Transition Systems Change: Exploration and Building Partnerships

This document is intended as a guide for state deaf-blind projects as they engage in systems TA planning and delivery related to transition for students who are deaf-blind and have additional disabilities. 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 transition 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 transition outcomes

The guidance is closely aligned with the Recommendations to Improve Transition Outcomes for Students with Deaf-Blindness and Additional Disabilities. Users should read those recommendations carefully before getting started.

“System” refers to a collection of agencies and individuals and the regulatory structures and processes that guide how they function. In the area of transition, there are multiple systems that, ideally, should be involved in preparing students with deaf-blindness for adult life. The challenge for state deaf-blind projects is to understand how each of the following three primary systems in their states are involved in transition services and how they work together to support high-quality transition outcomes:

- Department of Education
- Vocational Rehabilitation (VR) and/or Blind and Low Vision Services (BLVS)
- Developmental Disabilities Services (DD)

In addition, there are other key agencies that are not likely to provide funding or direct services but may influence the services and policies of the other three. These include:

- Parent Training and Information Centers and Community Parent Resource Centers
- Protection and Advocacy Agencies
EXPLORATION

Needs and Resources Assessment

You likely already have a significant amount of existing data about transition 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.

State Child Count

Analyze your child count data for findings relevant to transition-age students. For example, how many students do you have on your child count who are transition age? In what regions of the state do they live? How many have cognitive impairments?

Technical Assistance Data

Documentation from previous TA (training, facilitation, parent activities) provided to families and service providers can be used to identify common transition 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. The following questions can help guide your analysis:

- What common challenges do families and schools report as they plan for a young adult’s transition?
- What are the desired outcomes for young adults with deaf-blindness and additional disabilities after they leave school?
- What barriers to success for transition-age students have you observed as a TA provider?

Additional questions that can help you identify common problems in your state (based on your TA data or your own experience) include:

- Does your project have difficulty finding transition-age students not already on your child count?
• Are post-school expectations for students with deaf-blindness and additional disabilities high enough?
• Do they get connected to VR/BLVS while still in school?
• Do they receive services from VR/BLVS or are they determined ineligible as they are not seen as able to benefit from services?
• Do they have quality work experiences as a transition or Pre-Employment Transition Services (Pre-ETS) activity?
• Are students with long-term support needs connected to developmental disabilities services or mental health services as early as possible?
• Do school staff have the skills to provide meaningful instruction and support related community employment?
• Do adult services staff (VR, BLVS, DD) understand how to support and accommodate young adults with deaf-blindness and additional disabilities to have a meaningful adult life in the community?
• Are parents provided adequate information to enable them to advocate for a high-quality future for their child?

State Systems

This section provides information to help you explore the three primary systems involved in transition in your state—Department of Education, VR/BLVS, and DD.

DEPARTMENT OF EDUCATION

Policies. Does your state department of education have specific transition policies (e.g., a requirement that planning begin earlier than the federal mandate, directives regarding age-appropriate transition assessments)? See Recommendation 1 for information and resources about Federal transition-planning requirements.

Services. Does your state have model transition programs? For examples, see the Promising Examples sections of:

- Recommendation 2
- Recommendation 3
- Recommendation 4

Infrastructure. Are there activities in your state to build the capacity of educators and educational systems to improve transition outcomes? These might be conducted by regional or statewide task forces or coalitions or by agencies receiving TA from a national center such as National Technical Assistance Center on Transition (NTACT), Office of Disability Employment Policy (ODEP), or Workforce Innovation TA Center (WINTAC).
**Family Considerations.** How do families get information about IDEA and transition practices, policies and regulations? How do they receive support to advocate for their child or for systems change?

**VOCATIONAL REHABILITATION/BLIND LOW VISION SERVICES**

**Policies.** How does your state direct VR counselors to work with schools? How does it ensure that all students have access to Pre-Employment Transition Services (Pre-ETS)? Review Recommendation 1 to learn about the Workforce Innovation and Opportunity Act (WIOA) and how VR is now directed to work with ALL students earlier and support their preparation for employment.

**Services.** What Pre-ETS services are offered to students with disabilities in your state? What services are available to students who need additional support such as a job coach, interpreter, or intervener to participate in Pre-ETS?

**Infrastructure.** What is your state doing to increase VR capacity to provide customized employment (CE) and increase employment providers' ability to provide CE? What are your state’s VR eligibility processes (e.g., how decisions are made that someone cannot benefit from VR) and extended employment? See Recommendation 5 for examples of how some states are building CE capacity.

**Family Considerations.** How do families get information about WIOA, Pre-ETS, and CE? How do they get support to advocate for VR services for their child or to participate in efforts to improve the VR system?

**DEVELOPMENTAL DISABILITIES SERVICES**

**Policies.** Does your state have policies to prioritize service delivery in the community rather than segregated settings, including an Employment First policy? How is it responding to the Center for Medicare and Medicaid final settings rule? See the “What State Projects Can Do” section in Recommendation 2 for resources about Employment First to help you assess your state’s readiness to support community employment. See the same section in Recommendation 1 for information about the final settings rule.

**Services.** What is the eligibility determination process (e.g., when to apply, who is eligible) for DD services in your state? What long term-supports are available? Who do each of the Medicaid Waivers serve? How does the waiting list work? See Recommendation 2 and Recommendation 3, “What State Projects Can Do” for more information. What types of support (e.g., counseling, education, case management, funding) does your state’s DD services provide to transition-age students?
Infrastructure. Is your DD system engaged in capacity-building related to practices, policies, or funding to increase access to competitive integrated employment (CIE) or customized employment (CE), including how they relate to individuals with specific types of disabilities, such as deaf-blindness? For example:

- Do they receive TA or training from a national TA Center (e.g., State Employment Leadership Network (SELN), ODEP, WINTAC)?
- Do they receive training or technical assistance on CE or CIE from Griffin-Hammis Associates, Marc Gold and Associates, or TransCen?
- Does your state have an APSE or TASH chapter?

Family Considerations. How are families educated about DD services and supported to advocate for them as part of transition?

Other Systems

What agencies or organizations in your state are engaged in advocacy for community employment, long-term supports, quality transition planning and outcomes, and family education and support? How do they influence the three primary systems above? Systemic work may already be occurring for the larger population of students with disabilities. Joining existing efforts will expand your resources. See the “What State Deaf-Blind Projects Can Do” section of Recommendation 2 for suggestions about how to learn about advocacy and capacity-building efforts in your state.

The following are types of agencies that may be involved in transition advocacy efforts. What current initiatives or future plans do they have for (1) raising expectations for students with high-intensity and long-term support needs and (2) improving services to attain high-quality transitions and adult life outcomes. How can you participate to benefit students who are deaf-blind?

- Parent centers
- Protection and advocacy agencies
- State councils on developmental disabilities
- University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDs)
- Centers for independent living
- State mental health services

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 transition systems you are targeting. 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:

1. You may decide to target systems with which you already have significant expertise
2. 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

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?

Transition Systems Capacity

• How confident are you of your knowledge of the policies, services, infrastructures, and family considerations for each of the three main systems covered under “Needs and Resources Assessment” above—Department of Education, VR/BLVS, and DD?
• How familiar are you with the efforts of other agencies that may have transition services or initiatives (e.g., parent centers, protection and advocacy agencies, independent living centers)?
• What is your level of knowledge of current state and national systems-change efforts to improve transition supports and services?

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 transition?

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 related to transition 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. Expectations for the post-school lives of young adults with deaf-blindness and additional disabilities are too low and tend to not include community employment or community living.
2. Young adults with deaf-blindness and additional disabilities do not have work experiences while in school that prepare them for community integrated employment as adults.
3. Transition services do not include activities and training directed toward attaining meaningful participation and membership in the young adult’s community after graduation.
4. Schools and adult agencies do not collaboratively plan, fund, and support transition activities to promote a seamless segue from school to adult services.
5. School, vocational rehabilitation, and community rehabilitation staff lack the skills required to support students with deaf-blindness and additional disabilities in community employment, community living, and recreation.
6. Families lack essential knowledge—e.g., adult laws and services, the rights of their children regarding transition services and long-term supports—needed to effectively navigate the transition process and adult services systems.

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.

The following are examples of solutions to the problems listed in the previous section.

**DEPARTMENT OF EDUCATION**

The Rhode Island Department of Education has an Employment First policy for school-aged students that directs schools to emphasize preparation of students for community integrated employment rather than segregated nonwork options.

The Pennsylvania Department of Education funds the Arc of Pennsylvania to provide discovery and other customized employment services to students whose disability is a significant barrier to employment and who require customized strategies to access
competitive integrated employment. As part of this program, the Arc works collaboratively with the Pennsylvania Deaf-Blind Project.

**VOCATIONAL REHABILITATION**

Development of a policy that requires VR programs to provide discovery and customized employment to individuals before they can be deemed unable to benefit from VR services.

Minnesota vocational rehabilitation counselors meet with all students, whose IEP post-school outcomes do not include competitive integrated employment, to provide career counseling and information about discovery and customized employment strategies.

Several states have implemented the Transition Services Integration Model, which blends funding from school, VR, and DD services to provide students with access to adult agency employment supports for work experiences while they are still in school.

Several states, including Minnesota and Pennsylvania, offer regular training for VR counselors and other employment providers to build their expertise to provide customized employment.

**DEVELOPMENTAL DISABILITIES SERVICES**

In Washington state, students who are in community integrated employment upon leaving school automatically become eligible for long-term support via the state’s DD Medicaid Waiver.

Delaware has an Early Start to Employment program for students with developmental disabilities who need supported employment services as adults. DD staff reach out to students as young as 12 to begin discussing employment and the program offers supported employment services to students during their last 2 years of high school.

The King County Washington Developmental Disabilities Division works collaboratively with schools and the state’s Division of Vocational Rehabilitation to fund adult employment services that provide career exploration and work preparation during the last two years of high school for students eligible for DD services.

**OTHER**

Some parent centers and state councils on developmental disabilities are identifying transition to community integrated employment as an area of need in their 5-year plans and investing in training and pilot projects to build capacity to provide it in their states.
The Beach Center at the University of Kansas created a training curriculum (FEAT – Family Employment Awareness Training) that focuses on building family expectations of employment for their young adult children and making connections to local resources.

**Outcomes**

Outcomes should align with your grant objectives and include 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).

**EDUCATION EXAMPLES**

- Students with deaf-blindness and additional disabilities and their families receive information about community options and individualized support as part of their transition services. (short)
- Students with deaf-blindness and additional disabilities and their families make informed choices about the services and supports that will help them achieve desired post-school outcomes. (medium)

**VOCATIONAL REHABILITATION EXAMPLES**

- As part of Pre-ETS, students with deaf-blindness and additional disabilities receive career counseling and work preparation to prepare them for competitive integrated employment. (medium)
- Students with deaf-blindness and additional disabilities have access to discovery and customized employment services that lead to individualized work opportunities. (medium)
- Students with deaf-blindness and additional disabilities obtain competitive integrated employment and succeed in these jobs over time. (long)

**DEVELOPMENTAL DISABILITIES EXAMPLES**

- Students with deaf-blindness and additional disabilities are enrolled in developmental disabilities services as early as possible. (medium)
- Students with deaf-blindness and additional disabilities receive services from developmental disabilities programs during high school that prepare them for full adult lives. (medium)
- After exiting the school system, individuals with deaf-blindness and additional disabilities receive long-term services that support quality adult lives. (long)
BUILDING PARTNERSHIPS

Existing Partners/Relationships

Use existing relationships to gain access to a system or connect you with other individuals in that system. What current relationships do you have in the following systems or agencies that could be beneficial to transition systems-change efforts?

- Department of Education
- Vocational Rehabilitation Services
- Developmental Disabilities Services
- Helen Keller National Center
- Parent centers
- Protection and advocacy agencies
- State councils on developmental disabilities
- UCEDDs
- Centers for independent living
- Mental health services
- Other

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 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