blind services. Systems-change activities can range from fairly simple (e.g., working on implementing an instructional practice in a school district) to quite complex (e.g., developing an intervener-training program).

Examples of systemic needs identified in the 2017 National Deaf-Blind Needs Assessment include:
- Insufficient connections among and lack of support for families, including limited funding for events
- Limited funding and opportunities for professional development for a range of service providers
- Lack of recognition and a limited supply of qualified interveners
- Lack of a sustainable system of personnel preparation for teachers of the deaf-blind

Document Organization

The document has 5 sections:
A. Exploration - Identifying systems-change opportunities and setting goals
B. Building Partnerships - Figuring out which entities with whom to work
C. Systems-Change Activities - TA strategies to help you achieve your systems-change goals
D. Developing a TA Plan - An example of a form you might use to plan your systems TA
E. Systems-Change Opportunities by Initiative Area - Questions/suggestions to generate ideas regarding systems-change opportunities

A. Exploration

Exploration covers a range of activities:

1. Assessing needs
2. Evaluating your project’s capacity
3. Prioritizing needs and defining the problem
4. Identifying systems to target
5. Proposing solutions and defining outcomes

Systems can be poorly defined and systems-change efforts often involve a high degree of ambiguity. Committing time and resources upfront to exploratory work will go a long way towards keeping your systems work focused during challenging situations.

A1. Assess Needs

Systems-change activities start with a needs assessment to help you:

- Better understand the problems you want to address
- Prioritize and sequence aspects of specific problems
- Gather information needed to set goals
- Craft effective plans to reach those goals
- Learn from successes and setbacks
- Use resources well

You likely already have a significant amount of existing data about specific systemic issues, but may also need to collect new information.

Analyzing existing data

As you conduct child-specific TA you no doubt encounter common barriers that inhibit success across a wide range of programs. For example, a lack of knowledge about transition planning and the adult service system on the part of most service providers who work with transition-age students leads to poor transition outcomes.

Examples of existing data sources you probably already have include:

- Intake and needs assessment data gathered during initial contacts for child-specific TA
  - Completed intake forms (reviewing these should give you a good idea of needs you commonly run across)
  - Program and classroom evaluations
  - Service provider assessments
  - Child assessments
- Evaluation data from child-specific TA
  - Team/agency readiness evaluations
Feedback from team members
Change in practitioner fidelity of implementation

Child count data trends. Examples:
- An increase in the number of children with cochlear implants
- Fewer young children being identified
- Children being identified in specific districts for the first time
- A change in the racial/ethnic composition of the children on your census
- An increase in the number of children and youth reported as “dropping out”

State-level data (two types):
- Information about systems (policies, procedures, regulations) and how they function to serve students. For example:
  - How does the developmental disabilities system in your state provide ongoing support for employment?
  - What services are available to families of students with significant disabilities?
- Information about students served within a system. This can provide details about how successful that system is in general. For example, “What percentage of students with significant disabilities are served in inclusive settings?”

Collecting new information
To better understand an issue and inform next steps, you may need to collect additional data by:
- Surveying or interviewing stakeholders
- Searching for documents and evidence relevant to your state

Questions to determine the type of information needed:
- Who do you need more information from?
- Which stakeholders are not represented in your existing data?
- What information are you missing?

Questions to guide decisions about how to collect the information:
- How can it be gathered?
  - Information about regulations and service delivery processes can be acquired through documents
  - People’s experiences with or perspectives on a specific system can be obtained via outreach to stakeholders
- How in depth do you want the information to be?
  - General information can be collected through a survey
  - In-depth information about how a particular system works may require interviewing or possibly conducting a focus group with stakeholders
A2. Evaluate Your Project’s 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 systems you are considering targeting. It’s also important to think about how the system your project is a part of (e.g., a university or SEA) influences what you can do.

**General Systems Change Experience**
- What is your staff’s experience with systems-change efforts?
- What support might you need from NCDB or state deaf-blind projects to plan and deliver systems-change TA?

**Expertise with specific systems**
The knowledge and experience that individuals who work on your project have with systems you are considering targeting can inform your decision-making in two ways:
- You may decide to target systems with which you already have significant expertise
- You may decide to target systems where you have limited expertise and will therefore need to identify specific topics and issues to learn more about

In either case, here are some questions to ask:
- What experience do you have working with the systems being considered (e.g., early intervention, family services, vocational rehabilitation, developmental disabilities)?
- Do you have content knowledge related to the work of that system?
- What is your level of knowledge about how the system functions?
  - Regulations and legislation
  - Processes and procedures
  - Funding
  - Service planning and delivery
  - Major service providers (the agencies that actually provide services, such as early intervention agencies or employment services)
  - Advisory or other committees (e.g., developmental disabilities councils, special education advisory committees)

**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.
A3. Prioritize Needs and Define the Problem

Write a Global Needs/Problem Statement
Doing this allows you to get clear definition of what the problem really is, not only for yourself but for partners you are trying to recruit and outside constituents you would like to influence.

Prioritize Needs
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. For example, you may decide to disseminate information to raise awareness about intervener practice among school administrators before you offer training to interveners and teams.

A4. Identify Systems to Target
To identify the system or systems you will target to help address the problem, consider the following questions:

• Within what systems does the problem (e.g., poor transition outcomes) exist?
• What systems are likely to be able to help solve the problem?
• Does the problem involve multiple systems?
• At what geographic level does the problem exist? Examples:
  o Local problem (limited deaf-blind expertise in a school district with a large number of children who are deaf-blind)
  o State problem (important deaf-blind issues are not incorporated into statewide educational initiatives)
  o Regional problem (a common need identified by a number of SDBPs in a region)
  o National (a need experienced by children with deaf-blindness and their families throughout the country)

A5. Propose Solutions and Define Desired 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 of the solutions being implemented.

Solutions
As you identify solutions, think about how they “fit” with the existing priorities and values of potential target audiences and their organizations or settings. For example, if your solution to a lack of support for families is to integrate supports 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. Keeping in mind that your goals must align in some way with potential partner organizations’ goals will guide your thinking
about who to seek partnerships with.

Here are some examples of different types of solutions:

- **Policies/regulations**
  - Establishing job descriptions and pay differentials for interveners in a school district
  - Including interveners in state regulations
  - Developing district policies for transition planning and services

- **Programs**
  - Setting up model classrooms
  - Developing a teacher community of practice

- **Culture/norms**
  - Creating materials and activities to shift service provider attitudes about the capacity of children who are deaf-blind

- **Personnel and family knowledge and skills**
  - Creating a multistate family training program
  - Creating an online training program for vision and hearing teachers

- **Processes**
  - Developing a process for appropriate assessment within existing low-incidence services

- **Resources/funding**
  - Securing funding to support family activities

**Outcomes**

Outcomes for your systems-change work should focus on immediate changes you would like to see. While long-term outcomes are important, focusing on outcomes that are a direct result of your work is critical for helping you know when you have achieved your goals.

Outcomes differ depending on the focus issue and the systems-change strategies you use. You will likely have multiple outcomes, depending on the scope of the change you are attempting to achieve. As you set outcomes (and outputs), simultaneously make some initial decisions about how you will measure then down the road (e.g., survey, interviews, focus group).

Examples of outcomes:

- **Policies/regulations**
  - Intervener titles, job descriptions, and pay differentials are clearly defined
  - Interveners are listed in state regulations and IEP databases
  - Transition plans are appropriate to the needs of youth with deaf-blindness

- **Programs**
  - Effective practices are being used with students who are deaf-blind
  - Teachers are participating in community of practice activities

- **Culture/norms**
  - Service providers demonstrate attitudes indicating they understand that children with deaf-blindness can learn when they receive appropriate intervention

- **Personnel and family knowledge and skills**
Increased family members’ knowledge and skills
- Increased vision and hearing teachers’ knowledge and skills
- Processes
  - Students are assessed according to developed processes
- Resources/funding
  - Family activities are being conducted using acquired funds

**B. Building Partnerships**

Because services to individuals who are deaf-blind occur within existing systems, partnerships are critical when conducting systems-change TA. You will need partners within the systems you target to act as champions and assist you in navigating system-specific processes and procedures.

**B1. Take advantage of existing relationships**

Use existing relationships to:
- Gain access to a system
- Connect you with other individuals in that system

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?

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

**B2. Identify potential partners**

Start by identifying the agencies and organizations within the system you would like to target.
- Who in your state works on the issue you are addressing? Are there existing champions for the issue or related issues? Examples:
  - Who works on parent leadership in your state?
  - Who champions the needs of paraprofessionals?
  - Is there an organization for paraprofessionals?
- Who works on the issue nationally? What type of support can they offer?
- What agencies and organizations are responsible for regulations, policies, and services within the system?
- 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 SEA)?
- Is there a regionalized structure for services within your state (e.g., county-level provision of vision and hearing services)?
C. System-Change Activities

Systems-change efforts fall into two broad categories:

1. Those where you bring about change by **leading** the effort
2. Those where you bring about change by **infiltrating** ongoing efforts

There is clearly overlap between the need to lead and the need to infiltrate for most problems and none require purely one approach or the other. Nevertheless, examining what is most appropriate for situations you confront related to your chosen issue and determining how they are best handled, is a key decision you must make at the outset.

The approach you choose, depends on the issue at hand and the extent to which it is already embedded in existing systems and initiatives. For example, if you decide to focus on establishing intervener services in your state, you will probably need to provide a great deal of leadership because you are creating something new and trying to get people to accept an innovation that is unfamiliar to them. If, on the other hand, you decide to work on improving early identification, you will probably want to devote your energy to infiltrating existing systems.

Some of the systems-change activities you pursue can be done in collaboration with other state projects. Knowledge change activities, such as preparing for and providing professional development training, are one example.

C1. Leading

Providing leadership involves a range of strategies such as leading collaborative groups, synthesizing and sharing knowledge, and employing strategies for developing knowledge and skills.

**Leading collaborative groups**

Using the partners you have recruited, a collaborative group can be formed to serve a range of purposes, including:

- Providing advice on the overall direction of the work, as well as specific activities
- Developing necessary documents
- Providing feedback on documents
- Making connections to decision-makers

You may already have an advisory board that can serve the purposes you have in mind or you may need to form a new group depending on the membership needs you identified when thinking about partnerships.

A range of structures and strategies can be used to formulate and run groups effectively. The following factsheets provide ideas on how to manage collaborative groups:
• Managing Collaborative Activities (or see Appendix A)
• Facilitating Teams and Work Groups (or see Appendix B)

**Synthesizing and sharing knowledge**
Sharing concepts and ideas about the change or innovation you are promoting requires information to build awareness of deaf-blindness, the specific need you are trying to address, and the solution you are promoting. This information can range from general (e.g., overviews for administrators and decision-makers) to intensive (e.g., training materials for service providers).

**Developing knowledge and skills**
Many, but not all, systems-change efforts will require training of some type to improve service providers' knowledge and skills regarding students who are deaf-blind. Partnering with existing service delivery systems (e.g., early intervention or statewide special education TA) is essential.

**C2. Infiltrating**
Most systems-change efforts require working within existing systems and each has its own structures, processes, and organizations. The following are examples of committees or organizations you may want to consider approaching. When working within these structures you will want to identify potential champions and activities in which you and your partners can participate.

It also makes sense to facilitate the participation of parents and individuals who are deaf-blind in committees and organizations associated with the system, as they can have a significant amount of influence. Explore the nomination processes and membership guidelines of groups you are interested in infiltrating. Parents and individuals with disabilities are often required members.

**Committees and councils**
Many state-level agencies have committees that inform their service delivery, policies, and procedures. Examples include:
- Developmental disabilities councils
- Statewide early intervention coordinating councils
- Special education advisory councils.

Many of these types of councils and committees have county-level versions as well.

**Professional Organizations**
Most professional organizations have state chapters that provide professional development and guidance on issues important to them and the populations they serve. Examples include:
- Association for Education and Rehabilitation of the Blind and Visually Impaired (AER)
- American Speech and Hearing Association (ASHA)
- Council of Administrators of Special Education (CASE)
State administrative organizations
Most states have organizations for administrators who work in different systems, such as:
  • Special education director organizations (usually have annual meetings)
  • Early intervention administrator groups

These groups are typically overseen by an agency such as the state education department, which disseminates regulatory and practice information.

Professional development structures
State personnel development grants, comprehensive systems of personnel development, and state special education training centers.

D. Developing a TA plan

Once you have begun to formulate ideas about the problems you would like to address and the approach you will take, record your thoughts in a structured TA plan. This can be revised on an ongoing basis as you acquire partners and identify appropriate activities.

See Sample Systems-Change TA Plan.

E. Systems-Change Opportunities by Initiative Area

To identify systemic needs, formulate solutions, and work effectively with partners, you will need to increase your understanding of the system in which you have chosen to work. The following sections—organized by initiative areas—provide additional questions and suggestions to generate ideas regarding systems-change opportunities.

E1. Transition
  • Have you seen your WIOA state plan?
  • Is your state an Employment First state?
  • "What agencies assist individuals with disabilities in gaining employment in your state (e.g., job development, ongoing support)
  • Who advocates for employment and transition services in your state?
  • Who sits on your developmental disabilities council and what are the council’s areas of focus and interest?
  • Where is your protection and advocacy organization located?
  • What professional development opportunities and systems exist within the vocational rehabilitation and developmental disabilities systems?

E2. Early Identification and Referral

The Early Intervention and Referral Self-Assessment Guide will help you identify a system or systems to target. These include Part C, EDHI, medical providers, and community agencies. You
may also want to explore professional development opportunities and structures within your state’s EI system, such as the Comprehensive System of Personnel Development plan.

**E3. Interveners and Qualified Personnel**

- What is the regulatory change process for your state’s education code?
- Who are potential partners for intervener training (e.g., community colleges, agencies)?
- Who is involved in paraprofessional work and advocacy in your state?
- What administrative organizations, such as special education directors’ professional organizations may be useful in your efforts?
- What professional development opportunities and systems are available in your state for teachers and other service providers?

In addition, what you are able to do in the area of intervener services will be determined, in part, by where your project is housed. If you are at a state department of education, you may have opportunities to influence changes to your state’s education code. If at a university, you may have more freedom to support advocacy efforts.

**E4. Families**

Systems development for families is an area where you will likely do more leading and less infiltrating, because family support systems that meet the needs of families of children who are deaf-blind tend to be minimally developed in many states. Understanding the existing landscape, however, is still important.

- How do families access PTI training and other family support activities?
- What supports (e.g., funding, training) are available to families from educational organizations such as the state department of education?
- Are there family organizations that focus on sensory disabilities in your state (e.g., deaf-blind parent groups, NFADB affiliates, National Association of Parents of Children with Visual Impairments chapters, Parents of Blind Children, Hands & Voices)?
- What do general (not disability specific) family support organizations have to offer?
- Are there local- or state-level committees that family members can serve on?
References


KU Work Group for Community Health and Development. (2015). Developing a plan for assessing local needs and resources. In Community Tool Box (Chapter 3, Section 1). Retrieved from


Appendix A: Managing Collaborative Activities

(January 2018)

Implementation of systems-change projects and activities requires collaboration between multiple agencies and organizations. Although collaboration is usually seen as inherently good, it can be ineffective if not conducted within a framework of solid processes and structures.

Strategies

Create structures and processes that mimic a hierarchy

There's no established hierarchy when working across organizations, so it’s essential to create a replacement infrastructure that includes:

- A lead agency
- A manager from the lead agency who has overall leadership and coordination responsibilities such as:
  - Developing and updating a work plan
  - Delegating work
  - Monitoring progress and ensuring the work moves forward
  - Anticipating and preparing for potential problems
  - Making sure people follow through on their commitments
- Workgroups

The point of a hierarchical structure is not to dominate others or be controlling, but to ensure efficient processes and clearly defined roles and responsibilities. A good hierarchical structure supports participation at all levels.

Identify required knowledge, skills, and resources

Outlining the knowledge, skills, and resources required to conduct the activities in your implementation plan will help you determine:

- How your current collaborators can be most useful
- Who needs to be recruited

It is important to think of people and organizations involved in collaboration as implementers, rather than stakeholders. Stakeholder input and buy-in is crucial, but true collaboration involves in-depth participation. Don’t recruit people who have something to offer, but limited time to participate or people who have time, but none of the needed skills or resources.
Formally define the roles of workgroups and individuals

Clarity about roles:
- Provides a clear division of labor that limits duplication of effort
- Helps participants understand their responsibilities
- Holds people and organizations accountable for their commitments

Roles should be specified in writing and, when appropriate, outlined in MOUs.

Determine decision-making protocols

To ensure the work moves forward, there should be very clear decision-making protocols, that include a shared understanding of what each individual’s role is in a given decision (and where they are not involved).

Within the deaf-blind network there is often a desire to come to decisions via consensus. While this may work well in some situations, it can also lead to work getting stalled. Depending on the complexity of the systems change effort, your timeline, and the nature of the focus topic, you may want to consider some other options.

Online resources about decision-making:
- Facilitating Group Decision Making: We Need to Make a Decision!
- What’s the best decision-making method?
- Too Many Cooks Spoil the Broth, or Maybe Not? (See the "Styles of Group Decision Making" table about halfway down the page)

Establish clear communication mechanisms for collaborators

Develop processes for communicating with everyone involved in implementation efforts (a separate plan should be established for communication with stakeholders) to keep them informed of what is going on within their own and other workgroups.

Include:
- **What** - the type of information that will be shared
- **When** - the frequency of communication
- **Who** – the individuals responsible for writing, organizing, and disseminating messages

The process should detail how committees will report to one another (e.g., sub-groups working on specific tasks may report to a broader oversight committee).

In our network, communication typically involves phone calls, email, online meetings (e.g., via Adobe Connect), and occasional face-to-face meetings. To be most efficient, however, communication strategies should also include the use of an online group format where members can upload and share materials and engage in threaded chats (e.g., a group on the NCDB site, Facebook).
Encourage participants’ investment in the work

- Discuss and share accomplishments (individual and group)
- Offer words of appreciation to group members
- Periodically stop and reflect on where the group has been and progress that has been made

References


Appendix B: Facilitating Teams and Work Groups  
(January 2018)

Systems change efforts require facilitation in a range of situations including guiding workgroups engaged in specific tasks, obtaining input and feedback from stakeholders, and building coalitions. This document features strategies to strengthen relationships and communication among individuals engaged in systems-change efforts.

**Strategies**

**Organize and facilitate team meetings**

Facilitate discussions that allow team members to share concerns, questions, and ideas. These types of meetings provide “protected time to reflect on the implementation effort, share lessons learned, and support one another’s learning” (Powell et al, 2015).

**Facilitate relationships among team members**

Difficulties among colleagues or stakeholders can present a barrier to implementation, but through skilled facilitation, you can:

- Help team members create a shared vision
- Inspire commitment and action
- Encourage the involvement of all members
- Improve communication
- Promote awareness that tasks require collaboration or, at least, input and support

As you work with teams, be aware of how personal and organizational characteristics influence the effectiveness of teams and their response to TA:

- Personal—personality, attitudes, beliefs, goals, perceptions, expertise, position and level of influence in the organization
- Organizational—fiscal and personnel resources, leadership, urgency of need

**Identify and prepare champions**

Champions are individuals dedicated to supporting new ways of doing things. They can be influential in overcoming barriers or resistance to change.

**Additional Resources**

- [Group Facilitation and Problem-Solving (KU Community Toolbox)](Link)
- [NCDB Facilitation Factsheet](Link)
References


The contents of this publication were developed under a grant from the U.S. Department of Education #H326T130013. However, those contents do not necessarily represent the policy of The Research Institute, nor the U.S. Department of Education, and you should not assume endorsement by the Federal Government. Project Officer, Jo Ann McCann.