

STATE DEAF- BLIND PROJECTS

*2022 findings
from interviews
with State
Deaf-Blind
Projects about
the National
Center on Deaf-
Blindness*



**National Center
on Deaf-Blindness**

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“As a national technical assistance center, NCDB works with state deaf-blind projects and other partners to improve educational results and quality of life for children who are deaf-blind and their families.”¹ In all, there are 47 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 11 agreed to participate in the interviews. A third-party independent program evaluator conducted interviews during April 2022.

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

- Arizona DeafBlind Project
- Florida and Virgin Islands Deaf-Blind Collaborative
- Indiana Deaf-Blind Services Project
- Minnesota DeafBlind Project
- Missouri Deafblind Technical Assistance Project
- New Jersey Center on Deaf-Blindness
- Ohio Center for Deafblind Education
- Rhode Island Services to Children and Youth with Dual Sensory Impairments
- South Dakota Deaf-Blind Project
- Utah DeafBlind Project
- West Virginia SenseAbilities

Most interviewees are state project directors or project/program coordinators, with four state projects (SDBP) including more than one staff person in the interview. Twelve of the 15 interviewees work for the state project on a full-time basis; the other three are part-time. Interviewees have a wide range of years' experience in an SDBP—four have one year or less experience in their position; four have at least 15 years of experience; most have 2 – 10 years.

About half of the responding projects (n=6) are housed within state-funded universities and the others (n=5) 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 20 full-time positions, but most projects have 4 – 5 employees on staff. These numbers include staff who are in positions funded by their state education departments or other sources.

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

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

Technical Assistance to Schools and Families

Projects often identified that helping students who are deaf-blind succeed in school often requires teaching educators and families basic communication and behavior strategies.

“So we selected three families [with] children that were transitioning from birth to three into special needs preschool. And so we had families there, birth to three teams there, and we also had a team from the school. So it’s worked out really well. The first one we covered kind of MAPS individual planning. What the goals were for the families going forward, what the child’s strengths were, what their dreams and fears were, what an ideal day would be and how to hit those goals. And the second [training] we did communication, and then the last one...was transition...The school system actually did the IEP while we were there.”

“The most difficult technical assistance having to do with behavior and programming and communication...I mean, I did so many behavioral zooms. But I’ve got to be there, you know...It was every night and it’s still every

night, doing technical assistance this way, but now we're getting back in, I'm going to see kids."

The push to help students who are deaf-blind achieve grade-level standards in general curricula seems to be approached differently in the state projects interviewed.

"[The barriers I run into with achieving general education curriculum are]... helping teachers understand that it might look different, but it is the general curriculum and making that link between what they expect for all students...It might look different, but still be working towards that for a child that's got dual sensory impairments."

"[Whether children are following the state standards or alternate standards]...depends on the kid. Many of our students have additional disabilities, so they [use alternate academic achievement standards], but we always try to link it back to the general ed curriculum."

"Most of our students, and I would have to look at the list, but I'm guessing maybe all but one or two are using the essential elements of the alternate achievement standards, which are linked to the general curriculum, but alternate standards. And so, I would say we're to get them access to the curriculum and as much progress as they can on those alternate standards."

The focus of some state projects is to provide student academic success through child-specific technical assistance.

"The technical assistance...needs more than that. They don't need just training on topics. They need to talk about their kids and they need to have support in facilitating difficult challenges that they meet. And those challenges have not stopped since [the 1970s] when I got into the field."

Other state projects address students' needs through a broader, universal technical assistance approach.

“And we know that people need help getting better at how to support kids with complex needs. The other thing we continue to try to do is figure out how we hook the stuff into state priorities and initiatives. So, one example is [the state’s] work around literacy and the state has invested heavily in early language and literacy improvement, grounded in the science of reading. And so, through a number of projects here, we’re supporting module development. We support higher ed institutions to revise their core reading for courses to stop using approaches that are not supported through the evidence, through the science and to use the science of reading and align with the state’s plan. So the question has been, so what’s that mean for kids with combined hearing and vision loss who can’t hear the sounds and can’t see the words? How do we build that bridge for them? So, it’s a question. I don’t think we’ve answered it yet. We keep kind of toying around with getting an expert panel of people with experts on the literacy side, experts on the sensory impairment side, and together to at least figure out what are the questions we need to ask, to kind of build that bridge from kids who have no communication system to using evidence-based literacy practices to improve outcomes. So that’s a question out there.”

“Our philosophy around the work is to support the adults who are out there working with children, not to necessarily build kind of a separate universe around deaf-blindness. So, I think part of it is continuing to try to educate people, trying to kind of reduce the fear factor, trying to find ways that we can support people to do things instructionally that makes sense for kids. We [are] a large state with lots of layers and the work has been mostly oriented to helping and using existing networks to try to disseminate information, provide professional learning. Consultation, TA. It has not been focused on us going out to do direct service kinds of things with kids. So, the move to the common project measures is kind of pushing people in that direction, which creates some additional challenges for us to try to figure out how to, to do that.”

The pandemic created more challenges for providing technical assistance, particularly universal technical assistance. Several interviewees noted that they tried to do more outreach to families of deaf-blind children so that the students' academic progress was not delayed during the pandemic. One interviewee noted that the pandemic pushed universal technical assistance into a "state of flux."

"Like during the pandemic, we had been doing some zoom calls with families just to..., you know. It was a really rough time."

Several interviewees noted that NCDB offers several tools online that are useful, including an observational tool, a hand-under-hand practice guide, and a technical assistance readiness tool.

Professional Development

Nearly all of the project staff interviewed cited some professional development they provided during the last year. A few interviewees identified how they collaborate with early intervention and provide training.

"I've done a few [trainings] like deaf-blindness awareness trainings with birth to three from early intervention. I'm getting ready to go out to a county for a newly identified child to do some training, like individuals with the school's team there. And then getting ready to start our first deaf-blind intervener cohort. So that's exciting."

"We have a really good relationship with our early childhood, our early intervention folks. And so, once a quarter, we hold a professional development based on their needs, what they've requested. And so, some of the topics have been like for CVI, we've done pro tactile. We had a demonstration on pro tactile...[NCDB staff member] has done stuff about the communication matrix. When they get together at the beginning of the year is when the group decides what topics [they] want for the coming year."

Most of the professional development focuses on teaching professionals a general introductory overview about deaf-blindness. One interviewee

suggested that limited research funds has created a significant gap in published findings about deaf-blindness, which he attributes to fewer people going into the field of dual sensory loss.

"We do [professional development] for individual teams. But something else that makes us, I'll say special but probably not, is that myself and one of the other project coordinators teach a lot of the severe disability courses at [a state college]. So, anything new that we find that is appropriate for deaf-blind, we bring it into the classes that we teach there. So, it's professional development at the graduate level. They at least get an overview of deaf-blindness. Even if they're not specifically focusing on that. We enjoy having a base in deaf-blindness."

"There's a generational turnover of trained deaf-blind specialists. So, to find somebody who's comes directly trained in deaf-blindness is almost impossible. Most of the directors are now new, well-educated people who need to learn more about deaf-blindness. And it takes a little time because it's a small incidence and within that small incidence, it's highly, highly heterogeneous and it's difficult, you know."

Some professional development through state projects is open to parents of children who are deaf-blind.

"I just finished up three webinars where I had our parent connection in our state do...expanded core curriculum...And person-centered planning...They went over really well. I was really happy with them. Through our university system, I offered a functional sign course and that went well...The webinars were parents and professionals and mostly professionals...for the summer Institute, but is open to parents as well."

"We offer two conferences for professionals. We coordinated with the School for the Blind. All of their teachers/staff/interveners are trained; it's a mandatory training. Some parents come to that."

“Every August we do a workshop called Understanding Deaf-Blindness and the Role of the Intervener. And that is for families. It’s for special ed directors, it’s for nurses, it’s for the paras, interveners, teachers,...grandparents. We used to do it in person, but since COVID we switched to virtual and then we’ve realized that this is a really great workshop to do in that format because we can reach so many more people and we’re not limited by space...We offer continuing education credits of course, and we offer credits for interpreters and also for administrators. So that’s been really successful. I think the last August, we had around 140 [people attend].”

Some state projects provide professional development to general education educators. One state does an annual hand-Under-hand professional development event for general curricula educators to learn about how to teach students with visual and hearing impairments. Each year, about 25 general educators attend. Training evaluations indicate that deaf-blindness professional development for general curricula educators has been beneficial.

“We do a teacher cohort for the modules and we do an intervener cohort, and then we’ve added a cohort for interpreters. And we’ve had really great feedback from teachers going through because they don’t get this information in their teacher prep programs and, really, the strategies that you use in deaf-blindness you can use with all kids. So that’s what we hear time and time again — ‘this is the best information I’ve ever gotten’ or ‘this is the best professional development I’ve ever gotten in my career.’ It’s something they can work on at their own pace, within a timeline, plus they [get] CEUs for it. So, if they need that for their licensure or whatever.”

Much of the professional development continues to focus on communication skills, though some states are training in more advanced deaf-blind education topics such as literacy. Some interviewees teach communication as a vital foundational skill.

“Sometimes you’ve got a teacher who’s responsible for everything in the world and they’re not being judged whether a child has a communication system or not, but they are being judged as to whether their students score well on alternate assessments. Our answer is the only way to have that happen is if communication comes first. So, it’s convincing them that that is even though there’s not a standardized assessment on communication, it is just as important, even more important than access to the general curriculum. And you can do the two together.”

“[Students] must have reliable communication modes for school. Teachers need to understand that deaf-blindness is its own thing.”

One Project Director is focusing more on mentoring and coaching than traditional trainings for educators.

“One of the things that I’m trying to put in place is more of a mentoring and coaching type of structure that’s available to educators where it doesn’t have to be quite as formalized in the plan of the technical assistance. It’s like, ‘You work one-on-one with a student or the student is in your class. Let’s talk through the things that happened this week, this month, give you some additional things to try and help you recognize what tools you are already carrying in your toolbox.’”

NCDB has been an essential resource to the state projects as they train educators, paraprofessionals, and families. State projects rely on NCDB staff and website resources to help prepare professional development events.

“I’ve used the Hand Under Hand PowerPoint and training materials there several times for presentations to different schools. And I also used it for our state special education conference...and I had about 30 people attend that session.”

“Of course, their deaf-blind and intervener program and just the plethora of other resources that I can use.”

“We love to have those [NCDB] materials, like anything that’s already done. We’re looking for more help...[for] the intervener. [Interveners] are not recognized in our state, so it’s hard for school teams to realize how important that position is. And then in convincing school districts that, yes, this is a para professional role, but they’re specially trained.”

When interviewing state project staff, they often talked with a sense of pride about professional development they have conducted. Project staff seemed to not only enjoy providing professional development, but they spoke enthusiastically about how effective it was.

Still, there are many challenges when delivering professional development. Having to continue to provide training online instead of in-person was seen by some as an exciting opportunity to reach more people while others remarked about how in-person training was more effective. Another serious challenge identified was the limited number of substitute teachers and the lack of release time.

One Project Director remarked that sometimes educators will register for the OHOA modules but will not follow through. In that state, educators get a stipend for professional development, and the stipend is considered like wages from a second job. Therefore, educators cannot attend the training during the workday because it’s considered a second job and they don’t have enough free time to attend.

“The biggest problem with doing PD is the lack of qualified subs. There is a lack of time, support, and subs.”

“...It’s so important that at least the individuals who are working so closely with these learners [with deaf-blindness] have the opportunity to get the knowledge that they want. And do it with the support of their administration. That’s a hurdle.”

Family Engagement

While all of the SDBPs are involved in family engagement activities, most prioritize family engagement as a project goal. 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.

“I have that lived experience. And so, I could relate to families on that level and my son is pretty complex, so I really understand that complexity of what a lot of our families go through and what their day to day life is like.”

The state deaf-blind projects offer a variety of family events, such as conferences, camps, and retreats. A couple states host annual in-person weekend-long events for families that students and their parents and siblings attend. The family events typically combine an education and recreation focus. The Project staff spoke enthusiastically about the family events and how much they enjoyed being with the students and their families.

“We host a picnic for our families and interveners and it’s kind of a way to recognize interveners and then just get families to come together at the end of the school year type of celebration in June. So, we are looking forward to being able to actually have that this year because it’s been canceled for the last two years...We kind of surveyed families to see if they were open to it...And most said that they were looking forward to it and really missed having those connections.”

“It used to be that we kept parents in training sessions all day for the whole weekend, but we changed that because they wanted to be with the kids, and they wanted to have more time to talk and really network. And so, what we’ll do is we’ll bring them in on Friday. We typically do it at an accessible camp here. And then on Saturday, parents will be pulled out for the morning session and we’ll have whatever topic; it varies from time to time what we’ve done. We’ve done rec leisure, we’ve done art, we’ve done transition. We’ve done person-centered planning...So we’ll do a morning session with the

families and the kids are busy somewhere else across the camp. And then in the afternoon, they're all doing things together...They did ziplining and we had a picnic, the beach and they went fishing. They stay in cabins."

"We have a yearly parent conference that we provide information and TA topics to our parents. And then they get together and collaborate with one another which is pretty great...We invite the families and they can bring their students, their children with deaf-blindness, their siblings, grandpas, grandmas, aunts, and uncles, whoever they want to sign up...We love it so much. It's one of my very favorite activities."

"And then another thing that we do every year is a mom's retreat. Oh, and that has been really successful."

Some of the small state projects contract out family engagement or work with other entities to reach parents.

"We have a new a new partnership. We had a family engagement coordinator and she resigned. And so we were trying to figure out...We entered into a partnership with [a non-profit family organization]...And so we have a partnership where [the project] helps pay for part of a position of a parent support specialist. And so, we've been working with that person. We just did a training with all of their specialists about deaf-blindness and to make sure that they're aware of our services. So, we don't quite have our full family engagement system done."

"We have a good connection with [a non-profit family organization] in that they have a family support specialist that specializes in our native families and lives in that area."

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

"It wasn't highly attended, but the families that came, I think got a lot out of it and it was really just a place for them to process and to talk about what was

going on...I'm not sure we're going to be able to do the big events that we used to do. I just don't know if that's something that families are comfortable doing."

"We have not [held family events or trainings] since COVID...And that's something that definitely, I think that we need to do. But we have not since COVID."

Some of the smaller state projects focus their family engagement on training parents and other caregivers.

"We are having a webinar coming up about assistive technology with [an organization that can] provide assistive technology services to families and schools. They have the loan library. So two of their specialists are going to speak to our parents about their services because they have a loan library for parents."

Other states provide limited trainings or events for families but reach out to families by phone or email.

"[Parents of children who are deaf-blind] receive contact from me and information from the project and when their child is identified. We had a small group for a while to get kind of a family group together and provide an informal mentoring where I can connect one family to another, to just talk about things...I might actually connect them personally, but not anything formal...We do have some standard means of communication with them. We have a listserv; we have Facebook pages. I have some families I can only reach on Facebook."

"The other thing I was going to say is our family support specialist is in quite constant contact with the parents in many different ways. She'll push out whatever information is needed with text messages and emails and things. And then just as different things come up, she'll think of a family that this

might be helpful to...this family or the other family. So then she teams with our teachers of the deaf-blind to do family visits."

Engaging with families, particularly non-English-speaking parents, continues to be challenging in states. States that are geographically large but have a limited number of staff find family engagement to be problematic.

"We do try to make sure that our events are accessible to our Spanish speaking families, by making sure we have interpreters...anything we send out is in English or Spanish...But it's hard. It's really hard to get the engagement up on our reservations."

"We do have a family event that we've not had for the last couple years because of COVID. There's a retreat usually in the spring that parents are invited to. But even with that, with the number of kids that are on the census, we usually have about 25 to 30 families represented, even though it's open to any family that wants to attend."

"I guess our greatest challenge is and it might be in part due to the fact that [this] is such a large state is the active participation of parents. For example, we're participating in a Transition Institute, and we have for a number of years, but we have challenges in getting students to participate, families to participate."

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

"I can use [NCDB] as reference points as to what's available and providing that information to parents. There's a weekly newsletter that goes out. So, depending on the topic, there would be NCDB information or new publications have been highlighted in that newsletter, but I personally use it as a resource site."

“A lot of times when I attend the NCDB webinars or different events, I’m listening for what other states are doing [about family engagement]. So, I’m always looking for strategies that others are using that may be adopted here.”

“I do not [have a family engagement specialist] now. So [an NCDB staff member] has always invited me to participate with the group. I will admit I haven’t done a lot of it, but she makes sure I get the invitations and I get the materials that they produce. So that’s helpful. And certainly, you know, I’ve had an opportunity to talk to her a few times about different issues around families and ask what other states are doing.”

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 who are deaf-blind.

Greater Collaboration

Most of the state project staff interviewed identified stronger collaborations they have formed as a result of NCDB facilitation and support. NCDB offers six Peer Learning Communities. NCDB also connects state project staff to other state projects with similar concerns.

“I worked with [an NCDB staff member]. She’s really been a good support to me as far as linking me with other projects that have these kinds of systems already in place. So, I’ve been able to see, okay, what are they doing? And what could work for us? What could not work for us? And also taking a look at what our center has been doing, like saying, okay, what is working? What’s not working? How can we change it, working with our little team and saying, okay, what also works for all of you? Is this going to save you time? Or is this going to create more work? So that’s been really the bulk of a lot of things that I’ve been doing.”

“[I worked with NCDB staff] with the child count and stuff. She got me connected with [two other states], so some other connections have been made.”

“I should mention the Midwest transition Institute, that’s a group of states that do a transition training institute for students. I’ve been involved in kind of sitting in on their zoom meetings and their planning. So, knowing that if I have the right student for that I’m invited in. So, I’ve gotten to know some of those ladies.”

Better Practices

When asked how NCDB has benefited their state project, interviewees cited a number of NCDB resources that helped DB projects improve their practices. Many of these resources are shared with families, paraprofessionals, interveners, educators, and administrators.

“A lot of the [NCDB website] resources we’ve found helpful are some of the resources that are produced in different languages. That’s always helpful.”

“Number one, [NCDB staff] are the eyes and the ears of any new trends or new resources, information. So, they’re really good at communicating that. I don’t have to be searching around for it myself. And if I have something that I want to share, I can just post it on their platform and I know it’s going to get out to at least the state groups and probably more than that.”

“God bless [NCDB staff], she’s the best. So, she really worked on procedures. And we have forms. Now we make the districts sign agreements with us. Most of this was because of NCDB’s help. [NCDB staff] really worked with us. We met with them regularly to help us bring this system into place, our TA system. So, we now have a TA menu.”

“I’m excited to see those kinds of things like anything that they can prepare that we can provide to districts where we, you don’t have to come up with it ourselves.”

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 who are deaf-blind 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 who are deaf-blind.

“I don’t think I would be participating in the projects, if in fact the structure wasn’t that we had someone that listens to us. There’s not that many people who speak our language. Or understand it and such little time to explain it to them. With NCDB, they get it. And then they...offer suggestions or different ways to go or who to connect to.”

Another outcome has been the strong infrastructure of state deaf-blind projects across the country. NCDB works to build those interstate relationships by sharing information about practices and products in other states, and NCDB creates opportunities for states to collaborate on trainings and information-sharing.

“NCDB has all the structures in place. The good thing is when I worry about keeping up with all the new resources and things, it’s archived at NCDB. How wonderful that is! That is huge...We don’t need to duplicate and it wasn’t always that way, it really wasn’t...We could once again build the community and I don’t mean a community of practice, but the community itself.”

“I know though that if I need something, or if I need to run by something, I’m just a phone call away from [NCDB staff]...I think what they did through the pandemic was absolutely fabulous.”

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 who are deaf-blind, 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 who are deaf-blind
- Families having limited access to the Internet or technology
- Strained or non-existent linkages to school systems and Part C

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

- Connecting with Native Americans in reservations
- Retaining interveners and paraprofessionals
- Reaching families during the ongoing pandemic
- Lack of authorization for interveners
- Lack of understanding of the need for interveners
- Project staff having limited knowledge about deaf-blindness prior to state project employment
- Lack of academic attention to inform education students about deaf-blindness
- Low pay for interveners, resulting in recruitment and retention problems
- Intervenors having to substitute for other paraprofessional roles

Of the 11 state projects interviewed, only two small projects have interveners authorized in state code.

“Oh, the thing that we always joke about everybody is always talking about how lucky we are..., how wonderful our program is, which is true. We do not take that for granted. Because we have a very robust program with teachers. And we have anywhere from 50 to 60 interveners that work one-on-one with our students. That’s written in the state code.”

“Counties are interested in hiring interveners and we’re working on getting them trained.”

However, most of the states offer intervener or paraprofessional training through use of NCDB modules despite whether interveners are recognized in their state.

“We have the...cohort modules through NCDB. So, they go through the program and they get badges and certificates, but there is no certification through our state or anything they get. If they want to, after they finish the 27 modules, if they want to pursue the NICE certification.”

“When we talked about goals, [one goal] is around finding ways to improve [the state’s] system of preparation and personnel development. So we started this work back in, I don’t know, 2014, maybe 2015...[The state] for a long time had really few providers to work with children with visual impairment, blindness, deafness, hearing impairment and of course, deaf-blindness...So we created their multi-institution consortia preparation programs leading to licensure as...intervention specialists in place of special ed teacher...And then the third piece was creating a technical certificate in intervener studies...So the interactions that I’ve had mostly with NCDB lately have been around the intervener work...[We use NCDB’s OHOA modules] extensively.”

NCDB strongly supports interveners through training modules and other resources. The Open Hands Open Access (OHOA) modules offer interveners and others an opportunity to be informed about best practices to serve students who are deaf-blind.

“We used the [OHOA] modules... We’re trying to do some hybrid where we get [learners] together, so it’s not completely online. We’re trying to offer coaching visits on the campus where we have the most interveners. Part of their job is to submit a log of the work that they’re doing. So that gets reviewed by A and she provides them support and she meets with them once a month with the interveners on the campus.”

“I’ll be honest, like the Open Hands, Open Access modules, that has been a huge, huge help to me as far as really getting out there and jumping two feet in as far as providing technical assistance, relying on what they already have in place.”

NCDB Products/Services/Technical Assistance

As with previous interviews, 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, 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 materials, technical assistance, and support.

Peer Learning Communities

NCDB offers six Peer Learning Communities—Identification and Referral, Family Engagement, Training Intervenors Group, Improving and Implementing Professional Development Practices, Child-Specific Technical Assistance, and Transition. The groups collaborate on providing services, share knowledge and expertise, and work together to solve problems.²

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

Nearly all of the state project staff interviewed are currently in a peer learning community (PLC), or they have been in the past, or another person on staff in the project is in a PLC.

“I think they’ve all been very helpful,” commented one Project Director about the Peer Learning Communities in which she participates.

“[NCDB] is...a valuable resource. I really enjoy the leadership and I enjoy the way that they gather information and then share it.”

Information and Technical Assistance

All of the interviewees have had contact with NCDB staff in the last year. Some of the newer staff commented about how NCDB reached out to them to explain the NCDB website and help them get oriented.

“They were really good when I first got on board about setting up meetings with me. So [NCDB staff], they took me through the website and kind of explored that with me. Just kind of introduced me, gave me the lay of the land. So that was really nice and helpful.”

“I just think that NCDB has been a great resource for me and learning the new job. And I know my university works with [NCDB staff] all the time with these deaf-blind courses, and they’ve been very well attended. So, I think that is a great opportunity for people to get some training. Yeah, it’s been good. I’m glad I have that resource.”

“I can email [NCDB staff] if I have a question that I can’t get an answer to, and I’ll get a nonjudgmental answer back or directive back.”

“If I need [NCDB staff], I could just pick up the phone. You know, I’ve developed relationships. NCDB is kind of like it’s there for us, almost like saviors in a lot of ways. And I do appreciate everything that they do. And I just think that they’re going in the right direction. It must be so difficult because the wind changes and then they change.”

NCDB Website and Online Resources

The NCDB website <https://www.nationaldb.org> offers extensive resources for families, state projects, and others interested in deaf-blindness. Nearly all of the interviewees visit the website frequently and praised the website for its comprehensive resources. One common theme among the interviewees is how much they appreciate learning how other state projects operate and how they manage similar issues, which they often learn about through the NCDB website. Some state projects have websites that are linked to the NCDB website.

“We have NCDB’s website and several resources tagged to our training website that we share frequently. All of our interveners are accessing that regularly, especially when they’re in the new training phase. And then we share them with professionals as well.”

“Through base camp, projects share on there. NCDB does a good job of disseminating information and keeping their website up to date.”

“We have a link to NCDB’s website on our website and some of the materials that they have created or that other states have created.”

System Changes

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

Early Identification and Child Count

Of the 11 SDBP staff interviewed, the number of children who are deaf-blind on their registries ranges from 32 to 600 students. Some interviewees discussed their challenges in identifying children who are deaf-blind due to how deaf-blindness is coded as a multiple disability on their state's IEPs.

“Deaf-blindness isn’t even recognized by my state. [It’s] not a category. No. We use ‘MDSSI’ which stands for multiple disabilities, severe sensory impairment.”

Several state projects work closely with Part C to identify children who are deaf-blind. The state deaf-blind projects provide training to Part C providers and they, in turn, identify children for the Child Count.

“We also have a goal around early identification and intervention and we have a goal around transition. Our part C provider is...divided into what they call first steps, clusters... I will go to those clusters and provide training on deaf-blind 101 and identification...The other [trainings] were around strategies for early interventionists providing services to kids who have both a vision and hearing loss...It was great, but it was hard and long because it’s such an involved training. They met for seven months, three times a month for three and a half hours at a time. And we got 17 people who hung in there the whole time.”

Other state projects reach out to Medicaid, Special Education, the state department for the visually impaired and other state agencies to reach early identification goals.

“We have connections everywhere in the state. I mean, we have carte blanche to every director from the part C state director to the special ed director of the state.”

“We are just in the process of negotiating a contract with Medicaid, through Blue Cross and Blue Shield to help with that early identification in our inner cities...because those are the kids that we’re missing.”

“I do have a really good network with the TVIs [teachers of the visually impaired] and the deaf and hard of hearing teachers. And so, when I put my information out for child count, it goes to directors who I do go around and

do that kind of intro to deaf-blindness...But I also send it to these teachers who are probably the ones doing the counting.”

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

“We have a lot of work around outreach to try to get that to happen...for early identification. The [NCDB] peer community learning group has been really helpful in terms of understanding what other people in other states are doing and how that those can be adopted or applied [in our state]. I think that’s probably been the most valuable information for specifically for early identification.”

“Identification is a huge [challenge]. And I think they may not mark it as their primary exceptionality, or they just don’t think about it. So, I’m going through that checklist that NCDB has this summer and really sitting down with the information I have, because this year there’s just a lot of counties that are not reporting or they’re reporting, ‘We don’t have any anyone...’ [NCDB staff] have been extremely helpful in getting back and just answering any question that I have. Even when I think I’ve probably already asked the same question, probably a different way, they don’t sit there and be like, ‘Oh, we’ve answered this before.’”

Transition

NCDB leads a major initiative to address the high unemployment and social isolation of post-secondary students who are deaf-blind. “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 who are deaf-blind 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 peer learning community and a number of products including *Recommendations to Improve Transition Outcomes for Students with Deaf-Blindness and Additional Disabilities*, *Accessing the Dream: Preparing Deaf-Blind Youth for a Self-Determined Life* (videos from transition institutes), and the *READY Tool: Readiness Evaluation of Transition to Adulthood for Deaf-Blind Youth*. NCDB also provides support to state deaf-blind projects that conduct transition institutes for youth.

“[Transition is] my heart and soul. And I’m trying to bring that back in. I am spearheading our work with MTI, the Midwest transition Institute. And I am actually on the mentor-training committee for that with [a Midwest state deaf-blind project]...So I developed a whole transition program for learners with disabilities as they moved from secondary to post-secondary in conjunction with one of the local universities. And the program is actively running to this day.”

“I was in and out of the transition (Peer Learning Collaborative) group, although we still do things with [NCDB staff] around the transition institutes...A lot of times they’re held on college campuses so that those students then get kind of a taste of dorm life...What usually happens is that the students room with another student. So, they kind of get a taste of going to the commons and having lunch and being with other students in the dorm room and then there’s activities after all the sessions. And it was a really cool experience...That was a great deal of help from [NCDB staff] and those people in NCDB helping us replicate what was already being done and they had all of the materials.”

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

“We’re thriving with transition right now. We’re partnering with [NCDB staff] and then also with our local state university to help with some pre-employment trends. We’ve got a lot of work going on right now with that.”

Work Left to be Done

The gathering and sharing of information is vital to the work NCDB does, and is critical for the strong infrastructure of staff committed to helping deaf-blind children. Unfortunately, some of the new staff seemed reluctant to discuss their concerns with NCDB staff. Some indicated that while they appreciated NCDB staff reaching out to them, the interviewees gave the impression that they did not want to appear inexperienced or unknowledgeable.

Some more experienced project staff discussed how they miss the previous system of working with one NCDB individual instead of having NCDB organized by topic area. Others commented that they don’t always know the best NCDB staff person to contact.

“I don’t even know who to go to [at NCDB]. They don’t make it clear where to go to get your answers. And you know, there’s a point at which you’re so new, you don’t even know what to ask. They’re always like, ‘Any questions?’ even in the newbie group. We are all in silence and they take that to mean, ‘No, we don’t have any questions. We understand what we’re doing.’ And it’s like, no, we don’t even know what to ask. We don’t know what’s out there. Like we don’t know what fish are available in the sea or what’s on the menu.”

“It was a great support to have one person assigned from NCDB to support me.”

“Maybe the only other thing is just knowing who would be a good go-to for general questions. I know several people that work there [at NCDB], but who would I call there for this or that?”

Other suggestions for NCDB to work on include:

- Step-by-step guides
- One-page summaries
- Designated NCDB staff
- Centralized Child Count database
- Include on the NCDB website profiles of teachers of DB students
- A 1-page intake form (instead of the current 16-page intake form) so teachers have time to complete it
- Review and minimize the data collected for the Child Count
- Support research of evidence-based practices that promote literacy
- Share more information about how other state DB projects manage transition, early identification, technical assistance, and family engagement

Conclusions

All of the 11 state deaf-blind projects interviewed had high praise for the work done by the National Center on Deaf-Blindness. They discussed how the National Center on Deaf-Blindness 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 some area, and linking states together to address issues.

The interviews with the state deaf-blind project 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 DB projects and NCDB provide greater awareness of the educational and social needs of children who are deaf-blind, the schools will be better prepared to address their learning needs and create more positive academic outcomes.