Importance of Collaboration in the Educational System:  
*Identifying Your Team Players*

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Presentation Objectives

1. Participants will be able to identify parent-initiated strategies for advocating for their children when working with their child’s IFSP and IEP teams.
2. Participants will gain an understanding of the challenges that students with Usher syndrome experience in the classroom because of the dual-sensory loss.
Qualitative Research Study

- Purpose: to explore the strategies that parents of children who are deafblind use in fostering a collaborative relationship with their children’s IEP teams.
- Fourteen mothers of children who are deafblind were interviewed (in 2019).
Research Questions

Q1 - What experiences lead parents to develop and use collaborative skills with their child’s IEP team?

Q2 - How do parents define collaboration with their IEP teams?

Q3 - What knowledge and strategies do parents use in IEP meetings to promote collaboration?
Study Results

- Vital roles that parents play: case management, advocacy, and knowledge sharing.
- Three categories emerged:
  
  (a) problems parents experience that lead them to develop advocacy strategies,
  
  (b) valued family-school collaboration, and
  
  (c) advocacy strategies used by families.
Problems Parents Experience

● Team lack of understanding of Deafblindness and unique student needs
  ○ lack of team expertise
  ○ not understanding and valuing different communication modes
  ○ heterogeneous
  ○ collaborating within a large team of service providers
  ○ difficult transitions

● Other
  ○ district level issues such as lack of resources
  ○ IEP issues related to compliance and implementation
Valued Family-School Collaboration

- Collaboration is vital.
- Problem-solving and knowledge sharing - dual sensory loss
- Knowledge sharing is reportedly tricky.
Advocacy Strategies

● Direct strategies
  ○ pre-planning for IEP meetings, IEP meeting management, goal setting, ensuring their child’s needs are met
● Leadership skills
  ○ being firm, flexibility, leadership, problem solving, team mindset, thinking ahead, consensus building, positive approach.
● Knowledge Sharing
● Student Involvement
“The disability is not the problem. The accessibility is the problem” - Mohamed Jemni
Birth - 3 yrs
- Received Early Intervention Services
  - TOD
  - Parent Infant Group Program at the Summit Speech School
- Private
  - Attended local ASL Program

Age 3-5 years (November birthday)
- Attended the Summit Speech School
  - Services
    - Teacher of the Deaf (TOD)
    - Speech
    - Physical Therapy (PT)
    - Commission for the Blind & Visually Impaired
      - Teacher of the Visually Impaired-Consultative
      - Orientation & Mobility-Consultative
      - Visually Impaired
        - Braille Instruction
      - Orientation & Mobility-Consultative

Age 5-10
- Mainstream (Old Bridge School District)
  - Itinerant Services
    - Teacher of the Deaf (TOD) (2-3 week)
    - Commission for the Blind & Visually Impaired
      - Teacher of the Visually Impaired (TVI)
        - Braille Instruction (2-3 week)
      - Orientation & Mobility - As needed
    - Physical Therapy (PT) (1 week)
- Private
  - Attended local ASL Program
  - Hippotherapy 2x/week at Special Strides

Age 10 to present
- Mainstream (Manchester Twp School District)
  - Honors Math, English & Spanish
  - TRANSITION PLAN
    - Training for full staff elementary, middle and peers
    - Itinerant Services
      - Teacher of the Deaf (TOD) -Consultative
      - Commission for the Blind & Visually Impaired Teacher of the Visually Impaired (TVI)
        - Braille Instruction (2-3 week)
      - Orientation & Mobility- As needed
      - Deaf-Blind VR Counselor
**Conner - Age 20**
- Early Intervention -
  - Listen and Talk School
    - Parent Toddler Group
    - Speech/TOD
  - Private OT
- Preschool
  - Listen and Talk School
    - Speech service
    - No vision or OT yet.
- Elementary
  - A mix of private and public
  - Private speech in early years
  - No Teacher of the Deaf
  - Added vision in late elementary
- Middle
  - Public
  - Added O&M, more vision
  - No point person
- High School
  - Back to private
  - Larger team

**Dalton - Age 11**
- Early Intervention and Preschool
  - Similar to Conner
- Elementary
  - Public, Private, then Public.
  - Large team now (TOD, TVI, O&M, audiologist)
    - Includes resource teacher for writing, OT.
  - Brought in State Deafblind project
  - Starting to talk transition sooner.
    - Self-advocacy, self-determination, student involvement
- Middle School
  - Public charter school next year
  - New team
Breaking Down Barriers

- Identifying expectations
- Setting the tone
- Use challenges as teachable moments
You Don’t Know What You Don’t Know

- Child
  - I’m fine!
- Parent
  - Local programs and services
- Professionals
  - Deaf-Blind specific resources and service providers
  - Understanding the unique needs of a child with Usher syndrome (Invisibility Disability)
Plan Ahead

● Build a portfolio
  ○ The “A”’s of Ava
  ○ Ava in a nutshell
● Create a transition plan
  ○ Welcoming incoming and outgoing team players
  ○ Old friends new friends
● Ride the wave
  ○ Who’s up
    ■ When to step back
We Got Your Back

- Bearing Good Fruit
- Educate and involve your child early
- Being on the offense not the defence
- Collect the Balloons
Resources

2017 National Webinar: Educational Considerations for Students with Usher Syndrome

https://nationaldb.org/library/page/2700

Connecting with your state Deaf-Blind Project:

https://nationaldb.org/members/list?type=State+Project

Meet Ava Bullis As She Transitions To a New School

https://nationaldb.org/pages/show/meet-ava-bullis-as-she-transitions-to-a-new-school

Lane’s Podcast/Blog Info

http://www.hearseehope.com/blog/research-and-insight-from-lane/


F2F Call for families of children with Usher syndrome

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