STATE DEAFBLIND PROJECTS

2024 Findings from Interviews with State Deafblind Projects About the National Center on Deafblindness

NCDB

National Center on Deafblindness

"I depend on NCDB. I really do. I think that they are always out there looking for the latest research and that's super helpful. I can't imagine a deafblind world without them."

State Deafblind Project Interviews

"As a national technical assistance center, NCDB works with state deafblind projects and other partners to improve educational results and quality of life for children who are deafblind and their families."[1] In all, there are 48 state or multi-state deafblind projects throughout the United States that utilize the National Center on Deafblindness (NCDB) resources, including consultations, training, learning communities, technical assistance, webinars, tools, and materials.

The interviews conducted for this report took place as part of NCDB's evaluation process. Three additional interviews will be conducted in 2025, 2026, and 2027, with different state deafblind projects each time. The following report focuses on the start of the current funding cycle. The sample consisted of 12 state deafblind projects, three large and nine small. A third-party independent program evaluator conducted interviews during May through August 2024. Questions that formed the basis for the semi-structured interviews included:

1. Is 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?

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[1] **https://www.nationaldb.org/about/**

Participants

The 12 state deafblind projects that were selected for interviews in 2024 are the following:

- Arizona DeafBlind Project
- California Deafblind Services
- Colorado Services to Children with Combined Vision and Hearing Loss
- Florida and Virgin Islands DeafBlind Collaborative
- Kentucky Deaf-Blind Project
- Connections Beyond Sight and Sound – Maryland & DC Project
- DeafBlind Central – Michigan
- Oklahoma Deaf-Blind Technical Assistance Project
- Rhode Island Services to Children and Youth with Dual Sensory Impairments
- South Carolina Interagency Deaf-Blind Project
- Utah DeafBlind Project
- West Virginia SenseAbilities

All interviewees were state project directors or project/program coordinators, with three state projects including more than one staff person in the interview. In all, 15 state deafblind project staff participated in interviews.

Project Progress

All of the projects interviewed addressed the requirements of their grants, which include the following key activities:

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

The following section details project progress and how NCDB has been integral in providing informative resources to support the state deafblind projects.

Targeted Child-Specific Technical Assistance to Schools and Families

As required by the Office of Special Education Programs (OSEP), all state deafblind projects conduct technical assistance (TA).

> "I do a lot of child-specific [TA]. A lot. We have to set aside a fairly decent travel budget every year because I get requests to come to [a distant city] a couple of times a year, so I have to drive [there] and stay overnight because it's quite a distance from where I live...We do quite a bit of intensive TA...The way I try to get it to work out is that we want to meet the person on Zoom first and see whether or not we can provide the information that they're needing or the technique or the strategy that they're needing. And if it's something that can't be done on Zoom, then we'll set up a time to go in...We use a lot of the [NCDB] resources--the Child-Specific TA Guide. We'll use that for ourselves."

> "So in terms of how I spend my time every day, if I was still doing the level of travel that I was doing pre-COVID, I probably would have to say no more [to child-specific TA] often. But, connecting with people via Zoom, saving all the travel time makes a big difference...I connect with a lot of teams.

Sometimes it's just brainstorming. Sometimes that leads to a request for some child-specific training. I do some coaching, but that's specific to interveners…A lot of the TA I do is probably targeted and then some falls into the coaching."

"I go into the schools and meet with kids. And there's quite a bit…on our registry right now, and we had 12 come in between the end of April and the end of May. So we stay very active here."

"[The NCDB website is helpful for child-specific TA because it has] tons and tons more [resources] than we ever have in our bag, so it's kind of nice."

Universal Technical Assistance to Schools and Families

Universal TA is provided in a variety of ways. The NCDB website has been indispensable in offering resources for universal, targeted, and intensive TA.

"Our family engagement coordinator gets [families] involved in a lot of things. [With the family network], they work together to supply a lot of family information."

"We also do things like newsletters and things that's more universal."

Access to the General Education Curricula

All states are required by IDEA to provide access to the general education curriculum (GEC) for all students with disabilities. The state deafblind projects vary widely in how well students who are deafblind access the GEC.

"*How well is [your state] doing in terms of getting the kids up to general curricula standards?* Probably not great…We have center-based programs. So there are separate schools for kids with multiple disabilities…We do have some kids that are more in general education. We do not have a high number of kids who graduate with a regular diploma. Most of our kids are certificate. If kids have an intervener [when they are] younger so that their

communication and concept development is leading to more language…then they can better access the curriculum and that's all kind of interwoven."

"I really do think the majority of kids are spending some time in the general ed classroom and they are thinking about general ed standards. But it looks different for our kids. Like our literacy is much different…So many of the children are medically fragile, so families wanted to keep them at home. So you can access the curriculum, but not the environment. I feel like last year, the majority of kids are back, that they are in school and we're thinking about getting them in the general ed classroom, and our schools aren't closing down anymore [due to COVID]. So but we're back to more normal."

Family Engagement

As some interviewees indicated, families vary widely, with some families being very involved with the state deafblind project and others having little or no involvement. Several state project staff discussed their family engagement activities and events, often excitedly describing innovative ways for families to socialize, learn, and network.

"Family engagement is great. That's the one thing I can really say. Our family engagement coordinator keeps people very, very motivated and very engaged. They do the family- to-family calls, and then we have a family-to-family call in Spanish. And there's some other support groups that our family engagement coordinator works with from the family network on disabilities here--all these different leadership programs for parents. She gets really involved in that. And then a lot of good things come out of that. And we have…a conference that's put on by the governor and about 10,000 people attended every year. And it's all about disabilities, anything to do with disabilities, any entity. So they have a huge vendor area, and then tons of presentations. I am presenting this year on effective vision screening, birth to three, because nobody addresses birth to three ever. They wait till the child gets at least three years old before they start vision screening. And it could be, in a lot of instances, it can be too late…We try to sponsor a couple of families here to go…I don't think we're really that different than any state.

We have parents that are very, very involved and then parents that you can't get in touch with."

It's all about partnerships and working with people that you love…We try to get families to actually look into the National Family Association for [DeafBlind]. So [we] encourage membership, seeing what's happening at NFADB…COVID kind of really dismantled a lot of the motivation and getting people excited about different things…Pre-COVID, we offered family learning weekends. We were able to offer actual weekends at a hotel that was accessible. And so there was childcare; there was parent training all in one place. There were other activities and that was well attended. But they were expensive because we covered families' rooms and meals and the whole thing. So it's hard. We can't do that anymore."

"I think our family engagement is very good. I have no concerns about it other than I wish I could help the families more or help them somehow attend our engagement activities. But you can only do so much. You can't pick them up and pack their bags and provide childcare and, you know, you can't."

"We're trying to do more intimate family engagement, zoom around a specific disability or specific topic, or we'll do a face-to-face. [We] try to make it fun where parents can come and meet each other and meet at the park. A park that has equipment for children that have a variety of needs...I'm finding there is the desire out there. Parents have a desire to meet. The problem is a lot of times logistics in picking a time that works for everybody that's in a location that's accessible given the age of their child, given the multiple children. So the desire is there...So we're trying to offer things in various parts of the state at various different times."

"What we try to do with our [family] newsletters is make them useful. It's not just information. Like we do a lot of product development in terms of Cerebral Visual Impairment (CVI)...(like) books on tape...We try to include things that families would like to do with the kids. And that seems to be helpful, but again, it's not child specific at that point."

Early Identification

Early Identification of children who are deafblind is critical in order to assess needs and provide educators and families with resources that can improve learning and communication. Early Intervention (Part C), early hearing detection and intervention (EHDI) programs, and state departments of education are the entities that most often contribute to the state deafblind projects' child counts.

"We've done really well. We've increased our numbers. We've increased our 0 - 3 and 0 - 6 [aged children on the child count]...One thing I've noticed, like when I do child count, I have to read a lot of IEPs. And in reading them, if you go to the section that's health, vision and hearing, a lot of times you will see the first paragraph or the second paragraph is OT [Occupational Therapy] or PT [Physical Therapy] and there's huge paragraphs about OT and PT. And then there's like one or two lines about hearing, one or two lines about vision."

"I feel like early identification's getting a lot better."

"We do a lot of outreach to early intervention providers throughout the state so that they know who we are. Then during our child count, they all get packages and information about the child count, where we're relying on them to help us accurately keep that count. So they know to look for [children who are deafblind]. Our numbers remain pretty consistent, but think there still might be some kids out there, especially maybe kids that have CVI [cortical visual impairment] and maybe CAPD [central auditory processing disorder], so they have brain-based hearing and vision [disabilities] that people are not really recognizing the vision and hearing loss."

"Well, [deafblindness] is the smallest group of special ed population. There's a beautiful graphic [that shows] a huge circle of special ed kids. And then by the time you get down to the deafblind population, it's a pin prick dot that's down here. It's based on child count data of special ed kids in the country. And then we're less than 10,000 kids nationwide. And so it's a small

population…When I'm in districts talking to SPED [special education] directors or superintendents and they say, well, we didn't do this because the numbers are so small. I'm like, we're not in a number game. We're special ed. If we were in the number game, we're in the wrong field."

Transition

While most of the states interviewed identified problems with transition (see "Lack of Transition Opportunities and Resources" below), some identified progress in transitioning post-secondary students into jobs and post-secondary schools.

"We have a transition personnel prep grant. So we have contacts with teachers through that process. And we can dovetail that with the deafblind program...I would love to say that every single child that transitions into adult life has their own place to live and their own job and is independent. That's not the case, but I think we are making movement towards that, even though we're not there yet...It was a little bit easier during COVID because where the deafblind program was housed because of COVID, there was a community of practice and that connected us with a lot of teachers specifically about transition, how to do transition skills when you're at home. So we were really helpful with that. Not that I want COVID to happen again, but I think that that was a nice basis to start those relationships."

"We really take transition very seriously...We have just hired someone new that will work with zero to 14, and she will be specifically for transition. That's her gig. She is really good with transition. And we do a full ECC [Expanded Core Curriculum] week where we invite up to eight students, young adults who come with their family. We take the kids and we do some real hands-on social building, concept building...Everything is [embedded into] transition, looking at jobs and seeing what's there. We also have a big entourage of people who come to that...Everyone sits down and we write a comprehensive report that targets some areas of growth as they are getting closer to transition. So we may pull stuff off of NCDB at that point. I know that [a state deafblind project staff person] has worked with [the NCDB staff

member] some; I know that they've talked about transition. It's a huge thing for us right now because we're seeing all the gaps and holes in kids as they age out. And we're trying to back it up to when they're really young and what [they] are missing along the way to help build them towards that."

Quality, Relevance, and Usefulness of NCDB Products and Services

When asked about the most useful resources that NCDB provides, the interviewees most frequently mentioned the NCDB website; TA from NCDB; NCDB staff; the *Open Hands Open Access (OHOA): Deafblind Intervener Learning Modules*; the NCDB peer learning communities; and the resources for TA, training and professional development, family engagement, early identification, and transition. All interviewees expressed positive support for the work NCDB has done and praised NCDB's materials, technical assistance, and support.

NCDB Website

The NCDB website (nationaldb.org) offers extensive resources for families, state deafblind project staff, and educators and other service providers for students who are deafblind. All of the interviewees visited the NCDB website in the last year, to access the *OHOA Modules* and other resources.

"I love the [NCDB] website. I use it all the time."

"I do use [the NCDB] website. If we don't have a resource on our website, then we'll see if it's on theirs. But typically we try to compliment what they have for resources based on what we have. Theirs obviously is deep and wide. So ours really focuses on trainings and opportunities we have to offer. So I would definitely say that we use their website."

"We interact a lot with [the NCDB] website. We use the IEP guide for interveners with our IEP teams…I think it's organized very well. It has the categories and I can always find what I need."

"I frequent their website to get information all the time."

"So, we may not contact NCDB to help us with the training, but we definitely point everyone [to the NCDB website], that they're our number one source to go to and that other people could go to them. And then we specifically

point out the Practice Guides, the IEP discussion checklist. We do that a lot of times."

"We've used a lot of the reports on transition [from the NCDB website.] We'll use a lot of the things on CVI [cortical visual impairment]. There's so much on the website."

"I use their resources all the time. Especially their intervener IEP discussion, their tools about deafblindness. And this year, instead of creating my own PowerPoint and calendar systems, I actually used NCDB's. All I was doing was recreating the wheel anyway."

"I talk about the literacy [resources] when needed during TA...Like I really appreciate their literacy [resources] and I think that they were going to edit that as well and upgrade it. So that's been a good resource also for people. [We refer families to the literacy resources as well.] I think it's more user friendly now. It does appear to be more user friendly."

NCDB Technical Assistance to State Projects

While none of the state deafblind project staff interviewed requested intensive TA from NCDB, most have developed relationships with NCDB staff to ask questions, discuss a case, or brainstorm.

"If I have any questions or need help, I will send an email to [NCDB staff person] and see if she can meet with me…I don't feel they're separate. I just feel they're just a partner…They're the people that understand what we do. All our other partners, we have to go through almost like a big educational session to know what we do and who the kids are that we work with. We don't have to go through that with NCDB. They know what we do."

"I did reach out to NCDB when I [worked] with a family, but it's a really kind of tough case. And we were all brainstorming, so now the kiddo has an intervener, so things are better."

"NCDB has always, for me, been very responsive. Anytime I have a question or a concern I always feel like they go above to try to make sure that they get the answer for us."

"They respond quickly and they really do look for the answer. [NCDB staff person] is great about sending examples so that you have something...I was having some difficulty and reached out with a question about evaluation, and she showed me a sample document that really helped me focus my thoughts and saw, once I saw the example, I was like 'Oh, this makes sense.' So [they're] very good at that."

"I like that they're really listening to us and are offering good virtual opportunities. I like it when they offer us things where we don't have to travel to get together."

NCDB Staff

Interviewees identified NCDB staff, either collectively and as individuals, as being helpful in responding to questions and concerns, coordinating and engaging state deafblind project staff, communicating OSEP mandates, problem-solving, training, collaborating, and providing referrals to national organizations and resources.

"We used to hire an outside facilitator [for deafblind trainings.] For next school year, we are going to be using the modules [NCDB] developed for professionals working with students with deafblindness. And we've always used the OHOA modules that our intervener training is based off of the modules. It's a three-year training cohort...NCDB supports us setting up the [training]. [The NCDB staff person] interacts with us to get those done. And again, NCDB is always very responsive...[The NCDB staff person] is the most amazing meeting facilitator I've ever experienced. She has a way of making sure that everyone gets heard...All the meetings that I've been in that are led by NCDB staff are like that. Like they're very good about making sure you have an agenda and any materials ahead of time. I really like that about

them. They just sent out materials for our meeting that's coming up June 5th, so that we're ready…"

"I think [NCDB staff are] wonderful. I have nothing bad to say about them.

They're accepting of feedback and they incorporate that feedback into what they're doing. They've always been very helpful to me."

Support for Intervener Training

Several state deafblind projects interviewed conduct intervener training or collaborate with [institutes of higher education]. Interviewees often refer students, educators, and paraprofessionals to the *OHOA Modules,* or integrate parts of the modules into their own trainings.

"I use the *Open Hands Open Access* modules [on the NCDB website]. I refer lots of staff to those. [I also refer educators to the NCDB resources] the IEP intervener guide, the students guide, the IEP guide if a student needs an intervener resources…We usually use them as a resource for training teams…But if the school team or we are not able to fund that person taking a college coursework program, I always offer the OHOA modules as a backup that they could do as professional development on their own time, self-paced. I might pick and choose a video or two to use in my direct trainings with school teams."

"I use the OHOA modules and I have a contract with the state department of [education] to pay stipends for people to take to complete the OHOA modules. People like them and one teacher who actually completed them said, 'This is the best training I've ever had.' I really try to have para-professionals take those. That's who they were created for. But oftentimes teachers want to do that too…I love the OHOA modules; they've been wonderful."

"We use the OHOA modules with our university-based intervener training program. And we get really good feedback from the students like how they're set up."

"I go to [the NCDB website to get] information a lot about interveners, because we have a lot of questions about that here. It's not very well known or received. And so a lot of times either parents or even some districts will ask, 'We don't know what this is. Can you tell us more about it? Do you have any resources?' And so I usually give them an explanation of what it is and why the child needs that particular type of service. And then I always go on the website and get as much information resource information about interveners as I can to get to them."

"What's nice is for my student teachers and graduate interns as part of their internship [to access the *OHOA Modules*]. I introduced them to all the ones that are available. And I said, 'All right, pick one that we haven't done already.' And without fail, they want to do sexuality because they're curious."

NCDB Peer Learning Communities

NCDB offers peer learning communities (PLCs) related to the following topics: identification and referral, family engagement, interveners and qualified personnel, child-specific TA, and transition.

The PLCs operate to share knowledge and expertise, collaborate on service provision, and work on problem-solving.[2] NCDB initiative leads staff the PLCs. Of the staff from the 12 state deafblind projects interviewed, 11 currently participate in at least one PLC.

"I'm in, let's see. I'm in...the one related to interveners, the one related to professional development, and then I just recently joined the one related to transition. They're very helpful to me just because you have a chance to hear what other states are doing, and some of them are facing similar issues...Honestly, just to sometimes be around like-minded people that are working on similar things is good. I think the NCDB staff that are leading those groups are well-prepared for them. There's definitely some structure

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[2] https://www.nationaldb.org/for-state-deaf-blind-projects/support-from-ncdb/plc/

but they're flexible enough that they really are trying to follow what we as a group are saying that we'd like to do. I don't feel like they've got an agenda of what they're trying to achieve besides providing a venue and a means for us as different projects to collaborate and talk."

"I've worked on a PLC...I've worked with that a lot. And they've just been helpful, like answering questions and things like that. I worked a lot with identification PLC, but I like their PLCs because you're not the only one."

NCDB Resources for Technical Assistance

State deafblind project staff rely heavily on NCDB for TA resources. Helpful resources include a technical assistance coordinator and guides for providing child-specific TA, systems TA, and family TA. The NCDB website provides inks to multiple other internal and external materials helpful to state projects for conducting TA.

"So the past year, I've done a lot of technical assistance, basically once a month, like traveling on the road to schools, working with teens, teachers of the deaf...I always pull [out NCDB resources], like the fact sheet about deafblindness, for any presentation that I do. Just so that they're aware of what it is. We also talk about some of the common syndromes associated with deafblindness, because we've got some that seem obvious, but not for general educators that don't tend to deal with deafblindness."

"Sometimes we'll go hunting [in the NCDB website] and look in there...If it's a group about literacy, if they want to know how to embed literacy into their day with a student, we may go specifically to the information about literacy and use the literacy checklist. I mean, look at all the information they have there. If a team is just starting out and we're talking about concept development, we may go hunting on their site and try and find some really strong things that would either prepare them for the training or as follow-up to our training. We do it both ways. Sometimes we'll send out things ahead of time. Sometimes we follow up. Especially with families, like when we meet online for a new referral, we always send them something specific that

they've asked for. It's part of their plan as a follow up. And that may include something from NCDB."

"I use [the NCDB website] all the time. I'm probably one of their most frequent users. We share a lot of their resources. We share a number of resources found under the info center, the practice guides. During trainings and when we're out doing TA, we show people how that breaks down into different topical areas of how to find things. We share a lot of assessment tools that are found on the website."

"There's also a technical assistance document that NCDB did that I use. Kind of a readiness assessment."

"In NCDB's website, their resources are super helpful and the resources that they create that are generic; we can pop our logo on them and use them. Those are super helpful. If I get asked to do presentations or whatever, I don't have to create it; that's very time consuming…I think the name of the PowerPoint [I use from the NCDB website] is called Sooner the Better [*The Sooner the Better: A Framework for Training Early Intervention Practitioners on Deaf-Blindness.]* That's what I use all the time when I give presentations [to early intervention practitioners]…There's so many rare disorders that come along with deafblindness. And so NCDB has a lot of information on that. And I think they've collected things over the years. You know, one-page information sheets about communication or about different strategies and techniques, which are very helpful because I can just go to that and modify it and use it."

NCDB Resources for Training and Professional Development

As deafblindness is rare, most educators have little to no practical experience working with students who are deafblind. Professional development programs typically lack content on how to teach this population of students. NCDB's professional development modules directly address this need by providing information about high-quality practices for educating children and youth who are deafblind. NCDB currently has two modules "for practitioners who want to improve their knowledge of deafblindness and gain practical

information they can put to use right away in the home or classroom."[3] One is *The Impact of Deafblindness on Learning and Development* and the other is *Early Intervention for Children who are Deafblind*."

In addition to NCDB modules that can be incorporated into professional development, NCDB has a dedicated Intervener and Qualified Personnel Initiative Lead, as well as an extensive "Info Center" that includes info topics with countless slides, documents, one-page summaries, videos, and other materials on the following topics:
- Foundations of Learning
- Assessment
- Educational Services
- Communication and Concept Development
- Promoting Learning
- Socialization and Recreation
- Life Skills
- Transition to Adulthood

"We use some of the professional development modules that [NCDB] is making. We have a collaboration with the [state department of education's information materials]. And we are facilitating the professional development modules for them. We use the OHOA modules, and a professional development series of modules-- the impact of deafblindness...early intervention, and communication. We have a huge audience--teachers of the visually impaired mostly--but we do have some teachers of the deaf/ hard of hearing; we've had some speech path people on there, OT, PT. [We get] really good feedback. Yeah, the feedback has been great on the quality of the modules. The usefulness of the information has been really good because these are all people in pediatrics who deal with children who are Deafblind. You'd be thinking it'd just be teachers, but no, they deal with these children too, and they don't know exactly what to do when they encounter a child like that. And so they come to us for the information and

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[3] **https://www.nationaldb.org/national-initiatives/iqp/professional-development-modules/**

we get them set up with these modules, and they learn a lot about how to deal with the kids just by going through these modules."

"[We use] some of the OHOA modules and then some of the new learning professional development modules for teachers and related service providers…It's just foundational deafblindness and strategies. And then the other one is early intervention, and we use that with early intervention providers. Those modules are terrific."

"When NCDB offers a webinar, I typically log in…[I also] tap into the NCDB website when I'm looking for information on a certain topic or as I'm teaching other people, I will point to it as a resource for them to find other things. We try to promote any kind of training opportunities that we're made aware of so that our project constituents can take advantage."

"We did a fall conference this past year and we did a track that was deafblind. I had an interpreter who has tactile interpreting experience, and so she talked about tactile interpreting. I think in the spring we'll do more cortical visual impairment, which a lot of our kids with deafblindness have. We're going to do a kind of a workshop with that. And then next fall we'll do another one where [that is] a little bit more formal. And these are typically for the teachers, like all the teachers of the vision impairment and all the teachers [of students] with deaf/hard of hearing impairment."

"I always pull the fact sheet about deafblindness for any presentation that I do. Just so that they're aware of what it is. We also talk about some of the common syndromes associated with deafblindness, but not for general educators."

NCDB Resources for Family Engagement

NCDB offers a two-pronged approach to supporting families who have a child who is deafblind—resources designed specifically for families and resources designed to support state deafblind project family engagement coordinators and other professionals who work with families.

In terms of resources for families, NCDB has a section on its website that provides information about organizations, services, learning resources, news, and events. Families can also learn about events, announcements, and other resources through NCDB Facebook posts.

Resources designed to support state deafblind project family engagement coordinators and other state deafblind project staff who work with families include a dedicated NCDB Family Engagement Initiative Lead and the following materials:

- *Providing Technical Assistance to Families: A Guide for State Deaf-Blind Projects*

- *Implementing Evidence-Based Practices for Children Who Are Deafblind: A TA Reference Guide*

- Resources to guide TA services for culturally and linguistically diverse families

- A guide called *The Value of Family Engagement: Identifying Unique Needs and Priorities of Families with Children Who Are Deaf-Blind*

"And then we have family support providers, volunteer family support providers in our state that work with other families. So they share a lot of the resources from the [NCDB website] Family Resources page, especially in the Spanish section. So there's a whole section of Spanish resources that we use a lot with families here."

"Family engagement is probably something that I need to work on and I probably do need to reach out more to NCDB. But I also know that they have the needs assessment online that I will be using."

NCDB Resources for Early Identification

NCDB provides invaluable assistance to the state deafblind projects as they work on their child counts and identification of children who are deafblind. There are numerous NCDB resources to support these activities including

- An NCDB Data and Evaluation Manager

- A dedicated "Child Count Management" page with resources on collecting, reporting, and analyzing data for the *National Deafblind Child Count*

- Two Identification and Referral Peer Learning Communities (PLCs)

- An *Early Identification and Referral Self-Assessment Guide*

- An annual *National Deafblind Child Count Report*

"So over the lifespan of a student, I really have reached out to NCDB. I think one thing I like is they have the little self-assessments that you can do, like for early identification and transition. And I don't know if you've been on the website, but it's really cool…They give you some questions to think about and you kind of formulate your answer. And then based on your answer, they give you options to address, whatever your issue is. It's very good…like the self-assessment for early identification. Now I reach out to the medical profession more than I used to [to get referrals for the child count]. I used to just do schools. But that was one of the things that, based on that self-assessment, that I saw an area of need in the state. So that's nice, you know, that it's a document that kind of leads your thinking and you can apply it to big states or little states."

NCDB Resources for Transition

NCDB leads a major initiative to address the high unemployment and social isolation of post-secondary students who are deafblind. "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 deafblindness to experience better adult lives. This initiative supports state deafblind 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."[4]

Specifically, NCDB has a Transition Initiative Lead and Transition Consultant on staff and offers a peer learning community and helpful publications such as *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*.

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[4] **https://www.nationaldb.org/national-initiatives/transition/**

Outcomes

The major outcome of the work done by NCDB is that deafblindness is better recognized as a specialized disability and that students with deafblindness are recognized as having unique learning needs. NCDB has been a catalyst in creating greater awareness about deafblindness and creating an extensive system of resources to support state deafblind projects, educators, paraprofessionals, and families.

As a result of working with NCDB, state project interviewees cited stronger collaborations, a better understanding of OSEP mandates, more frequent information-sharing between state deafblind projects, improved preparedness of new staff, and better practices. The state project initiatives and activities, supported by NCDB resources, have led to a stronger infrastructure to support children who are deafblind.

Collaboration Between State Deafblind Projects and NCDB

"Because I have had success around certain things, I'm happy to talk to people in other states about how they might replicate what I've done or just learn from what I've done to try to figure out how to do it in their state...I just love what I do, so I have a hard time saying no. When someone contacts me and asks me do I want to do this? I often say yes. So, nothing's collapsed yet, so somehow, I'm getting it all done."

"I would say for NCDB, the person I have the most contact with is probably [NCDB staff member]. So she and I collaborate on a number of things. I feel like NCDB staff and I, we sort of consider each other a mutual resource in some ways."

Collaboration Between State Deafblind Projects and State Agencies

"Most of our kids are not listed as deafblind [on their IEPs]. They're listed multiple disabilities. So I just contacted [the state's department of education] and said, 'Can we have a meeting? Can we talk about this? Can that be changed in the IEP?' That vision and hearing is at the top and if you're listed as multiple disabilities, there's something that says, 'This kid is also deafblind'...So I'm real excited because we have a really good relationship with the department of ed... I go and meet with them, a cast of about five or six people. And so I sent it to all of them and I said, would you guys be interested in having a conversation about this? I really think we could make some change in our state. So the assistant superintendent hooked me up with the person, and then we're going to have a meeting, all of us and just talk about could something like this really make a change for kids that are out there?"

"We have a very good relationship with VR [state department of vocational rehabilitation]. Every year we get a contract with them. It's a whole year contract that we do a full week with the kids, but there's also follow up throughout the whole year. It's all using their money. So that has been terrific to do that. So yes. Otherwise we couldn't do it... Plus we train other teachers across the state. We invite them to apply to come and learn during the week. So that's why we hired the other person so that [state project staff person] now can really focus on that end of transition and then everything she learns from it, we trickle it down to all the little kids so that we find out what we can do better when they're little."

Collaboration Between State Deafblind Projects

"We've actually been communicating with other state projects just to kind of see if they are getting people to attend [family engagement events]. So kind of feeling the pulse of this. It seems like still the attendance is not what it was before COVID. I was recently talking to [two other state deafblind projects] about their upcoming CHARGE conference and the attendance is low, lower than typical."

"I reach out to other state project directors and say, 'Okay, how are you managing this?'"

Collaboration between State Deafblind Projects and National Organizations

"We are not very connected to our EDHI project, our Early Hearing Detection and Intervention, and not for lack of trying. We have tried multiple times to connect and we don't get responses. So but there's a concentrated effort right now to try to help states get more connected. So there's a number of states that are meeting with [NCDB staff member] in a couple weeks to hear some updates. I've been really working hard with EHDI on a national level to try to get this happening. So I think there's going to be some good outcomes to that because I think it actually will help with our early identification."

"So [a SDBP staff member] will get American Society of Deaf Children to come in [to family events]. We'll have an American Sign language storyteller. So we do whatever we can to try and that includes collaborating, even if it's on Zoom or in person with American Society of Deaf Children...We have a lot of collaboration around American Society of Deaf Children. We work with them [in] our parent training information center...We try to overlap and, you know, have a big hug around everything and make sure that we're capturing it for our families. So but I don't think we have any issue other than we're just trying to see if we could get them together again with a variety of different options."

Information-Sharing Between State Deafblind Projects

"[Basecamp, project management software that allows state deafblind projects to post questions and resources] is a nice way to send out something to the whole group and be able to put out a question to everybody to see what kind of feedback you can get. Like, 'does anybody know a kid that has Usher [syndrome] type three? And what are they doing

around vision loss or support for the family?' Things that are very unique and very, very low incidence that they need. 'Anybody else have this kind of assistive technology; how does that work?' It's usually a very unique situation and trying to see if anyone in the network has had any experience with it...That's an easy way for everyone to share resources and information around the country because we don't see each other enough. We don't really have that opportunity enough. So it is helpful."

"Typically the schools call when things are not going well at all. And so I might reach out to some other state and go, 'Have you ever worked with a situation like this?' Or maybe a child that has a really rare syndrome or something, I might reach out and say, 'Do you have resources for this?'"

Greater Support and Preparation for New Staff

"The first grant cycle that I took over as director, I was on a learning community for new directors. And that was a really good space."

"She just did [a meeting of the newbie group] a couple weeks ago, and she said it was wonderful, that she was welcomed with open arms, and she felt so wonderful and safe and liked to be able to ask her questions."

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 on family engagement, transition, professional development, and identification of children who are deafblind. Resources are shared with families, paraprofessionals, interveners, educators, and administrators.

NCDB staff and other resources also work with the state projects to strengthen their practices, work efficiently with few staff, and reach more children who are deafblind. 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 think NCDB does a great job. I'm sure you understand about how projects are not equally funded, and some projects are big and have a lot of resources, and some are small. And so I, as kind of the sole person on the project, don't have time to do the research. And so NCDB does, and that's very helpful."

"Do you think that [your state deafblind project] has developed better practices as a result of information, resources, or NCDB staff? Definitely. Really. So we reached out to NCDB for help in developing our technical assistance process. We were meeting with them every other month, every three months. And they really helped us in writing down what our procedures are, our processes, helping us develop our forms. They were instrumental in designing our technical assistance process. And so we took the time to really think about it. Like, what are we going to be doing? And so now we have a form and we have a process of what we do to really determine what level of TA we're going to be providing. Whether the school is even ready to accept TA. Because a lot of times we have parents that want us to go in and fix it. But if the school's not willing to have us there, we're not going to be able to really do much. So we try, but we really work then to determine where are they, and we start there wherever they're at, and then build on it."

"So most of our PD training, we do a best practice [training] two days every year that we invite a professional or we do it...We definitely share [the NCDB] site everywhere we go, every single place we go. Every professional development we do, we share their site. We may share some of their new guides that they have on their site, which everyone really likes. They're a little bit shorter. Practice Guides. They're wonderful. They're the ones we share probably the most."

"So [the calendar system is]...for our students that have a hard time regulating and that their routine and being able to anticipate things. It's kind of a calendar system to help them regulate and know their day and their

routine. And it also can lead to communication. So it's really great... [The NCDB website has] videos and it's got little case studies."

Stronger Deafblind Infrastructure

"[NCDB is] good on giving us that global information of stuff that we need to know because we don't always have the information...I can reach out to [the NCDB staff member] and say, 'What's changed on the intervener horizon? Is there something new happening?' And she'll say, 'Well, we had this university and then this change.' So she has that global picture and resources around transition. When you can pin people down and say, 'I have a kid that needs X, Y, and Z; what would you recommend?' Or 'Who is the up-and-coming person in the field?' And [NCDB] might say, 'You know, there's this new person in Arizona and they're doing some really great things.' You might want to reach out to them. So [NCDB staff] are very good in helping us network across the projects...And so I can reach out to NCDB. And they are really good at facilitating that partnership. They have reached out to many of us to provide mentorship to new people...They are good about putting us together and structuring a bubble of opportunities to collaborate. But to NCDB's credit, they get the conversation going. Some people at NCDB are very good at it."

"So I'm involved in the [NCDB] planning committee for the upcoming project directors meeting...So we've met multiple times. [The NCDB staff member] is the person in charge of that group."

"The new project coordinator [will] start teaching some courses in special ed. People are going to associate her face with kids with deafblindness...And when you're teaching the class, you can include tons and tons of NCDB resources... [Students and faculty come to] associate deafblindness with us, that we're not scary. We're very approachable, even when we're teaching. And so when people then become certified teachers, it's not that outrageous to have them give us a call and say, 'I remember you and I have a kid [with Deafblindness] now.' So that's really been effective and I am very thrilled that it will continue."

Gaps, Barriers, and Project Support Needs

There was quite a bit of consensus among state deafblind project staff about the gaps and barriers they face. The primary issues revolve around the lack of recognition of deafblindness as a disability category within most state educational systems. Relatedly, nearly every interviewee discussed the challenging issues around interveners—the lack of authorization under IDEA, the problem of recruiting and retaining interveners, and intervener training concerns. In addition, issues about state agency collaboration, transition, and limited family engagement were often discussed. Less reported but still problematic issues are the concerns about reporting and about project leaders being sufficiently trained. These issues are described below.

Lack of Recognition of Deafblindness

Some respondents reported difficulties with school districts and teachers not identifying children as deafblind due to lack of understanding of the disability as well as Individuals with Disabilities Education Act reporting requirements that do not count children as deafblind if they have additional disabilities. This leads to a discrepancy between the number of children who are deafblind reported on state deafblind project child counts and the IDEA Part B federal count, which is conducted annually by LEAs and SEAs and reported to the Office of Special Education Programs at the U.S. Department of Education. This leads to students struggling needlessly because supports are not put in place for critical educational services.

> So at the federal level, they turn in a number [of children who are deafblind], but that's not the same as my number. And the school districts on their IEPs, they use a category called MDSSI. That stands for Multiple Disability Severe Sensory Impairment. They may or may not have a student with a combined vision and hearing loss. It could be visual impairment and cerebral palsy, and a cognitive disability. It could be a hearing impairment and autism and something. So it, it muddies the water in that aspect...But our numbers never match because deafblind projects accept kids who may have been diagnosed with Usher syndrome and maybe the visual

impairment hasn't impacted them in the classroom yet, but we know it's coming, so they're on our count."

"I'm sure a lot of the special ed teachers have never been exposed to even the concept of deafblindness...So we did a fall conference this past year and we did a track that was deafblind. [NCDB] started modules for general ed teachers recently and I was really excited about that. And I've sent those out on our listserv."

"I don't think people really know they have a student who's deafblind. Especially if they're listed as multiple disabilities. Like most of our kids are not listed as deafblind. So how do you know you have a kid in your class and really understand access if it's not the top? [If I asked special education teachers] 'Hey, do you have any kids who are deafblind?' And I guarantee you most of them would say no."

"We have students with Usher syndrome. I've had teachers argue that they're not deafblind, and I'm like 'They are deafblind.' They're like, 'No, because they're not severe and profound.' And so we've had to back up and say, 'Wait a minute; we need to look at the whole definition.' And so that's been my big focus—getting everybody on the same page and it's getting better. It's been a process...The big D culture's very proud of that, but they don't want to identify with the blind or vision part of it. So it's interesting like, 'No, I identify as Deaf, but I don't identify as this part [Deafblindness]'."

"We don't have a teacher training program for kids with multiple disabilities or deafblindness or visual impairments. We have big gaps in our university training."

Lack of Teacher Retention

"We have huge numbers of teachers who leave our state. So it's constant, constant retraining. And so that feels like you spin your wheels a lot. We get them trained and then they leave. So I think that's a big issue."

Interveners: Recruitment and Retention Issues

Similar to issues of retaining teachers, states face high turnover of interveners as their pay is low and the mandatory training is often completed during their time off. While the goal is that each intervener stays with their assigned student, the low pay frequently is not motivating enough for interveners to last in their job.

> "*What are the biggest challenges that you face in [your state] in terms of doing your work with the deafblind community?* Interveners. That's like a brick wall that you're butting your head up against. They don't recognize them in [my state]. However, we had my first young lady to turn in her e-portfolio to be a national certified intervener...She'll be the first in [the state]. I've asked the DOE [state department of education] when she gets her certification to put it out in all of their information, their newsletter and all that, that goes out to all the districts, because I want her recognized. I said, 'That's a huge accomplishment for this young lady'...The other problem, of course, with interveners is because they do have specialized training, [DOE should pay more]. Just a tiny little bit, just a little boost in salary or something would make a huge difference. But they don't want to do that. And so it's hard to recruit people because their thoughts are, 'What am I going to get out of this at the end of it?'"

> "Most states have this problem. So our problem really is how the job description is written in state code so we can hire an intervener. Then there's always fear; [interveners are] supposed to go with the student. That interveners are supposed to stay with that student throughout their career. A lot of students move out of the area...We already have a shortage of teachers and shortage of aides. So that makes [recruitment and retention] difficult."

> "Sometimes a really good district will give [intervener trainees] time during the day to do some of the training modules. But a lot of times they're expected to do it on their own. They're not getting paid to do it on their own. And they come and work usually with a child with complex needs. So

they're working harder for not very much pay. So they may stay a year and then they decide 'I'd like to go somewhere else.'"

Interveners: Training and Certification

Training and certification requirements for interveners vary from state to state and the majority of states do not have a training requirement.

"All of us are kind of invested in whether or not there's going to be another national intervener certificate because we're kind of waiting to hear what happens that's changing a little bit with this cycle. OSEP now told NCDB that that's not their role to certify interveners. So now we're just trying to figure out how else [intervener certification is] going to happen, and I don't know what we're going to do in our state; we might be just going towards state certification versus having a national one."

"There are different training methodologies for interveners and there's a national credential that involves taking higher ed classes and then there's a certificate that doesn't involve higher ed classes, but they both require a portfolio. And then there are people who are training interveners, but the training doesn't lead to the portfolio at all. They're just training them and calling them interveners. So there's this just huge kind of mess. I wish sometimes that NCDB could say an intervener is someone who's completed the portfolio, they have a credential or they have their certificate, and anyone who has training but hasn't done a portfolio is not an intervener yet. You know, just some more strong stances."

Interveners: Lack of Authorization under IDEA

As IDEA has not been reauthorized since 2004 and intervener services are not recognized in federal laws or regulations, school districts throughout the country struggle to understand the need for interveners, how to determine whether a specific student would benefit from an intervener, and how to provide an intervener when an IEP team determines one is needed.

"It would just be nice if the federal government would get its act together and reauthorize IDEA and include interveners. But who knows when that's going to happen? Our state doesn't recognize the role of an intervener. However the deafblind projects, we're all trying...And then if we have a parent who's very savvy and very informed, if their child attends a district that isn't part of my state school for the deaf and blind system, they sometimes ask for an intervener, and of course the district has no idea what that is. And so they come knocking."

"So my question to OSEP and NCDB has always been how you send this letter out to every school district, every parent organization, every advocacy group, and we have these letters out there; parents are going to want what's best for their kid. They're going to be like, 'I don't know what an intervener is, but it says, legally I'm entitled to one and I want one.' But intervener does not appear in IDEA. It's not in the law. No. Only two or three states even recognize the existence of the position. So it's very hard for us to mandate that at an IEP/state level when we don't even know what it is. If we as a field ask people to identify what an intervener is, we get a gazillion different answers. So there's not a working definition, there's not a legal requirement."

"The whole area on interveners right now, it's a swamp. And we're not doing well as a country figuring out how to streamline the training or streamline the process, streamline the information. It's a little bit of a gray area because OSEP can't mandate interveners. It's not in IDEA. And NCDB can't force anything because they're kind of like this neutral party. And so we're left as state deafblind projects to really kind of go through this process on our own and try to work with our state department and see how other states are doing."

Lack of Transition Opportunities and Resources

State deafblind projects struggle to find employment and volunteer opportunities for students transitioning from secondary school, and many colleges and vocational programs are unprepared for students with deafblindness.

"Transition for us at the deafblind project is one of our weaker areas. When I first took over as director, I tried to make it a priority and like we were involved in the transition PLC, our [state's school] for the deaf happens to have a really good school-to-work program. So we try to get as many of our kids involved in that. Where we're lacking is in the opportunities for kids with more complex needs. It's difficult to even do a guide because each child is so individual and has such individual needs…And the kids who are more proficient communicators, that's a little bit easier. It's easier for the general public to imagine one of our students, maybe with a SSP [support service provider] being in the community. Whereas when you have a kid who's in a motorized wheelchair with a vent and all, the general public has a really hard time trying to imagine [their marketable abilities.]. Where would the work opportunities be for that child?"

"I do very, very well when it comes to transition, like for a child from birth to three. The high school [transition] has been a little bit of a struggle. I'm partnering with the schools for deaf and blind. I just hired a transition specialist and...we've already got a student identified for next year and employment opportunities for him. But they're kind of like 'We don't know what he needs.' And so she's going to help with that. So that is probably an area, like when it comes to that age group, it's a little bit harder. You know, DRS [Department of Rehabilitation Services] is a great partner, but DRS wants college and career [bound students] and some of our kids are not college and career. So when it comes to that transition piece, finding good outlets for that, that's the harder part."

"I would definitely say, when I look at the census and I see several students who are transition age, and our transition is just pretty poor. So our options are not good. I say 'We need help there in thinking about options and what

that looks like.' And I'm sure that's across, that's pretty common everywhere."

"I think we could do a lot better for post-secondary transition. I find that particular system very difficult to try to impact. I don't think I'm alone in that. I think in the field it's a stressor."

Challenges Collaborating with State Agencies

Close collaboration with state departments of education, vocational rehabilitation agencies, and state early hearing detection and intervention programs are essential for the success of state deafblind projects. They help promote early identification of children who are deafblind, and appropriate early intervention, education, and transition services. In many states, collaboration with these types of entities is limited.

"I want to figure out more ways that I can get connected with how states are connecting with their department of rehab and kind of determine how to kind of coordinate more what's happening with the school system and then the adult service system that's going to meet these young adults after school. Some states are further along in having a formalized plan and we don't really have that here."

"Most of us work with our state department of education. And when our state department of education says, no, you will not do that, please stop. And then we're being told by OSEP, 'We need you to do this.' It puts us in a rock in a hard spot...So with the intervener [issue], we were told that we had to put out a letter saying that families with a student who are deafblind should have access to an intervener to work with their child. In theory, I 100% agree with that. That's fantastic. If the student would benefit from an intervener and that's a process, we can figure that out...I'm not opposed to getting to their destination, but y'all have to tell me how to get there. And we have to stop pointing fingers on whose idea it was in the first place, because interveners do help certain kids with a dual sensory loss, but they

may not be necessary for all kids with a dual sensory loss. And sending out that letter will cause that problem. So that's very frustrating."

"Some of [the post-secondary students with deafblindness] could probably be better served by the agency that's the part of [the state's Department of Vocational Rehabilitation] or our regional center that is coordinating supported employment. That's what some of these youth are going to need. They're not just going to need short-term job coaching or vocational counseling. They're going to need support on the job in the same way that they needed support in school."

Challenges Engaging Families

Some state deafblind project staff struggle to engage families. Several interviewees suggested reasons for the range in interest, including lack of time, geographic distance, and the need to provide care to their children.

"We've tried different things like having parents Zoom meetings, nobody shows up. And again, that's not an NCDB deal."

"We do well with certain families and certain kids, and then other ones, they're just so overwhelmed with life in general that we're not exactly the top on the list. And I can understand that...We tried [family events and family conferences] for a number of years and we got like one or two families. When you look at the cost to do that, it just didn't make sense."

Lack of Project Management Orientation

While NCDB has done an excellent job training and supporting new state deafblind project staff, some interviewees said that new state project leaders need more training and follow-up, so they better understand the administrative aspect of their jobs. Coaching and mentoring would be particularly helpful. The lack of preparation became more apparent when the state projects had to submit new grant applications to OSEP.

"One thing I'd like to request, and this is not even for me but it's for newbies...I don't know if that would be NCDB or OSEP, it would be great if someone had some type of an orientation for [new project directors] because that's a pretty big position. And there's a lot of things that they don't know how to do. And I'll give you an example. The APR that we have to turn into OSEP, you're kind of on your own to figure it out, other than the few little webinars that OSEP does...And that can be difficult sometimes for people who are new that are not used to that...That's not so much about deafblindness. It's more of how to run a project. How to work with your team, how to do the admin part of it effectively so...it's not just guessing their way through APRs and things like that."

"So the first four months, four to six months, I don't know, I don't have a clue what I'm even supposed to do."

Reporting Issues

Some interviewees identified reporting mandates to be a barrier in their ability to serve their state's children who are deafblind.

"It takes days, weeks to do the reporting. We have to report for OSEP and the Common Project Measures, they're better this time. But that's a lot of collecting data. And some of it, I feel like we've reported three times, like the child count. So we do the child count for NCDB, then we do something related to Child Count for the Common Project Measures. That's new...And then, we all have goals that were in our proposals that were funded. So we have to address that in our annual performance reports. It would be nice if they all three asked for the same thing and then I just cut and paste."

"I need to write those reports and I want to do a good job on them...When we would write the proposal for the projects when I first started, they were like six pages. Now they're volumes and all that just takes a lot of time. And in a small state, there's not a team to gather all the stuff, get the support letters. I'm doing all that. So it just makes me have to stop working with kids and seeing families...I love that part. I mean, that's my favorite thing. And I

think things will settle down. It's a first year of a new cycle and that's always changes...I could see enough kids and feel good about seeing all those kids. I'll get back to it, I'm sure."

"And I will say this about NCDB and families, there's kind of a misunderstanding, where NCDB is like 'If you reach one, that's wonderful,' but that's really not what the feds want. The feds want numbers. So when I say, 'I've spent six hours trying to get parents to come to a meeting and only one parent shows up,' that's hard to report. That's hard to look good."

Recommendations

While there was close consensus in response to questions about the status of SDBP activities, the quality of NCDB resources, and the gaps and barriers that SDBPs face, the recommendations from interviewees tended to be more individualized. Recommendations to NCDB include:

- Provide additional information
- Create a national database
- Include ASL interpreters
- Fund family engagement
- Include people with deafblindness on NCDB and SDBP staff
- Build stronger leadership around transition
- Create more transparency

While these recommendations tended to come from just one or two interviewees, they are included here when there is potential that other state deafblind project staff would agree that the recommendation deserves consideration.

Provide Additional Information

State deafblind project staff need additional information about topics related to supporting students who are deafblind including

- Assistive technology
- Tactile and protactile signing
- Usher Syndrome screening

"I know we're getting a lot of people contacting us or asking us about protactile resources and who should be teaching protactile and how do you use protactile with a child that has multiple disabilities. I'm trying to find [all] the resources I can find, but I don't feel like the expert in that area. It's coming up a lot...I'm still curious how protactile works with individuals and even young children, children who are deafblind, but have additional

disabilities and might not even have any understanding of symbolic language yet...And it's geared towards really supporting families and educators to be preparing young children to be ready for protactile through engaging with them in meaningful touch and things like that."

"I had an interpreter who has tactile interpreting experience...There's also something called protactile, which is a newer form of that. And I would love to see more of that. [NCDB has] a module that talks about signing, but it doesn't talk a lot about tactile signing and it comes out of necessity. I had a student this year who is totally deaf, totally blind, and he has to have somebody hold his hands and do more of the tactile signing. And so it's his team; everybody's doing it differently. Everybody on the team's doing it differently, and that causes confusion. We need to know what the correct [way] is and what's offensive."

Create a National Database

One project director explained how each state manages its own database about students who are deafblind. These databases cannot access the much larger databases in state educational system. As a result of not having a national database, the status of students can be lost as they move to other states.

"We really would like some leadership and guidance from a national level to help roll out a data collecting system that has validity and integrity...We struggle because most states have 200 deafblind kids that we have readily identified...It's really hard and cost prohibitive to develop a database for that's going to track only 200 kids. We are so far down the list at a state level that they'll get to us when they get to us. It's just hard to keep elbowing yourself in to get to the table and say, 'I need you to be recording my 200 kids' when they're focusing on 200,000 kids. And so we have said, 'Wouldn't it be nice if NCDB would take some of their money or ask OSEP for additional funding to develop a robust data system in the way that they would want the data reported?' Our projects are paying for a database, but there's 50 of

those databases running around. We're suggesting there should be one for what we do with the child count that.

Include ASL Interpreters

One interviewee explained that closed captioning is not a sufficient alternative for an ASL interpreter.

"[NCDB modules] need to be put into ASL [American Sign Language]. We have people who have ASL as their first language and they try to take our modules and it's a lot, it's just so much. And for them to try to navigate the content in English is really too much. So we're training people who do not take college level courses. And so for them the modules are very over-whelming. And then to have the content only in English is really, really difficult. So if they could be put in ASL [interpreters], that would be amazing. This means having a sign language interpreter actually interpret into American Sign language. Like a little picture in a picture [within NCDB videos] with captions still in English."

Fund Family Engagement

State Deaf Blind Projects struggle with limited funding. As one interviewee noted, having additional funding for family events would greatly benefit families and children with deafblindness.

"An issue that we always have is funding. The issue I think all over is funding and covering all of the things that we would love to do. So we have to cover all the things we need to do first and then the things that we would like to do. And so I think family engagement events, ...That if they could help fund some of those things, that would be definitely something that would allow us to do more of those types of events."

Include People with Deafblindness on NCDB and SDBP Staff

Hiring people with disabilities, particularly those who are deafblind would offer employment to those whose work opportunities are limited and would benefit NCDB and SDBPs to understand contexts and impacts.

> "If [state deafblind projects and NCDB] can employ someone who's deafblind, who might not otherwise find employment, we can learn from them. They have the benefit of a satisfying career..."

Build Stronger Leadership Around Transition

Many interviewees identified significant challenges that post-secondary young adults who are deafblind face in the world. One suggested developing stronger leadership within NCDB to partner with national vocational rehabilitation entities to confront employment barriers.

> "I would love to see them trying to do some systems change, like on a national level that might trickle down. I think more could maybe happen around post-secondary transition...It is so difficult for many state projects to impact the voc rehab system. And I do know that Helen Keller National Center also works on that. I don't know if there's some sort of partnership that could maybe develop between the two so that a stronger stance on some issues could maybe be taken. It's an issue for parents. It's an issue for state projects and sometimes it's just hard to know where to start because it's such a big problem. There are some kids that go on to college and those are kind of the 'easy kids.' It's the kids with multiple disabilities, what do they get to transition to? Because that's where most of our kids are. They have multiple disabilities and voc rehab doesn't see them as people who can really contribute to the workforce."

Create More Transparency

State project staff interviewed would like more transparency and communication from NCDB.

"I remember when the grants came out, there were so many conversations about what does NCDB do because we were frustrated because our money was being reduced. And there were a lot of states asking, 'Do we even need an NCDB?' And that was a wakeup call for me because in the past I could tell you what NCDB did and how invaluable they work. It's getting harder to respond to that. NCDB needs to know that in the sense that there's still plenty of time to address that. Plenty of time to right the course and be more engaging and more transparent and visible of what they're doing. They may be doing amazing work behind the scenes, but if we as their audience don't see it, and they're catering more to other entities and it's not being communicated to the deafblind network, that's a PR problem. They need at the very minimum to work on their PR. In four more years we'll have another grant cycle, and if the ship's not righted, I think more and more people are going to be asking that question of 'Where's the bang for the buck?'."

"They're supposed to be working alongside of us. And when we don't see [NCDB staff], we don't know what their initiatives are. All we hear is they're in meetings with OSEP. At some point you're like 'What's the outcome of those meetings? To what end?'"

Conclusions

As the first year of a four-year evaluation study of NCDB ends, several conclusions seem evident. Foremost, NCDB staff and other resources are essential in the work of state deafblind projects. Repeatedly, state deafblind project staff reiterated the importance of having connections with NCDB to help with their TA, family engagement, transition, early identification, and professional development work. Interviewees also stressed how their interstate connections with other state project staff are vital, and how NCDB plays a critical role in facilitating and supporting those relationships.

While state deafblind projects vary widely in the number of students on their child counts, their funding, their number of staff, and how they are officed, they are similar in that they are isolated. Very few educators or families experience the unique learning and communication needs of children who are deafblind. The support from NCDB, then, becomes indispensable in connecting educators, family members, and project staff and in abolishing the silos so prevalent for systems serving children with low-incidence disabilities.