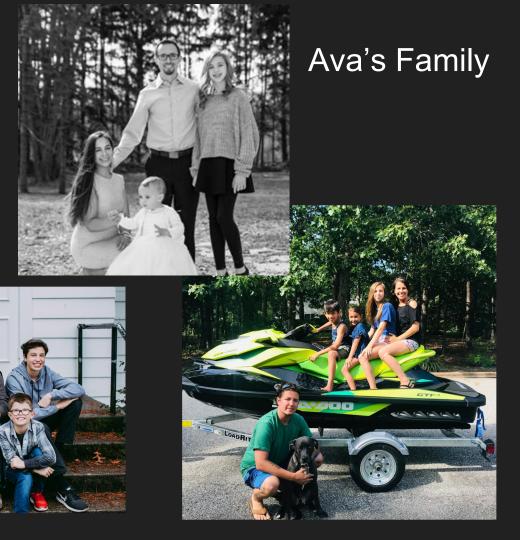
Importance of Collaboration in the Educational System: *Identifying Your Team Players*

Lanya McKittrick, Hear See Hope & Carly Fredricks, Ava's Voice





Dalton and Conner's Family



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

Data to Practice

"The disability is not the problem. The accessibility is the problem"
Mohamed Jemni

"The disability is not the problem. The accessibility is the problem"
Mohamed Jemni

Birth - 3yrs

- Received Early Intervention Services
 - o 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

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
 - o 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
 - o 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/

NFADB Podcast/Carly: https://podcasts.apple.com/us/podcast/03-avas-voice-ft-carly- fredericks/id1296816667?amp%3Bmt=2&i=1000399732180

Family-to-Family Communities Project (F2FC) Connecting Families of Individuals with Deaf-Blindness via Distance Technology

F2FC Registration is now open until August 10, 2019!



https://gsap.wufoo.com/forms/f2fc-registration-20192020/

Facilitators will contact participants in August; monthly calls Sept. 2019 to May 2020.

- . F2FC brings families together to connect, share information and resources, and offer support to one another in the journey of supporting their family member with deaf-blindness
- Each E2EC is comprised of 8-10 family members and is guided by trained Facilitators. . F2FC groups meet once per month for 90 minutes.
- via phone and/or video conference. Topics are chosen by the group and include structured.
- conversation and open sharing.
- · Your regular participation is vital to the group!





2019-2020 Family-to-Family Communities- adjust for time zones

Schedule may require minor changes. Topics listed are a sample

- . Self-Care Strategies for Parents: First Thursday of month at 8:30pm ET; topics-building your toolbox of self-care and wellness strategies as a caregiver; Facilitators- Heather Joy Magdelano, Donia Shirley, & Jennifer Hawkinson . Communication & Other Hot Topic: Second Sunday of month at 9:30 ET; topics-communication for your child,
- family, and educational team; open discussion about other relevant topics; Facilitators- Jackie Dalzell & Jenn Henkle Families with Members who have Peroxisomal Disorders: Third Monday of month at 8:30pm ET: topics
- communication, educational support, & life balance / self-care: Facilitators- Krista Olsen & Katie Sacra . Families with Members who have Usher syndrome: Wed. eve (time TBD); large group will meet for guest speakers
- and will be divided into smaller groups for conversation; Facilitators- Pam Aasen, Carly Fredericks, Lane McKittrick Families with Members who have CHARGE: Wed. eve at 8 or 9pm ET; topics- unique needs and services, building a
- network of support, family dynamics, planning for the future; Facilitators- Djenne Morris & Lori Beth Smith · Adoptive and Foster Family Supports: Day/time TBD (evening); topics- the first year, peer-to-peer relationships.
- innovative strategies, and communication vs. language; Facilitator- Courtney-Ke Williams
- Life Support: First Tuesday of month at 8pm ET: topics-empowering parents to advocate for their child & access resources and just talk about whatever is happening in your life: Facilitators- Ellen Bowman & Diane Foster
- . Adult Life (age 22+): Last Wednesday of month at 7pm ET; topics- adult service systems, employment, & housing; Facilitators- Jacqueline Izaguirre & Patti McGowan
- . Extended Family Members: Day/time TBD; topics-understanding the impact of having a child with deaf-blindness and other disabilities and how extended family can support their loved ones; Facilitator- Jana Villemen
- . 2 groups for Spanish-speaking Families: one focusing on support, the other on leadership; Facilitators- Silvia Verga, Alexandra Fiallos, Josefina Gonzales: registration for Spanish-speaking groups ONLY https://tinyurl.com/y5xed42v Questions??? Contact Carol Darrah, cdarrah@uga.edu / (706) 542-2433, or your state deaf-blind project

E2EC is a collaborative project enoughed by State Deaf-Blind Projects, NCDB, and NFADB.





F2F Call for families of children with Usher syndrome





One Community, One Mission, One Voice.

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