

STATE DEAF- BLIND PROJECTS

*2021 findings
from interviews
with State
Deaf-Blind
Projects about
the National
Center on Deaf-
Blindness*



**National Center
on Deaf-Blindness**

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“NCDB has been wonderful.”—2021 State Deaf-Blind Project interviewee

State Deaf-Blind Project Interviews

“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.”¹ 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 qualitative study was conducted by interviewing state deaf-blind project staff.

In an effort to ensure the sample included both larger and smaller projects, all state deaf-blind projects were sorted by funding received. Those in the top 25% were considered larger projects and the rest considered smaller projects. In planning the interview evaluation, 12 state projects, including three larger projects and nine smaller projects, were randomly selected after eliminating those previously interviewed. The National Center on Deaf-Blindness (NCDB) contacted staff at the 12 selected state deaf-blind projects and all agreed to participate in the interviews. A third-party independent program evaluator conducted interviews during April 2021.

Questions that formed the basis for the semi-structured interview include:

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?

The following report discusses findings.

¹ <https://www.nationaldb.org/about/>

Participants

The 12 State Deaf-Blind Projects (SDBPs) that were selected and participated in the interviews include:

- Alaska Dual Sensory Impairment Services
- Colorado Services to Children with Combined Vision and Hearing Loss
- Idaho Project for Children and Youth with Deaf-Blindness
- Project Reach: Illinois DeafBlind Services
- Iowa Deafblind Services Project
- Kansas Deaf-Blind Project
- Michigan DeafBlind Central
- Oregon Deafblind Project
- Puerto Rico Deaf-Blind Project
- South Carolina Interagency Deaf-Blind Project
- Texas Deafblind Project
- Wisconsin Deafblind Technical Assistance Project

Most interviewees are state project directors or project/program coordinators, with a few state projects including more than one staff person in the interview. Two-thirds (67%) of interviewees work for the state project on a full-time basis and one-third are part-time. Interviewees have a wide range of years' experience in an SDBP, with ten being the average number of years.

Half of the responding projects are housed within state-funded universities, and the other half are housed within their state's department of education. The number of staff at the responding state deaf-blind projects varies from one part-time position to six full-time positions, but most projects have 3 – 4 employees on staff.

Project Implementation

All of 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

Technical assistance to schools, professional development, and family engagement are discussed in this section on Project Implementation. The other areas of focus—transition, early identification and child count, and systems change—are addressed on pages 18-22.

Technical Assistance to Schools

The 12 responding projects address three types of technical assistance—universal, targeted, and intensive child-specific—but the extent of time spent on each type of technical assistance varies widely between the projects. Some projects are more caseload-driven and respond to the needs of individual students with deaf-blindness while other projects focus on the infrastructure of their states to teach educators about deaf-blindness in general.

“So we kind of operate under...a belief that if you can get the strategies into place or the instructional practices into place that we know make the biggest impact for students, then you will see them reach targets better.”

“We have an online referral process that they can use or a SPED Director would refer to us and sometimes we will use other specialists at the agency to help the team decide if they want to have a full in-service for the staff that’s working with that student...We also use the federal model of general targeted and focused TA. So we prioritize the TA depending on site need.”

NCDB has been an essential resource to the projects as they provide technical assistance to schools. NCDB offers several tools online, including an observational tool and a technical assistance readiness tool, that interviewees considered useful. Several interviewees discussed how NCDB staff have

provided webinars, guidance, training, and referrals that have enabled them to provide technical assistance to educators and school staff.

“Once a child’s referred, that’s how I get kids. Then I will go out and see a child anywhere in [the state]. And typically the vision and or hearing person will go with me.”

“With our deaf blind technical assistance team, I think there’s eight or nine of us. And those other people on that team have full time jobs. So they’re either an occupational therapist in the state, or they’re a teacher in the state and then they come and help us. So our universal technical assistance follow a more a more standard procedure of requesting TA through us identifying outcomes, scheduling something. And that targeted TA is usually there’s like one area the team wants help in we’re going to target it, maybe one or two visits and that’s it. And then intensive TA would be ongoing. Usually we set a timeframe of like a year. So it would be multiple outcomes for a team, multiple areas of growth. And we would be in and out, maybe multiple observations in a school building with a team.”

“We try to help the team come to consensus about the goals for the student.”

For a few states, helping students reach grade-level standards through child-specific intensive technical assistance is the project's major purpose.

“This is a new system that we’re trying. We promoted it last year and now we have four core teams and when you’re working with them, it depends on their needs...If you’re working with a team, the school is working towards...their core standards. It may be directly or indirectly, but if...you train them to work with these kids, you are impacting those outcomes.”

“I know some state projects just have so many kids that they can’t do a lot of child specific TA...That’d be crazy if every one of those kids had a specific TA plan. Like you couldn’t do that or there’s not enough people to implement that. But in [my state], I’ve been pretty lucky. I operate on a first come first

serve basis. So whoever calls dibs on my time; they get that day and time...But we only have like around a hundred kiddos, so we're considered a small state with small numbers, so it's a lot more manageable than some of the bigger states."

However, most of the 12 responding projects work on helping educators in general and focus on universal technical assistance. In some cases, the state deaf-blind project is part of the state's department of education. While this affiliation is often beneficial in gaining access into schools, it also creates barriers for the kind of technical assistance that would be requested.

"We cannot tell districts specifics on kids. So think of it. For example, if I went out and I saw a kid as a TA specialist and said, 'I believe this child has cortical visual impairment, I'm going to do an assessment.' And then I'm going to tell you what I think should be on the IEP, I am actually obligating the department of ed to those procedural practices. And if a parent files a due process, I could be indicted as a [state department of education] person."

"We make sure that people want to invite us back...Because we're the department of ed, we are extra careful that we don't do anything that tells the district what they have to do."

Projects most frequently identified communication as being the foundational skill they taught to educators.

"Sometimes it's helping teams...realize that maybe the targets or the standards they want their students to achieve are not the most appropriate. So if...we have a student who has maybe had some significant needs and who is not even paying attention or is aware that anyone else is in the room and you're trying to teach them letters without first teaching them that, 'Oh, hey, I want to have a conversation with somebody. I need to actually know that there's another person there.' And that there's this turn-taking thing that happens in life. If we're not acknowledging the need to teach that first before letters, that's the problem."

“We certainly focus most on communication and we do a great deal of in-service training to professionals on instructional strategies,...teaching folks about behaviors, communication. When they’re having a child act out and then they sit around and go, ‘I don’t know how to work with this kid. He never communicates with me.’ We’re like, ‘Oh no, he’s communicating a lot. He’s really ticked off. Let me tell you what he’s saying,’ but it’s those conversations that we have to have. People just don’t see that it’s the same thing. I would have to say hands down, the bulk of what we do is let people understand that if you want to get rid of inappropriate behavior, let’s strengthen communication and you’ll be surprised how quickly the energies can shift. These are kids who are deaf and blind and to figure out how they interact with their world, we have to help them.”

While most state projects are continuing to address foundational communication skills, only one state project identified the change towards meeting grade level standards. The other states noted that the overall purpose of their trainings and consultations are to help students with deaf-blindness ultimately meet grade-level or alternative standards, but the impact was more indirect.

“I feel like the request for application has shifted focus...[and] what their expectations were in terms of how we spend our time...Then after we had already written this grant, then the common measures came into play, which was nerve wracking because I felt like we needed to do a lot of changing around in order to feel like we were addressing those. So now I guess I try to do some more, what they consider intense [technical assistance].”

Professional Development

The state deaf-blind project staff rely mostly on NCDB staff and the NCDB website as major sources for producing professional development. State projects created several professional development offerings last year through webinars, presentations, and online modules. One state project director noted

that 11,000 participants were engaged in professional development last year. The trainings were often offered to professionals through a collaboration comprised of a few state projects. Others have included OSEP or NCDB staff in their professional development events. "It's been a great partnership," one interviewee said about her collaboration with NCDB.

Interviewees cited a broad array of topics covered, including deaf-blindness, communication, visual impairment, early literacy, transition, and Braille. One state has a teacher training program for educators with deaf-blind students.

"Another one of our products is the teacher of students who are deaf-blind pilot program. So the TDB pilot program has been running for several years and that's targeted training to specific district teams to build district capacity. For teachers who have students who are deaf-blind..., we actually just this last Fall, our state board approved licensure specific to teachers of students who are deaf blind. I think we're the second or third state to get that. So we're really excited. There's a lot of work ahead of us, but that's so exciting."

State project staff often used the Open Hands Open Access (OHOA) modules on the NCDB website to create intervener professional development or to refer educators. One state deconstructed the module to form a three-part online training, and another state translated the module into Spanish for paraprofessionals. Another state used the National Intervener Certification E-Portfolio (NICE) modules. Five of the responding state project staff indicated that they have interveners, though they may function more as aides. Among the states that offer intervener training, there are typically 3 – 5 interveners trained annually. However, most do not have state mandates to authorize interveners in school settings and do not have intervener certification programs. Some state project staff are involved in the intervener training and certification.

"I think that that model of how the whole community built the OHOA modules together set a standard for how we can all work together, the whole community of deaf blindness."

“We’ve just invented an intervener model project, and we probably could not have done that if we were elsewhere, but because we’re at the department, we have more relationships to kind of grease the wheels with school districts. So we’re basically saying to school districts, ‘We believe in this person called an intervener. We’re happy to train that person.’”

Family Engagement

While all 12 of the SDBPs are involved in family engagement, eight have a strong focus on family-centered trainings, events, activities, and outreach. When a state project has a dedicated family engagement specialist or an employee with a deaf-blind child, the project is more likely to have a very active family engagement program.

“We might be one of the more family centric projects, and that is because the PI on our grant is a parent of a child with CHARGE Syndrome...[The state] was called the ‘family project’ because it was run [by] a family. And so we’ve maintained that real family-centric focus and that’s a point of pride.”

“So many states employ parents of kids who are deaf-blind in that [family engagement specialist] position, which I think is phenomenal because...of the first person perspective.”

“Families are at the table for every place we can put them. So we try to keep two to three mamas or guardians at the table with our advisory council. Anytime we want to send out or start new programming, usually we have our family specialist...So it’s coming from parent to parent, not from me to parents.”

The state deaf-blind projects offer a number of family events and materials to help families network and to share information, resources, and contacts. A couple of states host annual in-person meetings for families that students and their parents and siblings attend. Other states provide online and paper materials.

“The parents really love it and they feel so isolated because this is such a low incidence disability. So the chances of running into another family that has a deaf-blind kid are pretty low, but at this weekend, they’re able to all connect and talk to each other and find out about resources and things they didn’t know about...So having them give little tips about what to do with insurance and how to get respite care and those sort of things, I think that’s really, really valuable. So we have this annual parent event and it was really well attended this year and it was really nice.”

“So I do a monthly mailer and...it’s usually a sort of a fact sheet about trainings that are going to happen. And those are all sent to families, hard mail...Every family gets something in an envelope with a stamp on it. And that is because lots of families don’t use the Internet.”

The pandemic created significant challenges in helping families be informed and supported.

“We figure parents are looking online, but they’re so fatigued now by online work that we try and also send hard copies and send things in the mail, like snail mail.”

“With the beginning of the pandemic, we recognized we’ve got to figure out a way to offer family support because we knew this was just going to be a trying time. Suddenly kids were learning from home and parents weren’t given much more than that. Like ‘Here’s your kid, here’s a computer, good luck.’ And so we started an initiative..., which is a weekly hour-long session for families only. So the families [have] the space to network and for collaboration.”

State projects often developed creative ideas to engage families. Last year, one state project held a movie night where families sent in video clips and the program sent the families fun props like top hats and snacks. They had the video captioned and called each student for an interview, which students and their families enjoyed. They also had an art night where they hosted a Zoom art gallery and interviewed each student about their art, giving them a chance to

discuss why they chose their subjects and how they created their masterpiece. Both family events were a big hit, and the program coordinator spoke enthusiastically about the events.

Other states have a more child-specific focus and have limited trainings or events for families. Some of these state projects reach out to families by phone or email about once a year.

“We seem to focus a lot on professionals and any of our trainings are open to families. We usually don’t have a lot that choose to participate.”

NCDB has been a valuable resource to state projects as they engage families.

“And so where I’ve turned to [NCDB Family Engagement Initiative Lead] is...having the broader perspective of what other family engagement coordinators are doing, what’s successful, what’s not...She’s really done some phenomenal things. She’s helped to standardize what goes on with family engagement coordinators and she’s providing some training for them and she’s kind of made it so that when those family engagement coordinators are getting calls from families who have kids with other etiologies, like they feel better and more equipped to respond to that.”

Outcomes

When asked how NCDB has helped improve their work, state project interviewees most often identified greater collaboration, better practices, and a stronger infrastructure to support students with deaf-blindness.

Greater Collaboration

All of the state project staff interviewed identified stronger collaborations they have formed as a result of NCDB facilitation and support. NCDB offers four peer learning communities as platforms to collaborate on providing services,

share knowledge and expertise, and work together to solve problems.² NCDB is also aware of the state project staff personally and often refer other states.

“[NCDB has] certainly worked very hard to build a network. Deaf-blindness is this very small field. We all tend to know each other and like each other because we gravitate toward each other when we have opportunities. I think they speak our language and that’s really important.”

“Whatever we have asked, they have provided. So if we need someone to work in this, someone is assigned to assist us.”

“I think it’s helpful in the sense that number one, it’s incredible networking with the people from all of the other states who are doing the same thing and it makes it easy when it comes to grant rewrites or other kinds of annual performance reports. If you have a question, you can call someone up and you know them and also it gives you a sense to feel the pulse of what every other project is doing across the country. I mean, so many things we do are similar, but then there’s innovative things that people come up with. And I think the other thing that’s important is learning from the researchers who come in to present because they tell us of cutting edge projects or apps that we could tap into.”

Better Practices

When asked about specific changes they have implemented as a result of NCDB resources, state project staff identified a number of areas in which they improved policies and practices.

“The other thing that I think NCDB is really great at is that their entire work that they’ve done is on a foundation of instructional design. And so I think everything that they put out, it has a solid instructional design basis...They provided very specific recommendations for the indicators that you could use

² https://documents.nationaldb.org/TA/PeerLearningCommunities_a.pdf

and what the performance measures were for those indicators. So it actually makes it easy to align those activities with the grant objectives and then have a very good model for how to pull the data together.”

“I did a lot of work with [NCDB staff] on my TA procedures. Like he basically helped me figure out all my steps for that, what documents I needed for the interview process and then conducting an agreement and all of these different pieces for child-specific TA and my different levels of TA. All of that got sorted over the course of several months, working with [NCDB staff] and I think that was really, really beneficial.”

“I recently engaged with NCDB to get technical assistance for our technical assistance, and they helped us...They helped me develop better processes and procedures for TA. So we did a lot of changing our request form, really laying out the steps that we would be following for TA, what questions we’d be asking the team, how we’re going to define outcomes, those types of things, because our process was really loosey goosey before and I really wanted to tighten it up. So they helped us do that.”

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.

“I can tell you something that I think is astonishing. So I’ve been trying for...two to three years to start a dialogue with our state EHDI (Early Hearing Detection and Intervention) and Hands and Voices people... I’ve talked to a couple of folks [at NCDB] about our early identification issues and the fact that...I just can’t get in at EHDI and they’ve let us know what they’re doing at the national level and kept me abreast of some of their national conversations, their presentations...Everything that NCDB did at

the national level, our conversations at the PLC (peer learning communities), the suggestions I got from my peers that were facilitated by NCDB, I think are what all just aligned for me to have a seat at the table at that state meeting. It wouldn't have happened otherwise...We get the majority of our referrals for kids under the age of three through that group. So if we can start embedding all this together, we are going to see the potential for us to get some links into a number of systems that touch those children. And it's all because of the number of things that NCDB was doing."

"If NCDB wasn't there, that state wouldn't really be offering much specific to deaf-blindness."

"So we've seen NCDB through its iterations long before it was this thing now called DB. So I would say we've seen kind of an evolutionary change. One thing that I think is really positive is these are people who understand deaf-blindness and that's sounds really silly, but sometimes you get people in deaf-blindness who don't have deaf-blindness backgrounds...Also I think they have really more of their infrastructure to target key initiatives that have value added to the project. So whether that's early identification working with families like family engagement, completing the annual child count, they've been super supportive."

Gaps, Barriers, and Project Support Needs

While the close collaborations with other state deaf-blind projects and with NCDB have enabled the state projects to reach students with deaf-blindness, the projects face extensive barriers. Like the 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

Several of the interviewees remarked that their state has no mandate to provide intervener services, and therefore, the school districts cannot hire for intervener positions. Nearly all the interviewees considered interveners to be a valuable service provider that needs to be offered to students with deaf-blindness, and many expressed frustration with their state's department of education for not supporting the position.

"The other challenge we specifically face is we constantly get told no about any changes to educational procedure, the idea of teachers of the deaf-blind or the other thing would be interveners, which are specially trained individuals that work with people who are deaf-blind. And so then you go to a school district and you say, really my recommendation would be that you hire an intervener. And then the school district says, 'What's an intervener? Explain what an intervener is.' And they're like, 'Well, we don't have the money to pay a person to do that.' If the educational code would change and an IEP team could make that decision, then a school district would be required to pay for that. That's the hurdle."

"There is no position like an intervener. We don't have that in [our state]. We were expecting that through the department of education, they will consider this an essential service for the students, but they haven't done much about that."

Relatedly, the broadest systemic challenge the state projects face is the lack of national, state, and local awareness about the unique academic, social, and communication needs of students with deaf-blindness. The pervasive lack of awareness leads to educators unprepared for engaging students and facilitating their academic success.

“When you’re in teacher school, they don’t teach you anything about deaf-blindness. And so you all of a sudden are a brand new special ed teacher and you’ve just been given the student who’s deaf-blind and you have no idea what to do. So then the deaf-blind project comes in and trains you and you think you finally have it figured out. And then the school district moves you to another classroom. Then a new special ed teacher is now with that student, so now you’re retraining that teacher or the student goes from first grade to second grade to third grade, and you’re trying to retrain those staff every year. It is a constant revolving door of trying to get people to understand the unique needs of these kids. And as soon as you have a really good programming for a student, the teacher will retire or leave or whatever, and then you are back to square one. So that’s the biggest challenge.”

NCDB Products/Services/Technical Assistance

When asked about the most useful products, services, and technical assistance that NCDB provides, the state project interviewees most frequently mentioned the peer learning communities (PLCs); the NCDB website and resources; technical assistance, consultation, and information from NCDB staff; and opportunities to network and collaborate with other state project staff. All of the interviewees expressed very positive support of the work NCDB has done, and praised NCDB’s technical assistance and consultations.

Peer Learning Communities

NCDB offers four PLCs—Family Engagement, Identification and Referral, Interveners and Qualified Personnel, and Transition—and has four initiative leads on staff who are subject matter experts on these topics.

“We are part of the [Transition] PLC. And so we’re learning, I enjoy learning what they’re doing, learning what they find is best practices by attending the monthly meetings. I’ve got a working relationship with [the Transition lead]. And I think that helps a lot too because he’ll push things

out my way...I think we've got the transition piece. We're in a real good place there."

"I think what [NCDB is] currently doing with the different peer learning communities and communities of practice--the ones that we're currently involved in have been meeting our needs. If they could continue to facilitate those, it's helpful. It's just helpful to have someone organize and facilitate it."

"The thing that I find the most helpful [from NCDB] is being part of their PLCs and their communities of practice. And so just having an ongoing platform to bounce ideas off...Even if it's not something we're involved in now, we collect ideas that we may use in the future."

Information and Technical Assistance

Most of the interviewees, particularly those who have been project directors for several years, call NCDB staff often. Some of the newer staff commented about how NCDB has reached out to them and helped them get oriented.

"We've gotten lots of technical assistance from NCDB. They've given us technical assistance with child specific TA...I'm getting very personalized support."

"If I need to talk to somebody, they are always available, always extremely helpful."

"They are a tremendous resource when we need to reach out and get some guidance. They may or may not be the people who can give us support and insight, but they seem to be the people who know who [or] what direction to point us in."

NCDB Website

The NCDB website (<https://www.nationaldb.org>) offers extensive resources for families, state projects, and others interested in deaf-blindness. About half of the interviewees visit the website frequently to review updates and learn how other states are approaching similar issues. The other interviewees visit the website more on an as-needed basis. Interviewees praised the website for its comprehensiveness and array of resources.

“I have found NCDB to be wonderfully helpful. And this year their website is extremely user-friendly. If I’m working with a student and have any questions, I can go right to that basecamp website and search and the information is there.”

“When we were developing our TA process, there are some really good examples that other states had and the TA readiness documents were really helpful from NCDB.”

“[NCDB] does a really good job of sharing resources. I’m on their website a lot.”

“We have a parent who wanted to have an intervener...So NCDB on their website has a guide on how you determine if a student needs an intervener. I gave that information to the team and there is other information.”

System Changes

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

Early Identification and Child Count

Of the 12 SDBP staff interviewed, the number of children with deaf-blindness on their registries ranges from 17 to 170 students. A couple of interviewees discussed their challenges in identifying children with deaf-blindness due to data-collection issues, like only capturing the first two categories of disabilities listed on IEPs in their state.

“I think it’s hard because deaf blindness is so broad in its definition. So we have a huge range of types of kids on the registry from middle school kids with combined vision hearing loss, but who are reading braille.”

Other challenges include disinterest by school districts in identifying deaf-blind students and resistance from students/families about being labeled deaf-blind.

“Some of our students choose not to identify as deaf-blind... Those families choose not to be an active part of the deaf-blind project. So those are the things you navigate. And the same goes for vision. Like if their hearing isn’t as big of an impact, then they find their community within the vision side.”

One state project interviewed provides up to \$3,000 for each student on the state registry that the school districts can use for services, assistive technology, and evaluation. This practice has incentivized school districts to identify students with deaf-blindness, and thus far, 34 of the school districts have requested the additional funding.

NCDB has provided invaluable assistance to the state deaf-blind projects as they work on the child count and identification. Supports include a PLC on identification and referral, the *Early Identification and Referral Self-Assessment Guide*, the *National Deaf-Blind Child Count Interactive Maps* and other resources, and an initiative lead and a child count coordinator on staff for training and technical assistance.

“I love how NCDB gathers that [child count] information. The interactive maps are awesome. I don’t want that to go away.”

“So the child count document--it’s super helpful what [the child count coordinator] has put together. That was super duper helpful.”

“We had several meetings with people from NCDB. [The Identification and Referral Initiative lead] shared the guide that we could use in the early intervention identification of the blind students. So that was another activity that was supported by NCDB.”

“[NCDB does] an absolutely wonderful job of reaching out to us and from the administrative side, I think anything that they request of us, they provide very clear directions on. And so my most recent example would be, they asked us to change the coding structure for the census. And so the directions were so clear that I was able to review it and just hand it over to our programmer.”

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.”³ Specifically, NCDB has a transition initiative lead and transition consultant on staff and offers a PLC, the *Accessing the Dream* video, the *READY Tool: Readiness Evaluation of Transition to Adulthood for Deaf-Blind Youth* for transition teams, and a transition toolkit to help state deaf-blind projects address post-secondary employment goals of students.

³ <https://www.nationaldb.org/national-initiatives/transition/>

“I make sure we’re super involved in transition because we’re trying to revamp that program and do better. When there are specific questions, I’ll call or get help and then get resources. We’re looking at a big picture thing and I need some suggestions, so I’ll call [NCDB staff] or call or email the group. I like the listserv...I like where you can just pull something out and get a question.”

“Working with [the Transition Initiative lead] and the transition team and getting best practices, we’ve spent a lot of time within the state taking the best practices they’ve shared with us and adapting them to make them fit into our system in ways that our parents are receptive. So we’ve got a team that meets weekly and we keep taking some of these great ideas....NCDB made a really good toolkit...and so we took the toolkit and just made a PDF guide on our website and just printed it and sent it to our families. And then we provided a one-page information sheet. We’ve mailed them every month and it’s just the front page, super easy to read. And it just goes to the families that are transitioning.”

“One of our specialists in transition, they contact employers, they visit the community to assess what is available for students after they finished high school. [We work with] Helen Keller on the Southeast project, NCDB, service providers and teachers. The support that they have provided us is immense. It’s a very good collaboration.”

Work Left to be Done

A recurring theme that many state deaf-blind project staff identified is that the educational system needs to be more aware of the unique learning needs of students with deaf-blindness. As a low-incidence disability, educators often address the learning needs of deaf-blind students from a hearing or visual impairment perspective, without awareness of the specialized assistance needed.

"On a broader scale, what I worry about is a social justice issue. When you really start to pick it apart, you have people seen as the experts in their state prepare professionals and families to support these kids but they're really not getting the supports and services needed to provide equal access to reach their potential. They are getting people who don't know deaf-blindness and are just kind of muddling through and consequentially, you end up with all these ablelistic kinds of issues because if you don't understand deaf-blindness, you...can really squash a kid."

Conclusions

All of the 12 state deaf-blind projects interviewed had high praise for the work done by the National Center on Deaf-Blindness (NCDB). They discussed how the NCDB offered responsive, helpful services and high-quality, informative products. NCDB staff function well in multiple roles, including coordination, training, communication, information-sharing, collaboration, and facilitation. They are prompt, supportive, collaborative, and knowledgeable. They are skilled in knowing who in the country has expertise in an area and linking states together to address issues.

When asked for suggestions to improve NCDB services, some interviewees identified a need for greater understanding about practices in other states. While several interviewees indicated that they often browse the NCDB website, particularly the Basecamp portal, others indicated that they do not have the time to fully investigate the information provided. A couple of interviewees suggested a one-page summary would be their preferred format for learning about how other states were approaching practice and policy issues. A few interviewees indicated that they need more help during the grant-writing process, and other interviewees recommended that NCDB provide greater orientation training, outreach, and mentorship to new project staff.

The interviews with the state project deaf-blind staff clearly revealed the challenges they face and how NCDB has helped them navigate as they provide training and technical assistance, identify children who are deaf-blind, engage families, improve transition outcomes, and facilitate quality educational

practices. As state projects and NCDB provide greater awareness of the educational and social needs of students with deaf-blindness, the schools will be better prepared to address their learning needs and create more positive academic outcomes.