

Working Together for Families

State Deaf-Blind Project and Parent Center Collaborations



NATIONAL CENTER
ON DEAF-BLINDNESS

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A key activity of state deaf-blind projects is to partner with parent centers to serve families in their states. In this report you will learn a variety of practical strategies—some small and some more extensive—that state deaf-blind projects and parent centers use to work together to increase the effectiveness of their services to families. This report is also available as a series of web pages:

<https://nationaldb.org/families/workingforfamilies>

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Quotes from State Deaf-Blind Projects and Parent Centers

Being collaborative and complementary, rather than competitive, has made our collaboration successful. We work hard to serve families so they are better able to support and advocate for their children with disabilities. This the central goal with all collaborative endeavors--supporting families to improve child outcomes. ~ Maryland



Gaining insight into the workings of each other's projects has made us better TA providers. ~ New York



We have a better understanding of each other's work and project initiatives, which has an overall impact on families from both organizations through direct services, parent trainings, and teacher/educator professional development. ~ Ohio



Another factor to our success is having a true understanding of each other's project and the services provided by the project. ~ Oklahoma



[The MI parent center and state deaf-blind project] both believe supporting parents is the most important service we can provide. We also have a "we are better together" working agreement. ~ Michigan



We have a strong collaboration that is considered a friendship based on years of collaboration. We all know who to call or email. Our collaboration is successful because of a long-term relationship built on trust . . . Everyone is on first name basis. ~Nebraska



Overview

An increased level of collaboration is often a specific requirement for groups and agencies involved in complementary grant program activities (Frey et al., 2006, p. 383-384). This ensures that programs with a common funding source are as efficient and effective as possible in areas where their missions converge. In this report, we highlight collaborative activities among two types of programs funded by the U.S. Department of Education's Office of Special Education Programs (OSEP)—state deaf-blind projects and parent centers.

State Deaf-Blind Projects

In concert with NCDB, state deaf-blind projects provide technical assistance to help ensure that family members, early intervention providers, special and general education teachers, and related services personnel have access to the specialized training and tools needed to address the early intervention, educational, related services, and secondary transition needs of children who are deaf-blind.

Parent Centers

The mission of the parent centers is to serve families of any child with a disability who receives early intervention or special education services in their state. Their training and support for families is centered on helping families to become true partners with their child's team to create a set of services to provide the child or youth with a free appropriate public education (FAPE). Parent centers are available in each state.

Although state deaf-blind projects and parent centers have very different work scopes and objectives, they share the goal of helping families partner effectively with early intervention and educational systems. This shared goal is so important, that OSEP has encouraged state deaf-blind projects to collaborate with parent centers to “provide training and supports to families of children who are deaf-blind so that they can successfully advocate on behalf of their children and help ensure that their children are better positioned for independent living” (Department of Education, 2013).

What is collaboration?

Collaboration has a variety of definitions but is generally viewed as "the cooperative way that two or more entities work together toward a shared goal (Frey et al., 2006, p. 384). A variety of models have been proposed that show collaboration as a series of levels. The model used in this report, which has four levels—networking, cooperation, coordination, and collaboration—is based on a framework developed by Hogue (1993) and later adapted by Frey and colleagues (2006). It has been adopted by other organizations that focus on early intervention and education issues (Resnick et al., 2015), including the National Center on Educational Outcomes (Meuller et al., 2014).

How was information for this report collected?

As state deaf-blind projects and parent centers carry out their collaborative work, NCDB is working with them to help them share their experiences. With the assistance of a family engagement technical work group comprised of representatives from regional parent centers,

state deaf-blind projects, the National Family Association for Deaf-Blind, CADRE, and the CHARGE Syndrome Foundation, NCDB disseminated a form that the state projects and parent centers could complete together to describe their current collaboration strategies. This form was disseminated in June 2015 and by the end of the summer NCDB had received 21 completed forms.

These forms were carefully reviewed to identify specific collaborative strategies and activities. The strategies and activities were then sorted into categories consistent with the collaboration literature as described above.

How can this information be used by state deaf-blind projects and parent centers?

Collaboration is at the heart of the work conducted by the deaf-blind technical assistance network. The purpose of using a levels-of-collaboration model to think about partnerships between state deaf-blind projects and parent centers is not to evaluate the level of their collaboration, but rather to conceptualize the types of activities in which states are engaged and provide ideas for ways they can use their combined knowledge, expertise, and resources to strengthen specific aspects of their services. The desired type and level of collaboration will depend on their program goals and characteristics of their states (Frey et al., 2006).

The ultimate purpose of this work is to create a system of collaboration between parent centers and state projects that can be sustained over time and promote a more equitable distribution of services to families across states. We believe that one of the best ways to achieve these goals is for parent centers and state projects to share their resources, knowledge, and skills with each other. To this end, NCDB will provide the following technical assistance during 2016.

Universal TA

Universal TA includes this report, which provides collaborative strategies and examples from many states. It will be updated as we receive new information. State projects can use this information to get ideas about how they can strengthen their collaborations with parent centers.

Targeted TA

State project-parent center pairs with particularly strong collaborative partnerships will share their insights and more detail about their collaborative structure and activities via webinars. These webinars will also be used to elicit input about how NCDB can further support the evolution of these collaborative relationships.

What have we learned?

The clearest message gleaned from the collective input submitted by SDBP-parent center pairs is that there is no one prescribed method of collaboration that suits all states. While working toward higher levels of collaboration, it is important to keep in mind that different strategies work for different states depending on their characteristics and resources. The respondents reported a broad range of collaborative strategies and activities that take into consideration their states' characteristics and their projects' level of resources. For examples of three states (Maryland, Montana, and West Virginia) see [State Stories](#).

We also learned that state deaf-blind projects and parent centers face a number of challenges to forming and maintaining collaborative relationships. Many relate to the fact that as grant-funded projects they are time-limited and have finite resources. Challenges include:

- Changes in the sponsoring agency at the time of new grant awards
- New personnel, including administrators (requires starting over to build relationships)
- Reallocation of personnel (e.g., the same staff are retained, but their hours are cut)
- Changes in representation on advisory boards or other committees
- Loss of, or decrease in, funding for either agency
- Numerous competing demands on staff member time

These types of challenges impede collaborative initiatives, potentially causing delays in positive outcomes for families. States who have encountered these types of challenges have dealt with them in a variety of ways, including increasing communication and planning to accommodate new personnel and use of technology to cut costs associated with meetings and information dissemination.

Learn More

In the navigation pane on the left-hand side of this page, you will find links to specific strategies arranged by the following levels of collaboration:

- Networking
- Cooperation
- Coordination
- Collaboration

We realize that there is not one way of doing things that works for everyone and that states have varying levels of resources to devote this work. Hopefully, the information will provide a variety of practical strategies that meet different state needs and enable state deaf-blind project-parent center partnerships to evolve in ways that increase the quality and scope of their services to families.

Networking

Networking is the stage at which organizations are aware of each other and have a general understanding of what each does, but communication is limited and no joint decision making is taking place (Frey, et al, 2006). There are no specific strategies associated with this very informal stage of interacting. Most state deaf-blind project-parent center pairs who responded to our request for information had already moved beyond this level.



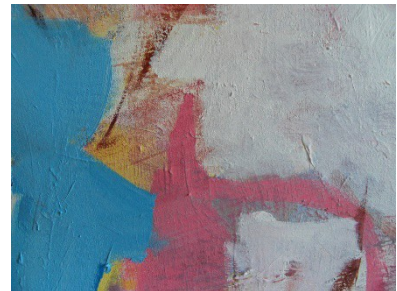
Cooperation

At the cooperation stage, agencies are beginning to establish professional relationships (e.g., know each other well enough that they feel comfortable calling to ask for help) and communication is becoming more formal (Frey et al, 2006). They share information and exert some effort to limit duplication of similar resources. They are also gaining a better understanding of the services offered by each other's organization and the strengths of their personnel. The strategies below illustrate interactions among state deaf-blind projects and parent centers that are consistent with this level.

Involve state deaf-blind project family specialists

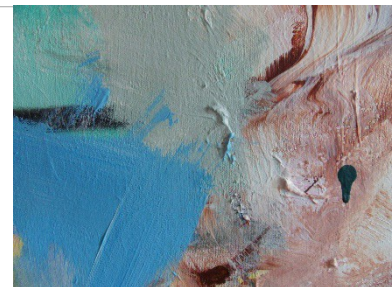
Relationships between state deaf-blind projects and parent centers are often facilitated by state project family specialists. They can serve as a bridge between the two agencies.

"Our deaf-blind project's family specialists have had long-term relationships with the parent center, both personally and professionally. They attend parent center trainings, forums, and annual conferences and encourage other PA families to do the same. In addition, the project hosts a family listserv. The family specialist who moderates it disseminates parent center information and announcements on an ongoing basis." - Pennsylvania



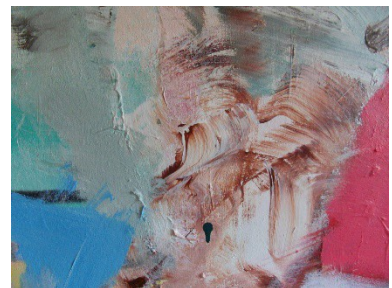
Attend each other's events

Attending events (e.g., workshops, parent weekends) provides opportunities to learn about the services of the other project and identify areas where collaboration is needed and likely to be beneficial.



Share materials

Sharing project materials, such as factsheets, brochures, and announcements is an easy way to begin to work together and stay up to date on each project's activities.



Coordination

At the coordination stage, organizations consistently share information and resources in a way that increases their efficiency, thus reducing duplication of effort with respect to common goals. This involves some shared decision-making and frequent communication (Frey et al, 2006). The strategies below illustrate examples occurring between state deaf-blind projects and parent centers that are consistent with this level.

Become Involved in Each Other's Activities

This refers to involvement that goes beyond mere attendance. For example:

- Giving a presentation at a workshop, conference, or family gathering for the other project
- Providing meeting space (real or online) to hold a family training
- Sharing audiovisual equipment
- Co-sponsoring groups (e.g., in South Dakota, the two projects collaborated on the development of an adult siblings group)



"As part of our efforts to identify children with deaf-blindness, three to five years of age, we've collaborated with the parent center to raise awareness on what to expect and sources of support for children with hearing or vision loss when transitioning from early intervention to pre-school." - New York

Develop an In-Depth Understanding of What Each Project Does

In order to partner with another organization, you need to have clarity about your common goals, activities, and resources (including staff members' skill sets).

"Gaining insight into the workings of each other's projects has made us better TA providers". - New York

"We have a better understanding of each other's project initiatives. This has an overall impact on families from both organizations through direct services, parent trainings, and teacher/educator professional development." - Ohio

"Another factor to our success is having a true understanding of each other's project and the services provided by the project". - Oklahoma



Meet Regularly

In a number of states, deaf-blind projects and parent centers meet at least quarterly on a formal or informal basis to make plans and share information.

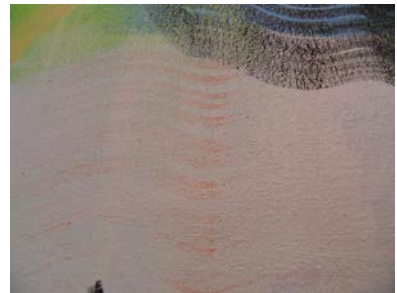
“Frequent, open communication allows us to proactively identify and address the needs of families and service providers”. - North Carolina



Disseminate News and Materials

There are a number of ways to disseminate materials for each other, including:

- Link to the other project’s website from your website
- Put their contact information on your publications
- Disseminate their brochures and information in packets you send to parents and professionals
- Post information about their upcoming events on your e-mail lists, website, and Facebook page



Example: The Oklahoma Parent Center director disseminates state deaf-blind project materials for the Oklahoma state deaf-blind project. This is extremely helpful for the deaf-blind project, which has just one employee and cannot attend multiple statewide meetings.

Make Referrals

Parent centers should refer all families who have a child with combined vision and hearing loss to their state’s deaf-blind project. State deaf-blind projects should refer families in need of information about parent advocacy, the law, health care systems, and similar topics to parent centers.

“When calls and or questions come to the [parent center], each of the coordinators goes through a process of taking information and providing guidance and technical assistance as needed. For questions related to deaf-blindness, each staff member knows to contact the director of the deaf-blind project. It truly is a continuous circle of collaboration and support.” – Nebraska



Provide Staff Development Training

Providing training to each project's respective staff members can help increase awareness of their mission and services. This strengthens collaboration and, at a very practical level, helps staff members gain knowledge about when and how to refer families.

"The state deaf-blind project provided in-service training for all parent center staff to give them a broader understanding of the needs of families of children with deaf-blindness". – Florida



Share Expertise

In addition to benefiting from each project's general areas of expertise (deaf-blindness at the state deaf-blind projects and advocacy and education law at the parent centers), collaboration can also occur in areas where staff have special skills or knowledge. This includes such things as fluency in languages other than English and specific topical knowledge.

"We benefit from each other's expertise. Theresa is amazing with technology. Mary is fantastic around the law and IEPs, and I know employment". - Montana



"Our collaboration helped us determine how to reach out to Spanish speaking parents and provide information using culturally and linguistically appropriate methods". - New York

Collaboration

This level is characterized by thorough communication based on mutual trust—organizations have established processes that drive and organize shared work and consensus is reached on decisions related to all joint activities (Frey et al, 2006). The strategies below illustrate examples occurring between state deaf-blind projects and parent centers that are consistent with this level.

Work together on activities to accomplish mutual goals

Working together on mutual goals involves first identifying shared goals and values. Examples of common goals include:

- The family is the center of the team
- Parents should be empowered to advocate for their children at state and local levels

[The MI parent center and state deaf-blind project] both believe supporting parents is the most important service we can provide. We also have a "we are better together" working agreement. - Michigan

"Collaboration has enabled both [the parent center and the state deaf-blind project] to reach a wider range of local families and, therefore, engage more families in training and recreational opportunities. It has also increased the ability of families to network with each other". - Maryland

Involve Other Stakeholders

True long-term change in child outcomes requires collaboration among multiple organizations. Recognizing this, a number of parent center-state project pairs expand their collaboration to include other partners who share their goals and responsibilities to families. These other stakeholders might be early intervention, education, or community agencies also charged with meeting the needs of families. By identifying workscope commonalities, these organizations can collectively leverage their resources to have a greater impact.

Work Together on State Systems Change Activities

Many states work together, typically with additional stakeholders, to influence service systems in their states related to such things as early intervention, transition, or healthcare.

Example: In North Dakota the state deaf-blind project, the parent center, and the PEPNET 2 Transition Team have worked



together on numerous projects focusing on transitioning youth. These include participation in a transition community of practice, the development of a transition guide, and work on "Teen Night Out" activities in the Fargo, ND-Moorhead, MN area. A representative from the parent center spoke at the 2014 Transition Summit, a collaborative effort among the state deaf-blind project, the School for the Deaf, and the PEPNET 2 Team.

Develop a Formal Working Agreement

Some SDBP-parent center pairs find it helpful to have a formal working agreement such as a memorandum of understanding (MOU) that outlines each project's roles, commitments, and a plan for evaluating the collaborative relationship.

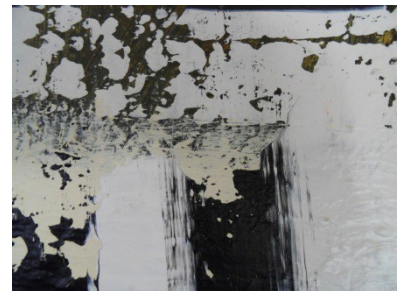
"Before we had the written MOU, we had challenges related to lack of clarity about the expectations of each other. We handled it by developing the MOU!" - New Jersey



Develop Strong Professional and Personal Relationships

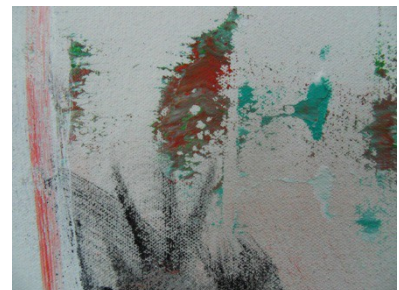
Literature on collaboration clearly shows that personal relationships are the cornerstone of successful partnerships (Gadja, 2004). Good relationships involve knowing each other's strengths and getting to know each other as people.

"We have a strong collaboration that is considered a friendship based on years of working together. We all know who to call or email. Our collaboration is successful because of a long-term relationship built on trust . . . Everyone is on first name basis." - Nebraska



Serve on Each Other's Boards or Other Committees

Many state deaf-blind project and parent center pairs have representatives on each other's boards or other committees. These representatives are typically staff members, but may also be other individuals who can bring the specific project's perspective to the group (e.g., a state deaf-blind project might identify parent leaders of children who are deaf-blind to serve on a parent center's board).



The Ohio parent center is on the state deaf-blind project's advisory board and on its Technical Assistance Design and Deployment (TADD) Team. This provides additional opportunities for planning and implementation of activities that meet the needs of parents and families in Ohio.

“We have the desire to serve on each other's' committees because it increases awareness of both agencies' programs and activities. This provides better outcomes for families.” - Utah

Develop Materials Together

Some projects work together to co-create materials such as fact sheets and slide presentations.



Collaborate on Family Training Events

Parent centers and state deaf-blind projects often jointly develop and offer onsite and online trainings. Often these collaborations focus on leadership training, but some projects have collaborated on other topics such as the IEP process.

Some states also give joint presentations at other venues. For example, in 2012 the New York parent center and state project gave a presentation at an OSEP Leadership Meeting about their work promoting family leadership.

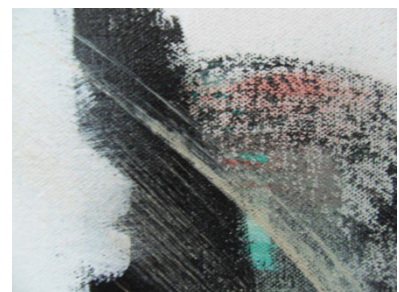


“We collaborate on quarterly parent online trainings during the school year based on topics of interest to families (solicited via a survey). The deaf-blind project helps host the sessions, and assists with recruiting speakers. The number one topic requested by parents has been behavioral challenges, a topic in which state deaf-blind projects have expertise.” - South Dakota

Example: The Florida and Virgin Islands deaf-blind project and the Florida parent center work together to host several family forum sessions (a Mom's Group, a Dad's Group, and a Spanish Family Group) at an annual statewide parent conference.

Work Together on Data Collection

Work together on data-collection (e.g., focus groups, needs assessment surveys) to support the development of materials and activities.



Share Financial Resources

A very small number of states have a formal financial arrangement that involves funding from one project to the other and, occasionally, projects share financial resources in other ways. For example, parent centers or state projects will sometimes pay for families to attend events sponsored by the other agency.



Share and/or Connect Parents Leaders

One very powerful way that parent centers and state deaf-blind projects can enhance their services is to train and connect parent leaders who are associated with each of their projects. This allows them to take advantage of family leaders' specific skill sets, especially skills that aren't disability specific and are likely to have value for both projects (e.g., grief counseling, navigating Medicaid, navigating the IEP process).

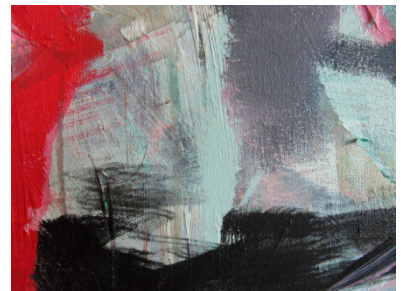


Examples:

- *In Michigan, the parent center and the state deaf-blind project are working to link the parent center's Parent Mentors with the deaf-blind project's Family Leaders in their local communities.*
- *In Arkansas, a parent of a child who is deaf-blind became employed as a parent educator for the parent center. This has assisted the state deaf-blind project in raising awareness of deaf-blindness and enhancing positive relationships with the parent center.*
- *Through collaboration with their parent center, the North Carolina state deaf-blind project added a family specialist.*

Evaluate Collaboration Outcomes

Evaluating outcomes of collaboration means that the state project-parent center pairs work together to determine the impact of their collaboration. At this point in time, most projects are not doing this. However, many do evaluate the outcomes of specific activities or events they co-sponsor.



"Parent/family surveys and interviews are a part of our program evaluation. We conduct such surveys and interviews during and at the conclusion of many of activities and training opportunities, and also during non-activity-related times (at least once a grant cycle, we gather feedback from families)". - Maryland

State Stories

States reported a broad range of strategies and activities that work for them based on the needs of families in their states, their state's characteristics, and their projects' resources. Let's look at some examples— Maryland, West Virginia, and Montana.

Maryland

State Deaf-Blind Project: Connections Beyond Sight and Sound (CBSS)
Parent Center: Parents' Place of Maryland (PPMD)

Submitted by
Donna Riccobono, Project Director of CBSS
Jeni Stepanek, Education Specialist at CBSS

At Connections Beyond Sight and Sound (CBSS), our goal is to improve outcomes for children with deaf-blindness in the Maryland and Washington, DC area. Among other services, we provide education and support to families. Our collaborative work with Parents' Place of Maryland (PPMD) makes it possible to expand the learning and social opportunities that benefit our families.



Educational Programs

CBSS works with PPMD to help them conduct one of their most popular annual educational opportunities, the Special Education LEADers Training Program, offered at no cost to parents and family members throughout the state. During six monthly workshop sessions, participants explore topics such as special education law, effective advocacy, the IEP process, and dispute resolution. PPMD returns the favor by supporting the CBSS annual Family Learning Weekend. This year's event was spectacular! Held in September in Columbia, Maryland, the weekend was well attended and earned great reviews by both participants and presenters.

Family Fun Activities

We also team with PPMD to help families make connections with each other and have fun. A recent example was “Family Day at the Farm,” held in May 2015. Children with deaf blindness and/or multiple disabilities from Maryland, DC, and Virginia were able to experience a farm, pet small and large animals, feed ducks, ride a horse, and much, much more.

In addition to providing programs and activities that support our families, a CBSS staff member participates as a member of the Board of Directors for PPMD and a PPMD staff member serves on the CBSS Advisory Committee. What makes our partnership with PPMD work is our mutual respect and excitement about working for and with families. Each year, we continue to meet new families who are dealing with challenges related to deaf-blindness. And each year we will continue to do all we can to improve the outcomes for their children, through our CBSS project activities and collaborative work with dedicated partners.

West Virginia

State Deaf-Blind Project: WV SenseAbilities Project

Parent Center: WV Parent Educator Resource Center (PERC)

Submitted by

Ruth Ann King, Project Coordinator/Family Specialist, WV SenseAbilities Project

The WV Parent Educator Resource Center (PERC) and the WV SenseAbilities Project are both based at WV Department of Education (WVDE). Having a common home agency provides a foundation for a high level of collaboration.

PERC works with families, educators, and other service providers via partnerships with local education agencies in 37 counties. A team, consisting of a parent of a child with special needs and an educator, staffs each local PERC. The services they provide include parent information, resources, and training; individualized assistance to help parents better understand their children’s educational needs; and training for educators to increase their skills, knowledge, and attitudes related to strengthening family involvement and positive school-to-home partnerships. PERC has a state level coordinator who attends the WV SenseAbilities Family Learning Weekend to address individual family needs and coordinates collaborative efforts among organizations and agencies that serve families in West Virginia.

The WV SenseAbilities Project collaborates with PERC to meet the needs of families of children who are deaf-blind in the following ways:

- Contributes to the annual PERC conference by providing information and presentations about sensory impairments

- Provides links to relevant websites, webinars, and articles that families can access through their local PERCs
- Provides training in sensory loss for families and teams
- Assists in recruiting individuals who have backgrounds in deaf-blindness to work at the local PERCs (currently this includes two parents and one grandparent of children who are deaf-blind)



One of the most exciting and fun activities on which the two agencies collaborate (along with numerous other state organizations) is Camp GIZMO, a five-day summer camp focused on assistive technology for children, birth to 8 years old, who experience significant and multiple developmental needs, including deaf-blindness. Camp GIZMO is a wonderful event for children, families, and professionals, where children participate in a daily fun activities, while professionals and families attend workshops and labs.

Montana

Parent Center: Parents, Let's Unite for Kids (PLUK)

State Deaf-Blind Project: Montana IDEA Services for Children and Young Adults with Deaf-Blindness Project

Submitted by

Ellen Condon, Project Director

Montana IDEA Services for Children and Young Adults with Deaf-Blindness Project

In Montana, collaboration between the parent center (PLUK) and the state deaf-blind project is fostered by personal connections. I've known two of the PLUK staff members--Mary Hall and Theresa Baldry--for more than 15 years.

Most of our work together focuses on helping specific children. We pool our resources and take advantage of each other's areas of expertise. It's nice to have two people assess the same child and situation and come up with creative solutions. This is especially helpful for children who have complex needs. For example, Theresa, who is based in Miles City, is great with technology. I contact her when I need advice about tech for specific students. Mary is amazingly knowledgeable about the law, and together, she and I have leveraged our collective expertise to schools and families related to transition planning.

The personal relationships we have developed over the years are what make our collaboration work. We really like each other and enjoy working together. There are a couple of factors that I think that led to the development of these relationships. First, as noted above, we each have strong areas of expertise. In addition to my role as the director of the deaf-blind project, I also direct projects that focus on transition planning for students with intensive support needs. I first met Theresa and Mary when they contacted me with questions related to transition, both for the families they serve and for their own sons with disabilities.

Second, personal connections are crucial in a state the size of Montana. When you have a service that covers a specific content area, as both our state deaf-blind project and the parent center do, you travel a lot and must rely on each other for connections in communities that are unfamiliar to you.

Although our approach is informal, it works well for us and I think we will be able to expand this style of working together in the future. Currently, much of our collaboration is centered around transition-age students and employment, but I hope that going forward we can forge new connections with parent center staff related to younger students and new topics.

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- North Dakota
- New York
- Ohio
- Oklahoma
- Pennsylvania
- South Dakota
- Utah
- West Virginia

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