

ADVOCACY STRATEGIES UTILIZED BY PARENTS OF CHILDREN WHO ARE DEAFBLIND

FINDINGS FROM A RESEARCH STUDY OF PARENT EXPERIENCES

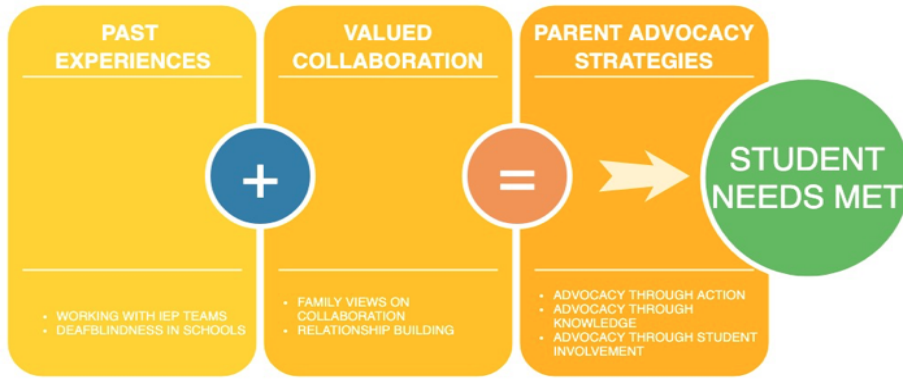
McKittrick, L. L. (2019). Strategies That Mothers of Children Who Are Deafblind Employ to Foster Collaboration within Individualized Education Program Teams. *ProQuest LLC*.

▶ THE REALITY FOR PARENTS

- IEP meetings can be stressful, especially during transitions
- The special education system can be overwhelming and confusing
- Parents may feel like there is a power imbalance
- Conflict can occur if families feel like their voices are not heard.

▶ DEAFBLIND SPECIFIC IEP EXPERIENCES - BASED UPON RESEARCH FINDINGS

- Lack of Professional Knowledge of deafblindness
- Parents taking on role of case manager and sharing knowledge
- Lack of knowledge of Interveners
- Need to bring in support – i.e. State DB Projects
- Professionals misunderstanding student needs
- Parents need to push for services
- Desire for appropriate goals
 - Not enough future focus
 - Lack of understanding of communication abilities
 - “your child does not have the communication skills necessary to [do what the other kids are doing]”
 - Underestimating abilities
 - “honors classes are not appropriate for children like yours”
- Professionals not valuing chosen communication mode
- Student unable to communicate needs directly
- Large team of service providers
- Lack of access to other families – need for networking
- Emotional impacts from diagnosis, etc.
- Impacts on entire family
- Transitions can be difficult (post-secondary but also each school year, new teacher, substitutes, and more) – a lot of transitions



► **IMPACTS ON ADVOCACY**

- Parent past experiences with IEP teams and sharing knowledge with schools PLUS parent/caregiver views on collaboration LEAD TO them to develop advocacy strategies:

► **PAST EXPERIENCES MATTER**

- Knowledge of deafblindness and needs
- May be only child in school/district who is deafblind
- Familiarity with IDEA and parent rights
- How have past IEP meetings gone - compliance, implementation
- Past conflict?

► **VALUED COLLABORATION - FAMILY VIEWS ON COLLABORATION**

- Collaboration benefits both families and professionals.
- We are “all in the business of education, together” (student, professionals, and families)
- There are student benefits to partnership – improved student outcomes
- Collaboration with parents but also between professionals
- Can reduce or prevent conflict

► **PARENT/CAREGIVER ADVOCACY STRATEGIES**

- Advocacy through taking action
- Advocacy through sharing knowledge about deafblindness and individual needs
- Advocacy by involving the students and helping them to be strong self-advocates

INDIRECT STRATEGIES	DIRECT STRATEGIES
Encouraging a team mindset	Pre-planning for the meeting
Using a firm but positive approach	IEP meeting management
Working to get team consensus	Goal setting
Encouraging flexibility and creative in team meetings	Ensuring needs are met, ensuring follow through from IEP team
Always thinking ahead	Conflict prevention - knowing options and not being afraid to use them
Having a problem-solving mentality	Involving the student
	Sharing knowledge with IEP teams (of deafblindness and individual)

