



Parents of Children who are deafblind face challenges in fostering collaboration within individualized education program teams

Citation:

McKittrick, L. L. (2022). Parents of children who are deafblind face challenges in fostering collaboration within individualized education program teams. *British Journal of Visual Impairment*, 0(0). <https://doi.org/10.1177/02646196221127103>

Summary:

A summary of the findings are as follows:

All the mothers that I spoke with shared that they had experienced challenges in working with IEP teams, which ultimately led them to develop and use collaborative and advocacy strategies with IEP teams. Understanding these challenges and their views of collaboration serve as building blocks to understand parent advocacy efforts and family needs.

The challenges they shared fall in two distinct categories:

- Challenges associated with deafblindness: Although specific problems varied, all mothers indicated that there were significant IEP challenges related to deafblindness issues. The related challenges include the following:
 - Professionals' lack of understanding of deafblindness and misunderstanding unique student needs
 - In our field there is a lack of qualified professionals in deafblindness. When parents receive the diagnosis, they often network with other families and search for knowledge in any way they can.
 - This results in families often being the most knowledgeable about deafblindness on their IEP teams, and certainly about their own child.
 - Because of the IEP team's lack of knowledge, the mothers in this study felt responsible for sharing knowledge about deafblindness and individualized student needs, bringing in outside support, if necessary.
 - Sharing this knowledge was not always easy, especially if the parent felt like their input was not welcome or valued.

- “The hearing itinerant said ‘I’m just the hearing itinerant. I can just worry about taking that part,’ and the vision itinerant, ‘Well, I’m just the vision itinerant. I can only worry about the eyes.’ If they are going to be so adamant about keeping those two services separate, then at least those two (teachers) could get some kind of knowledge in how they kind of interact with each other.”
 - One mom said she understood that the lack of knowledge was not intentional and that “educators don’t know that they don’t know.”
 - Six mothers shared that IEP team expectations of their children were too low.
 - Parents had to fight hard for interveners to be added to the team, because there is a lack of staffing and a lack of knowledge of the benefits of interveners.
 - Mothers in the study experienced challenges with teams not understanding and valuing their family’s chosen communication mode. Similarly families of children who use AAC devices, experienced challenges in appropriate use of the devices.
 - Emotional Impacts
 - Families experience emotional impacts as they advocate. Some mothers in this study described their IEP experiences as mostly positive, while others shared how stressful these meetings are. There are also emotional impacts in processing the diagnosis, with grief not having a start and end. Many families have received multiple diagnoses or have a child who has progressive vision or hearing losses. There can be unintended family outcomes resulting from advocacy activities that may cause emotional impacts:
 - Choosing to move to another school district
 - One parent needing to stay home to be caregiver
 - The financial impact of these decisions
 - One mother stated that “it’s tiring, it’s exhausting. You are already dealing with so much, so for any parent, do what you can and know that the more you do, and learn, the better it is going to be.”
 - There is an immense pressure to be a conduit of information for the team and that can be frustrating at times.
 - One mom described how it can feel isolating at times because their child is the only one who is deafblind in their school and community. “I don’t know anyone here in my city. I’m still connected with families around the country, but there’s no one local, and so I think it’s worth some networking online...I think it’s very important to be able to talk with other parents who understand.” But because deafblindness is so rare and because it is heterogeneous, it can be difficult to find others who understand the unique challenges.
 - Large team of service providers

- For many families, the IEP teams are quite large, which can bring challenges in team members collaborating with one another, sometimes leading to services and supports feeling “siloed”.
 - With such large teams, IEP meetings can be very long, which can add to the exhaustion and stress on families. Most of the mothers in this study felt that once-a-year IEP meetings were not enough and they advocated for additional meetings.
 - Challenges with the IEP process itself
 - The mothers in this study also experienced challenges with the IEP process itself, similar to other special education parents. These challenges included:
 - IEP compliance and implementation
 - One mom who has a son with CHARGE syndrome, after bringing in a Deafblind consultant, realized that her son’s IEP had not changed in 5 years. When she asked the team about it, she was told that her son had not advanced enough to change the goals. She was seeing progress at home but her team wasn’t seeing the same progress and would not update the goals.
 - Lack of coordination of service providers led six mothers to experience IEP implementation issues, in that services were being done in a silo without coordination.
 - Almost all moms in this study mentioned frustration with unproductive IEP meetings.
 - Half of the mothers expressed issues such as lack of staffing (paraeducators and interveners mostly).
 - Difficult transitions
 - The mothers in this study reported having to spend more time advocating during times of transition, not just the transition from school to adult life. These families shared about the importance of ensuring all transitions were handled well (Birth to three to preschool, preschool to kindergarten, elementary to middle school, middle to high school, new school year, and introduction of new or substitute team members).
 - During these transitions, these moms said they felt responsible for ensuring that everyone understood deafblindness and their child. Some strategies for doing this included “About Me” presentations or “one-pagers” about their children.

Conclusion and Recommendations:

- Parents of children who are deafblind often experience unique challenges due to the heterogeneity and low incidenceness of deafblindness causing parents to feel like it is up to them to be the “deafblind” expert.
 - IEP teams should do all they can to help facilitate parents sharing their knowledge with IEP teams.

- It is appropriate to bring in state deafblind projects or others who have experience with deafblindness into IEP meetings.
- There is a lack of awareness of interveners and the importance of staff who are trained in deafblindness. We need more training/preparation programs and increased awareness of the benefits of staff who are trained in deafblindness.
- Being a parent of a child who is deafblind can feel isolating at times.
 - Parent to parent networking can be of benefit to families of children who are deafblind. Find ways to facilitate these connections.
- Ease difficult transitions
 - Finding ways to help ease transitions to new schools, school years, IEP team members may prevent challenges. Ideas include offering in-service training any time there is a new IEP team member, ensuring that more than just the core teaching staff is knowledgeable about deafblindness and a child's needs, leaving notes for any substitute teacher, nurse or other staff member. Good communication during transitions is also vital.