ADVOCACY STRATEGIES UTILIZED BY PARENTS OF CHILDREN WHO ARE DEAFBLIND

FINDINGS FROM A RESEARCH STUDY OF PARENT EXPERIENCES


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

► DEAFBLIND SPECIFIC IEP EXPERIENCES - BASED UPON RESEARCH FINDINGS
  o Lack of Professional Knowledge of deafblindness
  o Parents taking on role of case manager and sharing knowledge
  o Lack of knowledge of Interveners
  o Need to bring in support – i.e. State DB Projects
  o Professionals misunderstanding student needs
  o Parents need to push for services
  o 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”
  o Professionals not valuing chosen communication mode
  o Student unable to communicate needs directly
  o Large team of service providers
  o Lack of access to other families – need for networking
  o Emotional impacts from diagnosis, etc.
  o Impacts on entire family
  o Transitions can be difficult (post-secondary but also each school year, new teacher, substitutes, and more) – a lot of transitions
► IMPACTS ON ADVOCACY
  o 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
  o Knowledge of deafblindness and needs
  o May be only child in school/district who is deafblind
  o Familiarity with IDEA and parent rights
  o How have past IEP meetings gone - compliance, implementation
  o Past conflict?

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

► PARENT/CAREGIVER ADVOCACY STRATEGIES
  o Advocacy through taking action
  o Advocacy through sharing knowledge about deafblindness and individual needs
  o Advocacy by involving the students and helping them to be strong self-advocates

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