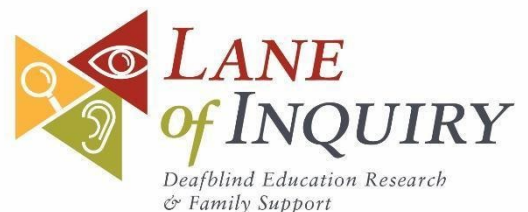


Synthesis: The Importance of Family- Professional Partnership in Times of Uncertainty

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

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BACKGROUND

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.



ABOUT THE RESEARCH STUDY

This past year I was part of a team of researchers at the Center on Reinventing Public Education (CRPE) conducting research on school and district response to COVID. In the spring, I interviewed parents who were also educators about their experiences and learned that I was not alone in feeling stretched in so many different directions. I then began talking with special education parents about their experiences, which gave me the idea for this study. Being a researcher with a special interest in collaboration within IEP teams, I sought to learn more about parent experiences working with their child's IEP teams during times of great stress and uncertainty. As a special education parent myself, I know firsthand the impacts that stress and uncertainty can have on lives, regardless of whether there is a pandemic. Knowing this, I wondered what others could learn from families of children with disabilities - about parent engagement, relationships, and collaboration. This is why I launched this research study.

As part of my work at the Center on Reinventing Public Education this past spring and fall, it worried me to see very little mention of special education in spring and fall. I hoped that I just was not seeing the communications because they were not publicly available. But, being a special education parent, I know that often special education feels like an afterthought, and given all the conflicting priorities in spring, summer, and fall, I was worried about our kids. This spring and fall, I saw glimpses of hope: some schools that were prioritizing family engagement, were individualized in their approach. In the field of deafblindness, I was seeing strands of innovation and how the deafblind field came together to serve our students virtually. As a field, we worked hard to overcome the challenges with accessibility, and more. There remain challenges, as I share in this research brief, but we have much to learn from this time.

SUMMARY OF KEY FINDINGS

Strong family-school communication made all the difference for families

- ▶ Communication was uneven amongst different schools/IEP teams.
- ▶ In spring, both general and IEP team communication was lacking, but most families were understanding. In spring, a quote from one mom describes it well,

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.
- ▶ Families awaited more communication in the summer so they could plan for fall but that communication did not come until right before school started.
- ▶ This late communication did not give IEP teams enough time to address accessibility and other issues before school started in the fall.



- ▶ During the pandemic, strong IEP team communication has reportedly been extremely helpful in addressing the accessibility and other challenges.
- ▶ Strong communication helped teams to effectively problem solve and individualize.

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

- ▶ Parents shared stories of educators going above and beyond, even without guidance from their schools. Educators dropped off supplies to families this spring, and checked in - because they cared. “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.”
- ▶ Families appreciate the one on one check-ins between their child and teachers and with the teachers and the parent.
- ▶ It meant a lot to families when educators shared their cell phone number for texting as necessary.

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

- ▶ 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.”

Parents are engaged and empowered

- ▶ One parent told her IEP 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.

The challenges that parents faced this year

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 not feeling supported in the same way as they were before the pandemic. “We’re barely making it through the regular classroom stuff and keeping everyone sane while staying at home.”
- ▶ Educators' hands were tied in how to revise IEP’s and what and how to support students and their families. In the spring many parents shared that educators' hands were tied and tried to be empathetic. But, when things hadn’t changed in fall, some parents began to get frustrated because of the lack of clarity, which did not allow them to plan for childcare and more.
- ▶ Because not all the services and supports have been possible, parents worry about potential regression in academic and non academic skills. Without in-person assessments and the ability to monitor IEP goals in person, parents are concerned about what it will look like next year and beyond. It is hard to quantify the potential regression at this point, which is worrisome.

The Silver Linings

- ▶ Parents have more confidence in sharing their opinions with IEP teams.
- ▶ Parents are finding the time to have their children focus on meeting non-academic goals (i.e. life skill goals).
- ▶ Some children are doing really well remotely and do not want to return to in-person.
- ▶ Many schools have increased communication and have employed new systems to do so: such as texting, Class Dojo, WhatsUp.
- ▶ Parents have a front seat to their child's education which has increased parent engagement “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.” Parents are seeing progress first hand so are advocating for teams to create goals that are appropriately challenging. Parents are seeing first hand what their children are capable of.



What we can learn from parents of children who are deafblind about collaboration during times of stress and uncertainty

- ▶ Relationships matter – partnership with families is more important than ever before.
- ▶ Make sure to ask families how they are doing and what they need, constantly. Needs and situations change.
- ▶ Find ways to build back any trust that may have been lost in spring. It's not too late.
- ▶ Work together to individualize solutions - do not just assume a “one size fits all” approach is the best we can do right now.
- ▶ It helped to have good relationships going into the pandemic but that doesn't mean it's too late.
- ▶ Deafblindness is a low incidence disability. A spotlight has been put on that reality during the pandemic. Teamwork has been vital to the success of children who are deafblind during the pandemic to address accessibility and other challenges that teams faced this year. Parents are at the center of that team.
- ▶ Through all of this, parents recognize the need to respect each other, to be kind. Parents are overwhelmed and parents recognize that teachers are also overwhelmed.

What are some collaboration strategies for parents, shared by parents?

This past year, highlighted many challenges that already existed in special education. Parent participation in IEP's has always been something that we can strive to improve on.

- ▶ Prioritize communication and relationship building – push for individual check ins with teachers, separately with students and parents. If you haven't from your child's team, continue to reach out and go up the ladder if necessary to get answers.
- ▶ Push teams to be flexible, to individualize, and to problem solve around accessibility, and any other challenge your family is experiencing.
- ▶ Reprioritize goals – consider the value of non-academic goals. Now may be a good time to create goals related to the Expanded Core Curriculum.
- ▶ Practice self-care - Be kind to yourself and make sure student expectations are reasonable given the amount of support you have right now.
- ▶ Realize that you are building your advocacy toolbox based upon new first-hand knowledge of how your child learns.



- And as one parent stated, “Be flexible. This year is difficult for everyone. Understand that the children are also feeling stressed. We need to work together as a team to be able to make progress for the child.”

Research Methodology

I began this study focused on families of children with disabilities but, because I am a parent of two children who are deafblind, I wanted to drill down in more detail to focus on the experience of families of children who are deafblind. The summary findings I present are specific to the deafblind subset of parents I interviewed, seventeen parents. This subset is part of a large research study in which I interviewed thirty parents of children with disabilities about their IEP experiences during COVID, 21 in the spring and sixteen in the fall.

The seventeen 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.

The purpose of this qualitative study was to explore the pandemic’s impact on the relationship that families with children who are deafblind have with their children’s 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 might 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 children’s IEP teams during the pandemic?
2. What challenges do parents experience when collaborating with their IEP teams during pandemic?

