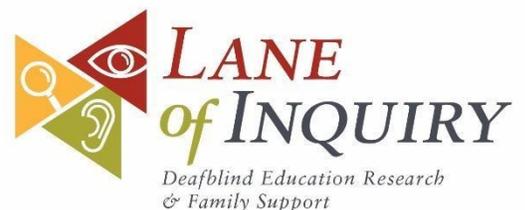


The Importance of Family-Professional Partnership in Times of Uncertainty

A study of families with children who are
deafblind during the COVID-19 pandemic

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Abstract

In March 2020, school buildings closed with little notice and students were forced out of the classroom because of the COVID-19 pandemic. The purpose of this qualitative study was to explore the pandemic's impact on the relationship that families of children who are deafblind have with their children's Individualized Education Programs (IEP) teams. The goal was to identify advocacy and collaborative strategies that might be worth continuing after schools reopen. Although another pandemic of this magnitude may not happen again, the experiences of the past year yield many lessons about the importance of relationships during times of high stress and uncertainty. The following research questions guided this study:

1. What knowledge and strategies have parents of children who are deafblind found most effective in collaborating with their IEP teams during the pandemic?
2. What challenges do parents experience when collaborating with their IEP teams during the pandemic?

Results from this study indicate that

- a) strong communication helps to build trust with families and strengthen relationships with IEP teams,
- b) families appreciated educators who showed professional commitment to their well-being by going above and beyond, and
- c) throughout the pandemic, IEP teams that engaged with children who are deafblind relied on collaboration to solve complex situations regarding accessibility and student support, but challenges remain.



Introduction

In March 2020, school buildings closed with little notice and students were forced out of the physical classroom because of the COVID-19 pandemic. Too many students with disabilities were left without the services and supports they needed—and that were included in their Individualized Education Programs (IEP). Special educators and related service providers struggled to quickly provide services and supports virtually. Some schools had systems already in place and were able to pivot more quickly than others, but for the most part special education seemed to be a planning afterthought. Fast forward to fall 2020, and not much had changed from last spring for students with disabilities. During the summer, districts made little mention of special education in their reopening plans and even when they did, there were few details—not enough for families to plan around. Planning was necessary for families because their involvement would be vital to the successful delivery of virtual special education services and supports, especially for younger children and students who are not able to manage their school day independently.

Families, which all had unique needs, experienced the pandemic in many different ways. Some families were able to pivot and keep up with the increased level of involvement. But many families did not have the flexibility to be home to help with remote learning. They were forced to support remote learning while caring for other family members, trying to make ends meet, working from home without childcare, and more. Parents of children with disabilities were being asked to take on roles they never had in the past: monitoring IEP progress, helping to provide accommodations, and finding engaging and accessible curriculum and activities. What used to be a student-teacher relationship became a teacher-family-student triangle (CRPE, 2020).

More than halfway through the 2020–21 school year, many students have not seen the inside of a school building for over a year. Some districts and schools have been prioritizing students with disabilities for in-person instruction, but not all families are comfortable sending their children back to school until the virus is controlled.

Family School Partnerships

Parent involvement in IEP meetings is recognized as part of the Individuals with Disabilities Education Act (IDEA), but the partnership envisioned by IDEA remains inconsistent with practice (Haines et al., 2017). Parents often report having low satisfaction with the IEP process because of the lack of collaborative partnership with educational teams (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004). Other parents have developed strategies to build stronger relationships with their children’s IEP teams (McKittrick, 2019).

These strategies are aligned with Blue-Banning et al.’s (2004) principles of family-professional partnership: commitment, advocacy, communication, competence, respect, equality, and trust. Stress is common for parents of children with disabilities—parent advocacy efforts have been shown to exacerbate stress, especially when parents feel their input is not valued in IEP meetings (Wang et al., 2004). Discovering a child has a disability also brings about stress for families; past



research suggests that having a strong family-professional partnership reduces maternal stress (Burke & Hodapp, 2014).

About Deafblindness

Parents of children who are deafblind report having unique challenges in IEP meetings because of the IEP team's lack of knowledge around deafblindness and the heterogeneity of how deafblindness impacts each individual. In order to understand these challenges, it is important to understand what deafblindness is: the dual-sensory impacts in the classroom and the supports and services that students may need. Because both hearing and vision are impacted, social interactions, learning, and communication are also all impacted (Corrrea-Torres, 2008). Dual-sensory loss means students may require accommodations in order to access information through audio, visual, or print platforms. When the pandemic forced students out of the classroom, accessibility became a challenge for those who are deafblind. Many also have additional disabilities that, for safety reasons, make it difficult for them to return to the classroom even if their school offers it.

Deafblindness is considered the lowest incidence disability recognized by IDEA. In 2019, 10,627 children in the United States, from birth to age 21, were eligible to receive services from state deafblind projects, and were served through Part C or Part B of IDEA (National Center on Deaf-Blindness, 2020). Deafblindness is defined in IDEA as “concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness.” (IDEA, 2004)

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Research Methodology

We used a qualitative research methodology because it was the best way to understand the experiences and emotions parents of children who are deafblind faced when working with their IEP teams during the pandemic. A researcher interviewed 30 parents of children with disabilities about their IEP experiences during the pandemic: 17 have children who are deafblind and 13 have children with disabilities other than deafblindness. Twenty-one interviews were conducted in spring 2020 and 16 in fall 2020. Initially we were planning to interview parents only in the spring, hoping that school buildings would be open by fall. When schools began in fall 2020 in a mostly remote model, we expanded the study, adding nine more participants and following up with seven parents from the spring interviews. We attempted to connect with all parents from the spring interviews but some did not respond. This paper is focused solely on findings specific to the families with children who are deafblind, although the nondisability-specific findings were consistent across all disability groups.

Participants were spread out geographically in 11 states, and all but one were mothers. The other was a father. Ten parents have children with Usher syndrome, three with CHARGE syndrome, and four whose deafblind etiology was something other than these two syndromes. About half of the children have disabilities in addition to deafblindness. The age of the children ranges from 3 through 18 years.

Before the interviews, we developed interview protocols and institutional research board approval was granted. We recruited participants through social media and by convenience sampling. Because the interviewer is also a mother of two children who are deafblind, she shared recruitment materials with other families in Facebook groups she participates in. Interviews were conducted using Zoom and lasted no longer than 30 minutes each. Interviews were recorded, then transcribed by an outside transcription company. In order to increase response for the fall interviews, some data were collected using a Google form instead of or in addition to interviews. All data remained confidential and were de-identified. The data were imported into Dedoose coding software. The researcher analyzed the data to determine systematic categories through open, axial, and selective coding procedures. Quotes were then selected to represent themes. To increase reliability, initial findings were checked by two participants.

Findings

Strong family-school communication made all the difference for families

Generally, district- and school-level communication with families was lacking this past year, especially at the beginning of the pandemic. Types of communications between families and schools fall into three main categories: a) general all district/school communication, b) resource sharing, and c) IEP team individualized communication. Families that reported strong communication gave reasons why this communication made navigating virtual learning easier on them and subsequently increased their satisfaction in working with their IEP teams.



Last spring, parents in this study reported that most communication was general—focused on health and safety and school closure details. Some parents were provided lists of generalized resources specific to health and safety and remote learning. However, most of these lacked specific information for students with disabilities. The few resources that were provided were not individualized to families’ unique needs. One mom stated:

I don’t know that it was good information coming out, but it’s something. If your kid needs behavioral support, here’s five resources you could go to. But, okay, what do you do with those five websites? I have no idea. That’s what I mean. It was like you were drinking from a firehose, but it’s not the right type of information that is coming and it wasn’t organized.

In summer 2020, much to parents’ dismay, the level of communication was consistent with last spring. Only a handful of parents heard from their districts or schools just before the school year started, and again did not receive much information that was specific to special education. Even fewer attended IEP meetings before the school year began. Of the communication that did occur in spring and summer, were because parents initiated it.

Parents in this study shared that they were disappointed by the lack of communication last spring but were also empathetic: everyone was focused on understanding the impacts of the pandemic and schools had various priorities to sort out. Many families were trying to make ends meet and working through all the uncertainty.

IEP team communications last spring, for the most part, were reportedly nonexistent. Some parents reached out to their IEP teams and were told that team members were “waiting for guidance from their districts.” For too many families this “guidance” never came: IEP teams did not provide support or hold meetings. Just one parent in the study had their IEP team call a meeting last spring. For others, IEP team members—even without guidance—dropped off supplies to families and “did the right thing because the teachers really care about my child.” Parents whose IEP teams proactively communicated with them—dropping off supplies and providing resources—shared how much this meant. Although the communication levels were not high, parents appreciated the effort.

This fall, most parents in this study reported receiving communication from their children’s IEP teams either right before school started or shortly thereafter. Parents were relieved and reported that this individualized communication was much more helpful than the school-level communication that made little mention of special education. Still, for most, fall started with a “one-size-fits-all” approach that left many students behind—without the needed supports, modifications, and accommodations to access the curriculum like their general education peers do. One mom shared about the lack of individualization this fall, “I don’t feel like my voice is heard with all the providers. Some have their routines down and are not willing to stray from their plans.”

Parent experiences varied this fall after school began. On the positive end of the spectrum, about half the parents shared how much they appreciated one-on-one check-ins, problem-solving, and



individualization they received. These check-ins happened not just between the teacher and student, but also with parents. One mom shared the benefits of good communication:

The relationship with my son’s [IEP] team has always been phenomenal. Since COVID, we are lucky enough they have gone above and beyond to help [our son] and we talk almost daily with updates and what will work best. Many new strategies have come into play. . . . They talk with me directly on new strategies they are doing and things I can do to help.

Parents of younger children and children with more significant support needs expressed that these check-ins were vital—helping them to know how to best support their children at home. Parents used these check-ins to communicate goals with the IEP team to ensure everyone was on the same page. For the most part, however, parents had to push for increased communication: “Midway through the quarantine I was like, ‘What can we do to get parents to really feel like they have a voice right now?’ I was surprised that there wasn’t more of ‘Parents, what is this like for you?’”

The other half of parents, however, did not have the same positive experience. These parents were continually reaching out to their teams and becoming frustrated with the lack of communication and support. They were left to fend for themselves in supporting their children’s educational needs. For this group of parents, the stark reality was no IEP meetings, no services and supports, and a curriculum that was inaccessible. One parent shared, “I really feel forgotten by the case manager, honestly.” Another mom had a similar experience: “It’s very inconsistent and I don’t know that [the case manager] is communicating with anyone else on our team at all. There has been no team communication, no coordination of services, nothing like that.”

Parent experiences with communication seemed to vary greatly, not just between IEP teams but from school to school. Parents in this study said they knew that some schools dropped everything last spring and focused on communication. But for the majority, communication was a struggle until school was back in session this fall. Once the school year started, communication improved - IEP teams started to hold IEP meetings and schools had figured out their method for communicating with families. Teachers and parents began texting and communicating more often.

Professional commitment was a bright spot during the pandemic: many educators went above and beyond

Last spring, about half the parents in this study happily shared stories about educators going above and beyond simply because it was the right thing to do—because they cared. Details about special education were scarce then, especially in how to carry out IEPs and whether or not revisions needed to be made. Instead of waiting for details from school districts about how to respond regarding special education, some educators brought supplies to families, shared individualized resources, and checked in about well-being. One mom shared a story about that time:

My team hadn’t been given any direction yet from the district but they knew I needed manipulatives and other supplies in order to support my son. Our son’s special education teacher, bless her heart, dropped them by our house. We got to wave to her from the



window. She then sent a video of how to use the manipulatives and other supplies. This small gesture meant so much to me.

Another parent shared that her son’s teacher planned a drive-by car parade to help her son, who was having a hard time understanding why he could not be in the school building with his class. As another show of commitment, some districts revised IEPs last spring even though it was not mandated—something that helped teams to problem-solve and find ways to individualize.

Parents in this study shared that educators this fall demonstrated commitment and support in similar ways—showing them how to teach from home, listening to what they needed, remaining flexible, and individualizing the approach. Commitment helped a lot, especially since the school year launched with what for many felt like a one-size-fits-all approach. To solve the complex challenges at hand, individualization, collaboration, and flexibility were necessary.

As one mom put it, “The team just wraps around [my daughter] to support her. They just go way above and beyond. I’m just like, ‘If every kid had this, parents would be so lucky.’” Another parent shared that because of the trust among the team, she had their personal phone numbers and was invited to call or text anytime. The parent mentioned how appreciative she was to be able to reach the IEP team, and how committed the team members were.

That said, some families did not have the same experience and felt brushed off and ignored by their teams, especially last spring and summer. For some, the lack of communication felt like a lack of commitment. Last spring the communication challenges were understandable, but when parents still had not heard from their IEP teams when school started in the fall, they were discouraged and frustrated. One parent wondered about why this happened: “The new [IEP] team is hesitant to try to implement any new strategies. They are holding on to hope that everything will return to normal.”

Parents are better able to develop new advocacy strategies now that they have a front seat to their child’s education

Most of the parents in this study shared that although they felt they were strong advocates before the pandemic, their advocacy increased as a result of being home with their children. As they provided remote learning support to their children, parents shared how they were seeing the learning experience for themselves: what support is needed and how their children learn. This new knowledge is helping them know what to advocate for. One mom shared, “I have learned exactly how my children struggle and what exactly they need to help them. I have seen the inadequacies of the district and can better prepare my children for them.” Another mom shared that, because of her time at home, she was able to realize that her daughter had dyslexia and, as a result, was able to provide her the reading interventions she needed.

Regardless of whether a parent had a strong relationship with the IEP team previously, all parents in this study shared that they gained new advocacy strategies as a result of the pandemic because they were home with their children. With this firsthand knowledge, parents have been able to more easily advocate for changes to schedule, increased accessibility, increased use of technology,



remote learning accommodations, and additional support. Parents shared that their hope is to figure out how to sustain that same level of knowledge, even as their children return to the classroom. “[I wish] for there to be some level of empathy [from the team], but also action, because it goes a long way. So we don’t have to advocate so hard all the time.”

Parents are engaged and empowered

Although every parent shared how overwhelmed and exhausted they were, many also felt more engaged and empowered. That doesn’t mean that all parents spent more time devoted to their child’s education than they did before the pandemic—many worked outside of the home or were taking care of family. But parents found an increased confidence to speak up about their family’s needs: what works and what does not. One mom who has a great relationship with her son’s IEP team shared what she told the team:

The most important thing you can do right now is support the parents to help them feel empowered, to make them feel like they know what they are doing, or to help them. Because if we can walk away from this in months or whenever that is all going to go away and help parents feel like they actually have an active role in their kids’ education. Because I know a lot of parents don’t.

A few parents shared stories about how they were misunderstood last spring when they followed their own educational agenda: “My school thinks I’m opting out, not having my child do the work because I don’t want to, but that wasn’t it at all.” Some families simply had different priorities. Several mentioned that they were realistic about what was and was not possible during the pandemic. For example, engaging on Zoom is not realistic for some students because of their disability. Instead of focusing on the negative, parents said they opted to shift priorities to work on life skills goals—goals the family or IEP team didn’t previously have time to focus on. Some parents shared stories such as toilet habits improving, their child doing more chores around the house, and finding ways to increase self-advocacy skills.

Challenges remain, many specific to deafblindness

In order to fully grasp the pandemic’s impact on relationships between families and IEP teams, it is important to understand the challenges that these families have faced this year in getting their children’s needs met. Although the challenges mentioned by parents in this study are not that different from those that all parents of children with any disability faced this year, there are important nuances. The deafblind student population has heterogeneous needs, and IEP teams must fully understand those unique needs—regarding accessibility, assistive technology, interpreters, and other supports.

Accessibility

Accessibility issues have improved since last spring but remain a challenge. Parents shared that accessibility was especially a challenge at the beginning of this school year, as well as last spring. Technology was slowly rolled out last spring and in early fall but training on accessibility did not



always accompany the rollout, leaving too many students unable to access the curriculum along with their peers. Closed-captioning was also mentioned as being unavailable for most students until well into the 2020–21 school year. Zoom recently launched live closed-captioning, which has helped but it is just one piece of the accessibility challenge.

Families found that their children need additional assistive technology in order to access the curriculum with their peers, such as FM hearing systems and magnifiers. Parents and students also need training on accessibility tools such as speech-to-text. Parents shared that they found it helpful when schools offered remote learning-specific accommodations, such as teachers wearing headsets to provide better speech clarity, and scheduling hearing/brain breaks. Parents described wanting clarification on how deafblind interveners or paraprofessionals would be used in a remote setting to support their children. A few parents also reported some challenges getting sign language interpreters for remote instruction.

Social-emotional development and disrupted routines

Parents worried about their children's mental health and the lack of social-emotional supports at schools. Many children who are deafblind already have a difficult time in social situations; learning remotely makes that even harder. Another concern of a few parents was that their children were not able to comprehend the concept of a pandemic and why they could not be with their classmates.

Similarly, students are feeling the impacts of disrupted routines, lack of in-home support, and the inability to receive some special education-related services. This was especially noticed by those parents who did not have in-home support. Some related special education services, once they were again possible, had to pivot to a virtual model. Many service provisions are possible virtually, but some have had to change, such as white cane training. Orientation and mobility specialists, who provide white cane training, have had to find other goals to focus on until in-person services are deemed safe.

Logistics of in-person instruction

Each family has unique characteristics that contribute to their individualized views on safety during the pandemic. Some families are eager for their children to go back to the classroom, but certain logistics must be addressed to make this possible. For children who are deaf or hard of hearing, the use of masks in the classroom poses challenges with communication. Maintaining social distancing requirements can be difficult for children who have a visual impairment because they may not be able to see the safety signage or other important visual cues. Social distancing may not be possible for students who communicate using touch or who have a one-on-one aide.

A few families in this study shared the reality that their child, who is medically fragile, would not return to school until the pandemic was over and everyone was vaccinated. There is also the issue of how to prepare students who are deafblind for the personal protective equipment that their teachers must wear: the smells might be different, and their teachers might look and feel different.



Overarching challenges not specific to deafblindness

Parents and students are navigating the uncertainty in the education system and the world today. Parents shared that they are not feeling supported in the same way now as they were before the pandemic. And many families have not been able to access their support systems as they did before. One mom shared, “We’re barely making it through the regular classroom stuff and keeping everyone sane while staying at home.”

Progress felt slow for many families—educators’ hands were tied in how to revise IEPs and support students and their families. Parents were empathetic when the pandemic first hit last spring. But when things hadn’t changed in the fall and it became even more challenging to get answers and move plans forward, parents began to get frustrated. A few parents worried about their children regressing in academic and nonacademic skills because not all of the necessary services and supports were available. They wondered if their schools would offer compensatory services or find other ways to compensate for any identified regression. Without in-person assessments and the ability to monitor IEP goals in person, parents were concerned about what that will look like next year and beyond.

Discussion

For families with students with disabilities, the pandemic put a spotlight on existing challenges. On a positive note, schools and families have recognized that family-school partnerships are paramount during this time. The emotional strain that educators and families have experienced makes these supportive relationships even more important. For families that already had strong relationships with their children’s schools, these relationships may have either become stronger, or families may feel disappointed that the partnership is breaking down. Families who had strained relationships with their schools before the pandemic may feel like the strain has intensified, turning toward conflict. With no clear end in sight, schools must figure out how to partner with families in new ways.

Communication is key. Past research shows that good communication increases parent satisfaction in the IEP process (Zeitlin & Curcic, 2014). Because of all the stress and uncertainty, communication became more important than ever before during the pandemic, although it was slow to roll out and was not focused on special education. In Latham’s (2002) qualitative parent study, parents reported they were often communicated to “too late” (p. 151), similar to the findings from this study. For too many parents, communication with schools and IEP teams remained a struggle—regardless of past relationships—brought on by all the uncertainty. But families that had good relationships with their teams have mostly been able to figure out a workable communication plan, especially now that the school year is more than half over. These were teams that developed individualized communication plans, a strategy that Turnbull et al. (2015) found could help eliminate misunderstandings.

When the pandemic hit in spring 2020, educators and families alike were struggling to make sense of things while shifting to remote learning. Everyone responded to the pandemic in unique ways



and focused on different things. Regardless of a family's capacity to focus on academics, findings from this study indicate that professional commitment meant a lot to parents during these times of stress and uncertainty. This past year—especially last spring—parents shared how much it meant to them when educators shared their cell phone numbers, drove supplies to their house, and checked in on family well-being simply because they cared. This finding is consistent with past research that parents appreciate it when educators go above and beyond (Blue-Banning et al., 2004; Francis et al., 2016).

Parents are more involved and engaged than ever before because their children were home learning remotely for over a year. One parent shared:

I've actually enjoyed it because now I can really see what he's capable of and what he's not. All these things I've been asking them to put in place at school, are working at home. It's really made me a better, or more engaged parent in many ways.

Findings from this study showed that during the pandemic parents were actively involved in determining what IEP goals their children would focus on and reprioritizing as necessary.

When parents have a front seat to their child's learning, their ability to advocate increases. Parents in this study also showed increased confidence in sharing their opinions with IEP teams; they were able to describe what to focus on. Many parents found the time to have their children work on meeting non academic goals (e.g., life skills goals). Parents are seeing progress firsthand and advocating for teams to create goals that are appropriately challenging. They have also been able to reallocate time and do things differently, which in many cases has made advocacy easier:

I feel like a big chunk of my life was just trying to be nice to everyone on my son's team. You're trying to advocate in a nice way, and I was just thinking, 'Right now I don't have to do any of that'—it's pretty amazing.

Implications for Practice

Findings from this study about parent experiences during the pandemic have implications for practice for families, educators, and school leaders. Family systems are complex and all families with children with disabilities have historically experienced stress and uncertainty at various times during their child's journey—at diagnosis, during advocacy efforts, and more. The pandemic only exacerbated these families' experiences. We have much to learn about how they built collaboration and relationships during the pandemic.

Findings from this study contribute to the research showing that relationships matter, especially during times of immense stress. Partnerships between schools and families are more important than ever before. Last spring and this fall, communication with families was lacking; past research has shown how parent satisfaction is dependent on strong communication. Those families whose schools and teams effectively communicated well with them were better able to problem-solve and individualize solutions. Many schools dropped everything last spring to ask families how they were doing—and not just with academics. But schools must sustain that level of communication,



continually asking students and their families how they are doing and what they need. Accessibility and supports for children who are deafblind have increased since the pandemic started, but family situations change, student needs change—more can be done. Collaboration between families and IEP teams can help ensure that each child's individual needs are continually met.

Parents lost much trust in their schools last spring. Communication was scarce, and families perceived that schools treated special education as an afterthought. One way that schools can earn that trust back is to ensure individualized solutions for students—and not assume that a “one-size-fits-all” approach is the best they can do. As IEP teams—families, students, teachers—develop these solutions, some will not work as intended; teams must keep communicating and problem-solving until they find effective and sustainable solutions.

Findings from this study shows that it helped to have good IEP relationships going into the pandemic, but that does not mean it is too late to build strong relationships with families now. In fact, this is an opportune time to rethink what we mean by parent involvement in special education, as part of IDEA. Just having parents at the table is not enough. We must stretch ourselves to develop new and innovative ways to actively engage families. We should lead with family engagement instead of following with it.

This past year highlighted many challenges that already existed in special education. Parent participation in their children's IEPs has always been something that we can strive to improve. When parents in this study were asked to offer their suggestions for educators and other parents, the main focus was on compassion—an encouraging sign. Through all of the challenges of this past year, parents shared their desire, and recognized the need, to respect each other—to be kind. Parents are overwhelmed and recognize that teachers are equally overwhelmed. We are all in this together and if we find new ways to work together to individualize and meet the needs of students, they will have better outcomes and parents will be more satisfied and engaged. In the words of Helen Keller, “Alone we can do little; together we can do so much.”



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