

# STATE DEAF- BLIND PROJECTS

*2023 Findings  
from Interviews  
with State  
Deaf-Blind  
Projects About  
the National  
Center on Deaf-  
Blindness*



**National Center  
on Deaf-Blindness**

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*“We really love the work that we do, and the people we work with, and NCDB is a big part of that. We just really enjoy working with them.”*

—2023 State Deaf-Blind Project interviewee



# State Deaf-Blind Project Interviews

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“As a national technical assistance center, NCDB works with state deaf-blind projects and other partners to improve educational results and quality of life for children who are deaf-blind and their families.”<sup>1</sup> In all, there are 48 state deaf-blind projects throughout the United States that utilize NCDB resources, including consultations, trainings, learning communities, technical assistance, webinars, tools, and materials.

As part of NCDB’s evaluation process, a four-year qualitative study was conducted by interviewing state deaf-blind project staff. Between 2020 and 2022, annual samples were randomly selected, and each year included two large (highly funded) state projects and nine to eleven smaller (less funded) state projects. In 2023, the fourth and final year of the study, the sample consisted of the remaining twelve state projects—two large and ten small.

A third-party independent program evaluator conducted interviews during May through August 2023. Questions that formed the basis for the semi-structured interviews included:

1. Is the project implementation progressing as planned?
2. Is the project producing the expected outcomes?
3. What are the gaps, barriers, and project support needs?
4. What is the quality, relevance, and usefulness of NCDB products/services/TA?
5. To what extent are changes happening within state systems?

The following report discusses the findings.

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<sup>1</sup> <https://www.nationaldb.org/about/>

## Participants

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The 12 state deaf-blind projects (SDBPs) that were selected for interviews in 2023 are the following:

- Delaware Program for Children with Deaf-Blindness
- Louisiana Deafblind Project for Children and Youth
- Montana Deaf-Blind Project
- North Dakota Dual Sensory Project
- Nebraska Deaf-Blind Project
- The New England Consortium on Deafblindness
- New York Deaf-Blind Collaborative
- Pennsylvania Deaf-Blind Project
- Virginia Project for Children and Young Adults with Deaf-Blindness
- Tennessee Deaf-Blind Project
- Washington State Services for Children with Deaf-Blindness
- Wyoming Project for Children and Youth who are Deaf-Blind

All interviewees were state project directors or project/program coordinators, with two state projects including more than one staff person in the interview. In all, fourteen state deaf-blind project (SDBP) staff participated in interviews. Nine worked for the SDBP on a full-time basis. The other five were part-time. Interviewees had a wide range of years' experience at an SDBP—six had five years or less experience in their position, three had six to nine years, and five had at least ten years.

Most of the responding projects (n=7) are housed within state-funded universities. The others are primarily housed at their state's department of education, often in a school for the blind or school for the deaf and hard of hearing. The number of full-time staff at the responding state deaf-blind projects varies from zero to seven positions. Most also have some part-time positions or hire consultants or contract staff. Most (n=8) have three to four employees.

## Project Implementation

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All the projects address the requirements of the grant, which include the following key activities.

- Technical assistance to schools
- Professional development and training
- Family engagement
- Early identification and child count
- Transition
- Systems change

SDBP interviews addressed the activities required in the grant, as well as how NCDB has supported these activities and led to greater collaboration, stronger deaf-blindness infrastructure, and better practices.

### **Technical Assistance to Schools and Families**

Several of the states interviewed identified that providing technical assistance (TA) to educators was a priority area. For the most part, the project director or project coordinator of the state deaf-blind projects conducted TA. Some operated using a team approach with other state agencies or providers.

Universal Technical Assistance. Some of the states, particularly those with large numbers of students who are deaf-blind on their child count registry, primarily address universal TA. Universal TA is "TA and information provided to independent users through their own initiative resulting in minimal interaction with project staff."<sup>2</sup> It raises awareness in schools and in families about deaf-blindness and provides resources.

Interviewees frequently remarked about how school personnel were unaware of the abilities and learning needs of students with deaf-blindness. Some interviewees indicated that they provide resources broadly for universal TA, then follow-up with targeted TA to better engage with schools and families.

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<sup>2</sup> <http://documents.nationaldb.org/TA/OSEPTADefinitions.pdf>

*“You have to change expectations...[and] change this long-held set of beliefs about a group of kids.”*

*“I feel like it’s one of those hamster wheels that you never get off and a part of it is just the turnover [of teachers]. As soon as you let up on that awareness level training that’s when it starts to fade. So we have to do a lot of awareness training, getting in there, building relationships, and from there that builds the interest for people to engage in our trainings, which we’re doing all online now...[We’re] hoping to add requirements for an action plan and coaching.”*

*“We would engage with those schools that obviously have need and have administrative buy-in and commitment...We do lots and lots of general outreach through general informational webinars. We do a very big distribution of our electronic newsletter, things like that for general [TA]. And then we do a lot of professional development, and that’s where we engage with the schools a lot, trying to beef up the skill set of staff.”*

*“We start off by sharing information universally to schools that are connected with us, but then when schools share with us a specific area of interest or information they’re seeking out, that is shared with them. We’re always sending out pieces that we think may be opportunities for them to consider and just to kind of stay on their radar. As far as direct interest, we’ve had a couple projects that we’ve worked on with schools specifically...focused on communicative competencies.”*

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Targeted Technical Assistance. Targeted TA is “based on needs common to multiple recipients and not extensively individualized...This category of TA includes one-time, labor-intensive events, such as facilitating strategic planning or hosting regional or national conferences. It can also include episodic, less labor-intensive events that extend over a period of time, such as facilitating a

series of conference calls on single or multiple topics that are designed around the needs of the recipients.”<sup>3</sup>

State projects interviewed frequently identified their collaboration with other states in their regions to provide professional development and conferences, most commonly through the Southeast Transition Institute and the Midwest Transition Institute—regional conferences for students about to transition from high school. These events help students with deaf-blindness and their families learn about post-secondary school opportunities through in-person workshops, networking, and social gatherings. Other states collaborate to provide webinars to educators and families.

*“So usually we push broad professional development activities into regional or statewide trainings for teachers of the deaf, teachers of the blind, teachers of the deaf-blind. We do that component based on that analysis of what targeted technical assistance and content needs to be brought to the forefront. Over the past couple years, we did emergent literacy and a more conventional literacy trainings one per year, or for a year we focused on emergent literacy through a series of modules and trainings. And then the next year focused on more conventional literacy skills. And then last year we did new early numeracy skills development and that was great.”*

*“We worked with the center for literacy and disability at the University of North Carolina...And so she helped us with this yearlong numeracy initiative where there were a series of little webinars that people watched, and then a coaching and group discussion. Some exciting stuff is starting to happen there. Mostly just making people think differently about the state standards and how they really align into some core skills and core concepts.”*

*“We’ve come together in the summers and I’ve been involved the last two years and put together a two-day, three-day in-person transition institute for youth with deaf-blindness and their families. So the youth come, the family member comes, more than one family member can come, a team member,*

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<sup>3</sup> <http://documents.nationaldb.org/TA/OSEPTADefinitions.pdf>



*whatever the state can support...Helen Keller [National Center] comes in, National Center [on Deaf-Blindness] has people there. And those have been really great...I feel like I've connected to those projects pretty well, so that if they're doing an event like this, I can support a family to attend."*

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Intensive Technical Assistance. Some states, particularly those with few students who are deaf-blind, have a strong focus on intensive, child-specific TA. Intensive TA refers to "TA services often provided on-site and requiring a stable, ongoing relationship between the project staff and the TA recipient." They involve, "a negotiated series of activities designed to reach a valued outcome. This category of TA should result in changes to policy, program, practice, or operations that support increased recipient capacity and improved outcomes at one or more systems levels."<sup>4</sup>

*"The state implementation teams...are the people that are already in there in the trenches working with kiddos. And what we're going to do is really provide some intensive TA to those folks so that it hopefully will trickle down to more educational teams."*

*"Well, we have a pretty close relationship with outreach staff from [the state's] School for the Blind Vision Services and [the state's] School for the Deaf. And so we have some formal paperwork, but a lot of times it's just outreach staff from the School for the Deaf or the School for the Blind saying, 'Hey, we have this IEP coming up for the student.' I cover the whole state. They cover specific regions and are out in the schools a little bit more often. So I really lean on them for support. But I do attend IEP meetings [and] go into the home if necessary. I think of the TA that I did this last year, and I kind of did it all. I drove to the location, met with the Teacher of the Blind, met with the Teacher of the Deaf, met with the school staff, went to the [student's] home, met with the parent."*

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<sup>4</sup> <http://documents.nationaldb.org/TA/OSEPTADefinitions.pdf>

*“If somebody starts to see decline in progress for a student, ...they will reach out to us. Then we can pull them into some more intensive level of support if we need it.”*

*“[By state Code], in order to have the classification of Deaf-Blind, somebody from the team, typically me, has to be on board for that eligibility determination. And then at the IEP meetings, it has to be a Deaf-Blind representative if they have a classification of Deaf-Blind.”*

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Access to the General Education Curriculum. A number of respondents described issues and strategies related to providing access to the GEC.

*“I would say for the most part, the kids that we serve are in the gen ed curriculum as much as they probably could be. When you get those home bound students, I think that they’re making sure they’re still having access to the gen ed curriculum.”*

*“[The State Deaf-Blind Project will] look at those areas of needs in terms of student performance and outcomes so that we can determine what our project activities should be. And so as a result of that...we really started to look at literacy and numeracy development and which dovetails into having students in less restrictive environments and more access to the general education curriculum. So that’s...because we’re small in terms of number, not size--not square mileage--but because of the number of students that we serve.”*

*“We have to tackle alternate assessment in [the state], and they haven’t been so great at it...[Schools] have adopted the dynamic learning maps...It’s the same struggle that I would say all other states [struggle with.] Teachers really struggle to meet these crazy objectives they’re supposed to, on a plan or in the curriculum, but...that pace just does not work for the child. So we’re kind of working in that mid-range to support teachers. And a lot of it is around modifying the curriculum and with some of these best practices.”*

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Features of TA. Some of the state projects interviewed described specific features of the TA they provide. One project, in which a full-time educational consultant provides TA, addresses the school and home environment, “so that students have the best access where they are.” Another does home visits for deaf-blind children ages 0 to 3 years old. A third participates in an interdisciplinary team to provide comprehensive assessment.

*“We have a transdisciplinary assessment that we do in the state. So that may be sending in a few members of a transdisciplinary team to do a functional vision evaluation for a student who the team really doesn’t have any idea what their visual functions like...We have a team that will go into a school district early next year after facilitating a student getting an optometric exam and then looking at functional vision based on the information that they get back. It was a student who was identified as deaf and after an assessment, their educational team felt like there was maybe some vision concerns. And when we had staff look at that student, it was striking. So then the school’s getting an optometric evaluation this summer, and then we’ll be able to push specialized folks back [into the school with] that Teacher of the Deaf, Teacher of the Blind, Orientation and Mobility specialist, and a Physical Therapist because of the needs of the student.”*

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NCDB and TA. State DB program staff rely heavily on NCDB for TA resources.

*“We actually received help from NCDB looking at our process and how we deliver child-specific TA. We wanted to make sure that we were consistent across teams and so NCDB helped us. There was a resource guide. We’ve used a lot of NCDB products to look at our own practices, whether it’s in child-specific or other areas, looking at how to develop a TA process. So we had support from [NCDB staff who] met with us...frequently. We set like goals what we would do next time, and we actually have a process that’s mapped out. It’s always going to be something that we tweak because we created it with certain teams; ...our process is not going to be a one-size-fits-*

*all. So we need to make sure we constantly look back on it and see how we need to tweak it to make it more equitable across teams.”*

*“We would not be able to do what we do without the National Center [on Deaf-Blindness]...for Universal TA...We have a really robust website...We include resources, we include links to outside resources, which a lot of the time is resources directly linked to the NCDB website and some of the other organizations that are heavily invested in the deaf-blind population.”*

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### **Professional Development**

Nearly all the project staff interviewed cited some professional development they provided during the last year, mostly foundational professional development events about deaf-blindness.

Intervener Training. Whether or not states recognize interveners as necessary para-professionals for deaf-blind students, several state deaf-blind projects conduct intervener training or collaborate with Central Michigan University.

*“One of our previous staff who still does some work for us...worked on the Open Hands Open Access modules. When those modules first came out in 2013, we were early adopters because we knew the work that had gone into them and the usefulness of them...And now we collaborate with Michigan, with Central Michigan University and Beth Kennedy. We have scholarships for up to five para-educators in to attend Central Michigan University’s deaf-blind intervener program.”*

*“Interveners aren’t recognized as a position, but we do have two certified interveners that went through the program about two years ago. But because of the lack of pay, it’s been hard to get additional people to actually go through and get their certification for us. And we’re still working, of course, at the state level to continue that awareness piece. But if we get a new student and they have a para[professional] that’s working with them, we*

*encourage them. We can help support them to go through some of the modules with them. So we use the OHOA modules more for paras that are working with DB students. But if we're looking at a team or OTs, PTs and a teacher, we will typically use the professional learning modules for that."*

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NCDB and Professional Development. One resource NCDB provides to help state projects present consistent and easily-accessible information for intervener training are the OHOA modules, which cover foundational information for interveners, as well as educators who are new to deaf-blindness.

*"[NCDB's] continued support of the OHOA modules are such an integral part of our intervener training. We couldn't do it without OHOA. But the other thing that I've so appreciated just in this last year or so, are the new modules they've been coming out with for general education teachers, the module that's going to be released for early intervention. All of these types of online ready-on-demand modules really help us in our work, especially for our teachers that are, basically for lack of a better term, freaking out because they've never had a student with a combined vision and hearing need. And they're like, 'Oh my goodness, I've got this student, what do I do?' We're like, 'Take a breath. We're going to send you this link, start here. Don't worry about anything else right now. Just start here and we're going to work with you to get you everything you need to feel confident and well-supported in working with your students.' I've so appreciated that because a lot of our teachers, they're being asked to do more with less all the time and they don't have the time to be sitting and doing a two-hour long webinar every time. So these new modules that, even on a 15-minute break, they could be working on something, is really appreciated. I've been so happy to see that."*

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One strength of the OHOA and other modules posted on the NCDB website is that state projects can create individualized learning materials to meet the professional needs of both new and experienced educators, administrators, and families.

*“The modules are not for everybody. We need to look at the time commitment, their availability, how much capacity they have for training. And so that has made us make more curated professional development for teams. So I might take an assignment from one module, videos from one module, and kind of put it together and give it as like a curated package to teams saying ‘I think this would be really helpful,’ rather than the whole module with the quizzes and everything.”*

*“Those who were first in touch with us were begging us to do some Deaf-Blind 101. The time that NCDB was releasing their Deaf-Blind 101 module that they put together, I was able, instead of having in a very short period of time to create a customized training, could access the training that NCDB had done, review those modules, think about what components I would pull out because maybe that wasn’t a piece they were ready for yet, or they wouldn’t be able to relate to it. But I could take the videos that were already done, look at what minutes I was going to share, and identify key concepts I wanted to share around deaf-blindness. And it wasn’t just our expertise. We were pulling national expertise for it. And within that, was able to use those two one-hour sessions for this community on deaf-blindness awareness 101. It worked really, really well and was a huge help to us to have that resource to pull.”*

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Much of the professional development focuses on communication skills. Again, NCDB resources have been vital in providing professional development to educators.

*“Usually it focuses around communication, looking at the communication supports and needs and environmental supports in the classroom. We look a lot at those kind of things, how the classroom’s set up, how the learning environment is, and really helping the teams to understand what that individualized student’s needs are and getting access to information in the classroom. We’ve started using a lot, which I have loved, is the professional development modules that NCDB uses. We have been using those not only in our general deaf-blind training, but also our more specific TA and training.*

*We've been having teams look at that when they get a new student...It's kind of at the end of the school year this year, but that's really been successful. And also using the practice guides. We've been including those in some of our trainings also. And that's been a really good way because it's such a nice package to be able to just show some of the video clips and then have the teams talk about using some of those approaches. And I think that's been really helpful."*

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### **Family Engagement**

States with a low number of students on their child counts tended to have minimal hours allocated for a family engagement specialist or they contracted activities to an off-site family engagement consultant.

*"Well, the family engagement coordinator also works for [the university] and I only have her 10%. So she does teach some of the OHOA modules and provide feedback to teachers and participates in the Summer Institute to engage families. I would say most of our efforts in engagement really comes from the family weekends that the School for the Blind or the School for the Deaf would host. And we sort of piggyback off of that."*

*"The difficulty [the family engagement coordinator] has is that she is such a good advocate that she's pulled in many directions. Everybody wants her to advocate for them. And so that's positive for us because she keeps us very informed about every agency in the state that's doing something. So she's a wonderful resource in that respect."*

*"[We have] a family engagement specialist on staff. She's contracted. She has very limited hours, probably five to ten a month. But it's better than nothing."*

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Family Engagement Opportunities. The state deaf-blind projects offer a variety of family resources, such as information centers and annual conferences. Three host annual in-person weekend-long events for families that children, their



parents, and siblings attend. The purpose of the family events is to provide networking with other parents and training. Family engagement was one topic in which project staff spoke enthusiastically and at length.

*“We just started recently and have only been able to meet once, but we started a new family CHARGE group because we have quite a few new kids with CHARGE. And on the Census, we have around 30 to 35 kiddos identified with CHARGE. So we just started that and we’ve had a couple parents come in, so that’s been good. So we continue to hope to build that. And then also, we typically do a family conference during the year. We haven’t been able to because of COVID, but now as we get into this next grant cycle, hopefully we’ll be able to start that up again where we bring families together in person, not only online, but in person. And so that’s always really a great way to connect our families.”*

*“The Family Learning Conference is also known as Deaf-Blind Family Learning Weekend. It always happens the third weekend in June, and it’s a Friday and a Saturday. And any family in the state who has a child with a combined vision and hearing need is able to come to this conference. It’s held at [a university] in the middle of the state... So deaf-blind children come, their siblings come and families are invited to come and do learning together, sharing together, celebrating together. [On Friday nights,] we usually have what we call our triumphs and challenges session where families just kind of share together...And it’s always a wonderful opportunity to see families really connecting with one another and sharing those joys and those struggles. And it’s amazing how many families make connections with each other that then last beyond the weekends.*

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One state project discussed family engagement in terms of the integrating family members into the project and including them on committees.

*“Families bring rich experience. Providers want to hear from families...The family engagement piece is literally bringing them into our work. So a good example of that was our early identification advisory committee meeting.*



*When we were forming that committee, we invited all of the families we had contact with... And so, it's more than just 'How do we make sure that we're engaging with families out there and getting them resources?' This needs to be a family-driven project, and as such, how do we help, teach, mentor, nurture families to take on these roles of leadership? Where they really are driving what the project is doing and the activities of the project rather than just advising or providing feedback after the fact."*

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NCDB and Family Engagement. NCDB has been a valuable resource to state projects as they work with families.

*"We work closely with NCDB's [staff] with our family portion. We're getting ready to work with [them] and our state Parent Training and Information Center... And so we'll be having NCDB help guide that discussion with us to look at additional ways to support the work we're doing...It's hard for projects to have everything that they want with the amount of funding that we get.*

*"We have a very strong ethic that way of always including the family. If a district reaches out, we say 'Will the family member be at that meeting?' So we really appreciate the work that's been done that way over the years with NCDB and their honoring of families."*

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## Outcomes

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As a result of working with NCDB, state project interviewees cited improved collaboration, better practices, and a stronger infrastructure to support students with deaf-blindness.

### **Greater Collaboration**

NCDB has actively connected states together to share resources and work jointly on projects. Several interviewees in the southern and eastern United States identified the collaboration of states for the Southeastern Transition Institutes, resource-sharing, and conferences. The Western states, which have smaller numbers of students on the National Deaf-Blind Child Count, are more involved with their own state agencies yet some participate in the Midwest Transition Institute. A couple of projects are active in the international Association for Education and Rehabilitation for Blind and Visually Impaired.

*“Do you do any collaborations with other state DB programs?” “Yeah, and that’s really been my saving grace for the whole time I’ve done this...We collaborate together into the Western Regional Early Intervention Conference every other year. That has tracks focusing on students who are blind, low vision, deaf/hard-of-hearing, or deaf-blind. Throughout the pandemic, we did a webinar series in collaboration with [another state’s] School for the Blind and Visually Impaired. In the past, we’ve done large regional virtual parent groups and things like that...Having some of the other people that do the same job who you meet with regularly to be able to share information has been super useful.”*

*“So we have the Southeast collaborative group and we do a lot. It’s with most of the southeast states...We do a lot with those states. We have our Southeast webinar series where we bring in professionals to talk about variety of topics. And we’ve gotten amazing presenters. We couldn’t do it without each. We also provide captioning and interpreting and Spanish interpreting for those. It takes a village to be able to pay for all that.”*

*“It is an opportunity to share and learn from other states...I like something tangible to take away—ideas go out the window. Take ideas from state staff and move forward. Let’s look at what we’re doing and move.”*

*“If we get syndromes that come up that we’re not used to, we’re looking for regional support some way. NCDB is kind of the hub we go to and we’d say, ‘Hey, here’s what we going on. Who else has got this? Who else can we talk to about this content or this syndrome?’...That’s been a huge help...The Deaf-Blind Summit meetings is where, actually, we’ve gotten a lot of good work done with regional states on planning or brainstorming collaborative events.”*

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### **Better Practices**

NCDB helps state projects develop better practices by posting up-to-date and accurate information on their website, creating training modules and resources for no-cost use, facilitating peer learning communities, hosting an annual conference, giving state projects technical assistance, and providing initiative lead staff for family engagement, transition, qualified personnel, and identification of children with deaf-blindness. Resources are shared with families, paraprofessionals, interveners, educators, and administrators.

NCDB staff share resources and with state projects to strengthen their practices, work efficiently with few staff, and better reach children with deaf-blindness. As a result, resources are shared nationwide, within states, and between states. This resource-sharing practice frees state project staff from duplicating resources or having to learn new technology.

*“I don’t have the capacity or the bandwidth to actually run the modules for anybody, and nor do I have the staff to do it, but I can pay to send people to it. So at that time when NCDB offered the whole modules for zip, and someone there would run it, we put two people through it...Both of the [trainees are] now are going through the NICE modules [National Intervener Certification E-portfolio (NICE) System] and we’re paying for that again now to send them through that.”*

*“We share resources from the website. It might be the NCDB website, it might be our website. We might share the materials like the role of the intervener. And then we typically would meet with the team including the family and just share observations. Sometimes that happens in person, sometimes by Zoom.*

*“I’ve used the resources that NCDB has and some of their brain power, a lot of the trainings and technical assistance tools that they have readily available. But I think one of my challenges is time. They’re very willing to help anybody who needs it, but I almost don’t have time to ask. So what we’ve just dovetailed into stuff that exists already...There’s a literacy initiative going on, and then I was able to just add another layer of literacy focus for students with complex needs, including those with deaf-blindness. So by bringing in some training and technical assistance and coaching stuff into that process for those particular kids, [the state has] extended standards for our students who are taking the alternate assessment. And we were sort of ahead of the game on that. “*

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NCDB staff model best practices for TA processes and professional development.

*“It’s great to think about things, but I also like something tangible to take away it...Once I disconnect from that PLC [Peer Learning Community], I’m back into my day-to-day and...those ideas that I generated or thought about, they go out the window until the next time in the PLC and the same thing happens again. I like taking those ideas and having those work groups actually have time during the PLCs. We’re starting that in one of our PLCs--the professional development one [Improving and Implementing Professional Development Practices PLC].”*

*“[Technical Assistance with NCDB staff] was about the outreach to districts and recognition of the role and how to have conversations with everyone from union leadership to state Department of Ed leadership people who provide the state standards [to]...teachers of the visually impaired. So it was really some*

*helpful conversations around those stakeholder groups and the deaf-blind adult population and understanding what interveners are in an educational setting. So I would say the TA process around understanding how to facilitate some of those conversations was very helpful. And NCDB had a huge knowledge base around that...I think what is most helpful is NCDB staff who have also been deaf-blind project directors in a state and are aware how different the states are, but know who some of the players are."*

*"We are in the child TA PLC, the Intervener PLC, the Professional Development PLC, and so all of those connect to working with schools. I would really applaud how NCDB has pushed those PLCs and been responsive to the participants, but also shifting to more adult learning engaging strategies...Trying to learn and make our work better...I know these strategies come from other resources, like whether it's more reflective practices or deeper engagement through processes...It naturally came back up as something that the groups wanted to try. So it was like really interesting to kind of watch as a participant...I know that some people want to go and get a presentation with information and walk away with it. But that's not best practice when it comes to like adult learning. And so I applaud and can see the effort of how [NCDB is] facilitating these groups."*

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### **Stronger Deaf-Blindness Infrastructure**

One key outcome of the work done by NCDB is that deaf-blindness is better recognized as a specialized disability and that students with deaf-blindness are recognized as having unique learning needs. NCDB has been a catalyst in creating greater awareness about deaf-blindness and creating an extensive system of resources to support students with deaf-blindness.

State project staff interviewed identified close collaborative ties with NCDB and most have strong collaborations with their state education, visual impairment, Part C Early Intervention, and Early Hearing Detection and Intervention (EHDI) state programs. NCDB builds stronger interstate and intrastate infrastructures so that resources are shared widely for families,

educators, and providers of children, youth, and adolescents with deaf-blindness.

*“How does NCDB [support our SDBP]? Well, I think around Part C [they’ve] been useful. They did the Bridges program some years ago, and we used that training with agencies birth to three. And then school age. We have a statewide partnership with the people who do Blind - Visually Impaired, and the people who at Deaf and Hard of Hearing, and they partner with us; we’re under one umbrella with the State Department of Ed. So we do quite a lot of partnership with them... Sometimes we go for the preschool transition IEP meeting, just to introduce ourselves, if that’s the only way for us to be known to a school team. It’s better if we have some Zoom meetings or video or before the IEP meeting just to say, ‘These are the services that we have.’”*

*“All of our states [in the region] are sort of smaller population centers and so we end up with kids with a syndrome that there’s no other parent in the state who has that experience. So we tried to pull those groups together and pull parents across multiple states so that they could start to make those connections... And so we’ve really worked with our Hands of Voices chapter to disseminate information through their conferences and to connect us to kids. They had a Read Plus program where they teach parents how to teach deaf babies early emergent literacy skills.”*

*“We’ve set up some sort of natural networks across the state that have helped us in our outreach. Like we created something called the Deaf-Blind Advisors and the Deaf-Blind Parent Advisors. And so we put out this call for people who are in the local areas already doing the work, and then we brought them into our fold and trained the heck out of them so they could beef up their own knowledge and skills so they can be turnkey then for us out there in the community. So we have to be really creative with that sort of stuff, because we do not have the money to be on the ground in all these places. It’s just not possible.”*

*“[The state] is a real word-of-mouth state and people need to trust you, and it’s also a state where people tend to be very private and distrustful of government. And so it takes time to develop those relationships. And that’s a big piece of what [the SDBP] has been doing for the last four years is really establishing trust and credibility with people...Then it seems like you get two or three more calls from other families who have heard that you helped. I think it will continue to spread and grow that way. But it takes time.”*

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## Gaps, Barriers, and Project Support Needs

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While the close collaborations with other state deaf-blind projects and with NCDB have enabled the state projects to reach students with deaf-blindness, they still face extensive barriers. Like project staff interviewed in the past, the challenges cited include the following:

- Extensive job responsibilities
- Geographical barriers (e.g., distance, rural isolation)
- Population barriers (e.g., size, diversity, language, literacy, poverty)
- Limited public and school awareness about deaf-blindness
- Limited systems of support for SDBPs
- Limited interest among educational systems in low incidence disabilities or deaf-blindness
- Limited resources for transitioning students with deaf-blindness
- Families having limited access to the Internet or technology
- Strained or non-existent linkages to school systems and Part C

Some additional challenges that the project staff mentioned this year include:

- High turnover of educators and paraprofessionals
- Varying state structures to support state deaf-blind projects
- Pervasive belief about the limited capacity of students with deaf-blindness to learn literacy and numeracy
- Lack of authorization and state funding for interveners
- Project staff having limited knowledge about deaf-blindness prior to state project employment
- Project staff having limited experience with the full spectrum of birth through 21
- Project staff having limited knowledge about the educational, health, early identification, and medical systems in their state



## NCDB Products/Services/Technical Assistance

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As with previous interviews, when asked about the most useful products, services, and technical assistance that NCDB provides, the state project interviewees frequently mentioned the peer learning communities, the NCDB website and resources, technical assistance, consultation and information from NCDB staff, and opportunities to network and collaborate with other state project staff. This year, as NCDB was able to provide their annual conference in-person, several interviewees mentioned the Summit as a strong feature of NCDB, in contrast to the pandemic years when the Summit was held virtually. All the interviewees expressed very positive support of the work NCDB has done and praised NCDB's materials, technical assistance, and support.

*"We couldn't do what we do without NCDB."*

*"I go to NCDB and the information is screened and of the highest quality. It's kept active."*

*"The support they've given me and that I've utilized has been fantastic."*

*"It's a labor of love and I have been lucky to have great team members and colleagues and some of them at NCDB."*

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### **Peer Learning Communities**

NCDB offers five Peer Learning Communities (PLCs) related to the following topics: *Identification and Referral; Family Engagement; Interveners and Qualified Personnel; Child-Specific Technical Assistance; and Transition.*

The PLCs operate to share knowledge and expertise; collaborate on service provision; and work on problem-solving.<sup>5</sup> Six NCDB staff members lead

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<sup>5</sup> <https://www.nationaldb.org/for-state-deaf-blind-projects/support-from-ncdb/plc/>

the PLCs. Nearly all the state project staff interviewed, or another member of their staff, currently participate on at least one PLC team.

*“So I didn’t know a lot of these people in the Project community and hearing other people talk, it was clear that they all knew one another really well. And I’m like, ‘Oh, gosh, I don’t know these folks.’ But then getting into that Newbies [group], it’s like we all now know each other and we’re friendly with one another. We see each other at meetings and conferences. We’ve even co-presented with one another at some conferences. So it’s been a really nice support that the National Center has offered...So I think it’s wonderful that the National Center not only gave us their blessing, but also gave us their support and collaboration when we needed it.”*

*“Even before I took on this job, I feel like I had a strong background coming in. And so I really appreciate the newbie group that we meet; I think it’s monthly. I like being part of the child TA [PLC] group. And so I think those [PLCs] have been really helpful...everyone’s been so kind and welcoming and so I appreciate that, too. That’s very helpful. It feels like it’s a small field, so it feels good to connect.”*

*“[The State Project Coordinator and I] learn from the other teams that are doing this work. The [DB TA] network--I’ve never seen a place where they share more. [The message is] ‘Don’t reinvent it, we’ve got it, use what we have.’ I’ve never ever seen a place more like that than the deaf-blind community. So [PLCs] give me that great opportunity.”*

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## **Information and Technical Assistance**

All the interviewees had contact with NCDB in the last year and some initiated meetings with NCDB staff for information or technical assistance. Interviewees discussed how NCDB staff provide assistance, support, and information to help SDBP staff address needs in their state and share resources.

*“That’s where I felt the TA from NCDB was really important because as we began meeting with the team in one of the Native American reservations, [NCDB] quickly let us know that we needed to back this whole train up a big ways. We needed to start at the beginning of what is deaf-blindness. We couldn’t start at transition and customized employment because [the school] hadn’t even embraced the concept of deaf-blindness.”*

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Some respondents commented on NCDB's responsiveness and how NCDB works collaboratively with the state projects.

*“If there’s anything I need, I can reach out to any of the NCDB staff via email and I get a response. I’m never left hanging. So sometimes you’d email something and you may or may not hear back from people. [But with NCDB], they’re always getting back and they’re always checking to make sure what they sent me works for me.”*

*“[Some people work] in hierarchical structures where they expect this person always stays the boss. [NCDB] is not like that. It’s a partnership. And sometimes they’re the boss of the product they’re making, and we are the ones following their lead. And sometimes we’re the lead saying, ‘We need this,’ or ‘We’re doing this, can you assist us?’ And they are following us on our lead.”*

*“Anytime I’ve had questions or needed help with something in regards to interveners and trained paraprofessionals, I can always reach out to [NCDB] and be like, ‘Hey, can you give me the most recent information?’ or ‘Can you jump on a call with me?’ And she’s always great to help guide me...Anytime*

*I've reached out to NCDB, they've always been very receptive in answering our questions and supporting us in any way that we're asking for. So I've always had a great relation with the team there."*

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Some state deaf-blind project staff commented about how much they appreciate NCDB serving as a liaison between the Office of Special Education Programs and state deaf-blind projects.

*"That's the piece that is invaluable—for NCDB to meet with the OSEP staff that oversee the deaf-blind projects and then being able to like translate that language into the language we speak...It's super nice to have a technical assistant center that's really thinking about 'This is going to be challenging and how do we make it more accessible and doable for these states...and how do we take the information that the Office of Special Education programs wants these grantees to have and figure out a way to make it more like functional and less time consuming?'...My biggest appreciation of NCDB is having somebody who can watch out for us, like 'Land ahead. Shallow water, don't go here.'"*

*"Just participating as a whole group with all of the state projects, either in person or virtually through the NCDB-facilitated conferences and meetings is just awesome to have facilitators who are assisting in discussing pressing content and upcoming [policy and programmatic changes]...The thing that I love the most [is NCDB] seeing things coming up...and to be able to prioritize that stuff and to prepare and disseminate information back down to all the states."*

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### **NCDB Website and Online Resources**

The NCDB website <https://www.nationaldb.org> offers extensive resources for families, state project staff, and providers of students with deaf-blindness. All the interviewees visited the NCDB website in the last year.

*“2013 was the development of those [OHOA] modules. That was key in starting our training of interveners. So that’s 10 years of their digital materials online. And that support continues with the [NCDB staff members]. So they help enroll people in our state into those national modules.”*

*“I’m grateful for NCDB. I’m grateful for having that resource. I’ve sent so many people to [the NCDB website] to get content. I don’t know what I’d do without them, to be honest. I know what I’m doing and I can run a project without a problem. And I may not be reliant upon them as others may be, especially those who are new to the field. But I still find their resources immeasurable. You can’t run projects without having something like that, you know?”*

*“I want to make sure that whatever information we’re sending out is high quality. I’m starting at NCDB [website] because I feel that when I go there, the information I’m going to provide has been screened and is at the highest quality. So I start there.”*

*“I’m in charge of the census, so any information that I need for the census, I’m going to those resources on the NCDB website to follow that process and feel supported that I have that information.”*

*“If [another staff member] is leading one of the meetings providing intensive TA and I hear her mention calendaring systems or communication books... While we’re on the call, I can go to the NCDB website and find some of the resources there.”*

*“When I first started just being able to go to a place where there was just tons of resources to educate me since my background isn’t deaf-blindness has been really helpful, [like] the OHOA modules. So many articles are tucked away in their [NCDB] site about communication and literacy, all those different pieces of the puzzle.”*

*“Perkins School for the Blind, HKNC, and the National Deaf-Blind Project...broke down silos to make sure that information was cataloged in a useful way and that they weren’t duplicating. They did a great job creating materials.”*

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## **Summit**

The National Center on Deaf-Blindness held the 2023 *Deaf-Blind Summit: Reset, Rebuild, Recharge* conference on March 4-5 in Cincinnati, Ohio, between the Council for Exceptional Children and the Early Hearing Detection and Intervention conferences. This was the first in-person Summit since the pandemic. Attendees expressed appreciation for NCDB providing the opportunity to gather together, network and learn.

*“I’ve been loving this community of all of the state deaf-blind projects and NCDB, like when we were just in DC for the project directors meeting. It’s just a really nice group. I’m happy to get to know everybody for sure.”*

*“Another thing that I really like that we do is the Deaf-Blind summit. I think that’s a huge piece for the deaf-blind practice because we are such a low incidence group. When we’re able to come together in person and really talk through some of these different initiatives, it’s really great to hear what others are doing and looking at those next steps. I always learned so much at that. So that is something I’m really appreciative that we’re able to do, come together because that’s the best ways for us to learn, definitely.”*

*“The deaf-blind Summit. What’s kept me in this field this long is those yearly meetings to talk to other people who get deaf-blindness. And this is what our kids and our teams need, right?...Anything that we get anywhere else — OSEP or any of the workshops I have to attend for my district or the state — I have to take it and adapt it to my kids and my team. NCDB adapts it for us. ‘Here’s the content that you’ve asked for. Here’s the content and how it gets changed for your folks’...So what NCDB has brought to me is all of those experiences that took who I am and loving working with kids and problem*

*solving with teams and gave me the content and the resources to dig deeper into what is good communication, what is active learning, and the brain stuff.”*

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## System Changes

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NCDB has helped state projects build stronger collaborations, create better policies and practices, and form a stronger infrastructure to support students with deaf-blindness. Other system changes discussed include the early identification and child count, and transition activities.

*“We did put in a request for TA with National Center on Deaf-Blindness and we worked with [them] on transition and [it] was fantastic. So that was like the systems change work...And so [they] partnered us with the Center on Transition and Innovation at [the university] who we didn’t have those connections with. And they have just become a fantastic collaboration. Like they’re now reaching out and including us on things. Like when they’re looking for a young adult to interview, ‘Hey, do you know someone with sensory impairments? Because we’re looking for that.’ We’re co-presenting on panels together or on at work at conferences. So that’s been just phenomenal...support and introduction.”*

*“System change is messy and it’s hard to do that...It’s time to really push the work forward. At least that’s how I feel. The people who joined initially are at the retirement age. One has stepped out and brought in somebody else from their agency...So it’s been really nice to have the next generation coming up in this as well. And I feel like right now we have some momentum with that group and have more recently been exploring a systems change model from like the theory of change.”*

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### **Identification and Child Count**

Of the SDBP staff interviewed, the number of children with deaf-blindness on their child count registries ranges from 36 to 605 students. Referrals for the child count come from Part C Early Intervention (EI), Early Hearing Detection and Intervention (EHDI), state education and special education departments, local school districts, and healthcare providers. Timely identification of children with deaf-blindness is one of the most difficult challenges state projects face.



Oftentimes, the under-count is due to the fact that 85% to 95% of students on the child count have other disabilities, so students are often labeled without identifying deaf-blindness.

Early Identification. A few state project staff identified close relationships with Part C Early Intervention and EHDI staff for early identification of children with deaf-blindness. However, many others revealed little or no contact, often because of their state's structure. Those with a limited Part C EI collaboration seemed to have child counts under their state's target count.

*“So for the early numbers, like zero to three, we’ve put a big effort into the medical community. And that’s something that traditionally has not been done on these grants because they’re education focused really. So we start to realize we’re missing the kiddos who really have pretty significant needs at birth, and then they get lost in the EI system, and then the families don’t know how to find us. So we’ve actually put a big effort there. But that being said, we still hover kind of around the same numbers we have right now. I think we’re at 445, and we probably should have doubled that, and it’s truly based on the mislabeling of kiddos and that’s where our constant struggle is with, and so we’re always looking at ways that we can make that jump even higher. In [this state], the EI structure is very challenging cause it’s all privatized, so the EI is at the Department of Health level and then they contract to all private agencies for services. There’s no direct way to reach out to EI providers. We literally have something like 1100 agencies in the state that provide EI services. We can’t call up 1100 agencies. That’s tricky. We’ve done big outreach, as best we could, to email and what have you. But we decided to focus in the medical community.”*

*“And so now, so we spent the biggest part of the last 10 years trying to increase our numbers. We’re up to about 125 and we’re finally feeling the effect of all of the outreach we’ve been doing because we get somewhere between five and ten referrals a month. We went months without any referrals for several years... The political disruption of the Department of Ed really took its toll on special education programming in general, not just the*

*deaf-blind project. It really made it really hard...The superintendent at the time, the philosophy was all decisions are local. So the IEP team was the one who made the decisions...What happens is we have a lot of rural communities and a lot of rural districts, and unfortunately those districts just don't have any professional staff. And so it's awful hard for them to refer."*

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NCDB and Identification. NCDB has provided invaluable assistance to the state deaf-blind projects as they work on the child count and identification. Supports include an archived webinar on the deaf-blind child count data collection process, a peer learning community on identification and referral, the *Early Identification and Referral Self-Assessment Guide*, an Identification and Referral Initiative Lead on staff for training and technical assistance, and other resources.

*"We work closely with NCDB with the child count...I do work really closely with the early identification and referral process and with [NCDB], we've done national trainings with EHDI, so that was really great for our work in early identification."*

*"I worked with [NCDB and] attend Topical Thursdays. I want our data to be accurate. Then I can send a report. What I learned is that we are below the national Child Count for early identification of 0-2. How do we change this? We don't have contact with each kid. Child count is anonymous. We're not collaborating with Part C. We don't provide direct service. But I have weekly meetings with families."*

*"So I interacted with [NCDB] a lot that way because I wanted our data to be accurate and reflective of [our state]. We had to develop a system for doing child count...We have focus around early identification because we can tell from our census, we have a need to be identifying in the zero to two, we are below the national average. And I can report that back to our advisory committee, which we formed a year ago, to help us think about how could we change this practice and we'll be meeting with them again. And I can let*

*them know that we didn't drop to zero as I feared <laugh>, but we only had one in that zero to two. So again, we're not meeting what would be a national average. It's not just that I want to do better is that when we're looking at national trend data, here's where we should be for our state and this is achievable. Unless you know what that information is, how do you know what you're shooting for? So I think that's really important to have that kind of information to be able to go back and say, here's the national trend data."*

*"We do a lot of technical assistance, birth to three home visits...[NCDB] has been useful."*

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## **Transition**

NCDB leads a major initiative to address the high unemployment and social isolation of post-secondary students with deaf-blindness. "Changes in national laws beginning in 2014 and the evolution of state policies and practices related to transition, employment, and community life, however, have opened a window for students with deaf-blindness to experience better adult lives. This initiative supports state deaf-blind projects in their efforts to improve services and outcomes for this population of students and facilitates existing partnerships between the projects and other organizations and individuals dedicated to promoting successful transition to adulthood."<sup>6</sup>

Specifically, NCDB has a Transition Initiative Lead and Transition Consultant on staff and offers a peer learning community and several products including *Recommendations to Improve Transition Outcomes for Students with Deaf-Blindness and Additional Disabilities* and the *READY Tool: Readiness Evaluation of Transition to Adulthood for Deaf-Blind Youth*, to help state deaf-blind projects address post-secondary employment goals of students. NCDB supports the regional Transition Institutes for youth 16 to 22 years old.

*"I offered [the transition conference] in-person and we offered to pay [the families'] hotel and travel and stipend and things like that. And we got about*

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<sup>6</sup> <https://www.nationaldb.org/national-initiatives/transition/>

10 people. It's early August, so we're trying to get people in the summer to attend. We had Jonathan Pringle from the Helen Keller National Center talk about pre-employment transition services... We usually have someone from the assistive technology realm. We have a program called [State] Assistive, which houses pretty much all the AT stuff. They have the I Can Connect program, so they usually present on that. We had a speaker on Braille, the VI program in the state. We have one university program for deaf and hard of hearing education and one university program for visual impairments. And she actually just updated a book on braille literacy. And so we had her present and we gave everyone a copy of the book... Then we had a CODA [child of deaf parents] present from South Dakota. She attended the shared Reading Professional Development in Charlotte that NCDB hosted in collaboration with UNC, I think it was."

"We've collaborated with NCDB staff in the past to be able to plan for different webinars that we've been recorded to use as future training when it comes to doing secondary transition. That was a heavy focus of our last grant cycle."

"We're having our own transition retreat this summer and we have six families coming. And so that's a really nice number to look at... And so part of it was like learning through the other network of state deaf-blind projects in the southeast region and being part of their planning because they have been doing this for years. At the same time, I joined the Transition PLC through NCDB which certainly has started to open up different possibilities of where to explore... So it started Friday evening to Saturday, Sunday afternoon where we had families get some time with our family engagement coordinator to talk about what their goals were for their children. And then we worked with the young adults and talked about what they had in mind and how we could support them and action plan for those goals in the next year. I think that was so successful."

"Transition is always a struggle. We work really closely with our VR [Department of Vocational Rehabilitation] and have a really good

*relationship with them. It's just continuing to help providers understand what transition is for our kids, and some of our more complex kids, customized employment, looking at those different options for a lot of our students and trying to help them to get on board early on at 14. And we do work really closely also with our HKNC rep."*

*"Our child count informed us of two important pieces. One being the number of individuals on our count who are transition age. And so last year we had a specific project focused around transition because we had a higher population, probably more than many projects, of individuals who were in that transition age."*

*"Because there are some other components that I think are really important to us that are part of the early ID advisory council. Also the transition pilot...where we worked very closely with the families who were involved in that pilot. And we make sure that families are compensated whenever we call on them to assist in this work. And so that to us is just a critical piece that they're compensated fairly, not just a \$20 Starbucks card or something, but we look at \$25, \$30 an hour depending on what they've done. The other piece that we actually like right now [is] we have on temporary hire a parent of a young adult with a dual sensory impairment...She came on board to work with us as part of the pilot, as part of our staff, and now she's continuing on with us through the summer to help out with some additional projects that we're working on."*

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### **Work Left to be Done**

State deaf-blind project staff identified several areas in which they need more help. These include more communication and transparency by NCDB, more resources for families, more resources for professional development, and more direct work to build state infrastructures to improve educational outcomes for children with deaf-blindness. Many suggestions may not be feasible.

Communication and Transparency from NCDB. Interviewees recommended several ways in which they would like to have improved communication and transparency from NCDB, including:

- Share more information about how other state deafblind projects manage transition, early identification, technical assistance, and family engagement.
- Conduct routine check-ins with each state.
- Provide monthly, friendly “this is what we’re working on” emails with warm, informal notes from the director.
- Describe conversations between NCDB and OSEP, such as the rationale behind no longer certifying interveners and how decisions are being made.

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More Resources for Professional Development. Interviewees recommended having more user-friendly and research-based resources. Suggestions include:

- Update the BaseCamp on NCDB’s website to be more user-friendly.
- Indicate if webinars are accessible or not.
- Provide a speakers’ bureau so state projects can share resources.
- Provide accessibility resources available nationwide, such as interpreters and Communication Access Realtime Translation (CART) services.
- Develop and disseminate more evidence-based best practices for literacy training.
- Provide more nationwide synchronous and nonsynchronous professional development organized by NCDB and featuring experts in the field.
- Post more lessons learned from other state DB projects.

*“I know how to get to the practice guides, but then like we were looking for systems change resources [and could not find them]. I feel like there were so many amazing recorded sessions that came out of COVID that I think are still somewhere on the internet. And I just wonder if there’s a way to collect*

*from the deaf-blind projects any recordings from that time because that's also awesome professional development to share with teams."*

*"There's limited materials for kids with disabilities based on the science of reading. It's almost like being able to utilize alternative methods, accommodations, modifications, but still trying to utilize evidence-based and research-based practices."*

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Improve State Infrastructures. Each state interviewed identified different state structures that hampered their ability to identify children with deaf-blindness or assist in improving educational outcomes. While only one interviewee directly cited a need for help from NCDB, there is a clear difference between infrastructures across the country. State deaf-blind projects are much more visible in some states than others, and some have more statewide support and resources.

## Conclusions

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As the four-year evaluation study of NCDB ends, several conclusions seem evident. Foremost, NCDB staff and other resources are essential in the work of state deaf-blind Projects. Repeatedly, interviewees reiterated the importance of having connections with NCDB for technical assistance, coordination, training, communication, information-sharing, and collaboration. They also stressed how their interstate connections with other state deaf-blind project staff was vital, and how NCDB played a critical role in facilitating and supporting those relationships.

Another conclusion is that the state deaf-blind projects are structured very differently across the country, with some projects located in universities and others in state special education departments. Where a project is housed makes an immense difference in how it can gain access to infants and children with deaf-blindness.

Regardless of a project's funding level (and whether they have funding sources in addition to the federal grant), the number of children on their deaf-blind child count, the number of staff, and where the project is housed, the fact remains that deaf-blind project staff would be isolated and ineffective without NCDB. Because deaf-blindness is rare, very few educators or families experience the unique learning and communication needs of children who are deaf-blind. The support from NCDB, then, becomes indispensable in connecting educators, family members, and project staff together and in abolishing the silos so prevalent for systems serving children with low incidence disabilities.



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**National Center  
on Deafblindness**



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