Self-Esteem and Self-Advocacy: Implications of Single-Sided Deafness

Cheryl DeConde Johnson, Ed.D.
The ADEvantage consulting
University of Arizona
Take Aways: Children with Unilateral HL/SSD

Advocacy

- Hearing loss is generally physically invisible but behaviorally insidious.

- Identity as a person is paramount to well-being; identity as a person with hearing loss with UHL/SSD is unclear but requires support and counseling.

- Every child is different but all are at risk for same problems as a child with bilateral HL.

- We cannot assume that these children are fully accessing their environment, communication, or learning – even with the best hearing technology.
  - Or that with access they understand and process what they hear.

- There are often a variety of interacting variables. However, the sensory impairment should be given precedence in the evaluation and investigation of a child’s behavior and learning abilities by qualified professionals.
Promote choice making

Support exploration of possibilities

Encourage problem solving

Develop and understand the process of goal setting and planning

Promote reasonable risk taking

Evaluate outcomes of choices and problem solving solutions

Promote self-advocacy

Help children understand their hearing loss

Promote the development of self-esteem
A Case Study: Kevin

Early History

- 12 year old male (now 13), has lived with grandparents since age 4, adopted at age 6 along with a younger sister, now referred to as mother and father
- Prenatal, birth, and developmental history mostly unknown except biological mother reported to have bipolar disorder and history of drug use
- Attended community preschool
- At school entry for kindergarten, no reported significant learning or medical issues
A Case Study: Kevin

- Educational History
  - Kindergarten
    - passed hearing screening
    - Teacher noted difficulties with “listening comprehension”
  - Summer:
    - Mother consulted pediatrician: Diagnosed ADHD and referred to ENT
    - ENT Audiologist: Diagnosis of SSD- Right Ear
A Case Study: Educational History

First grade

Fall: Mother refers Kevin for special education

Multidisciplinary Education Team (MET) assessments: Speech-Language, Audiology (ENT audiology evaluation), Occupational therapy

Findings:

- Audiology – Right sided deafness as per ENT audiology report, 100% speech discrimination
- Receptive Language – low average; Expressive Language moderate delay range; normal intellectual functioning, academics estimated to be in average range
- Social-Emotional – concerns related to hyperactivity, conduct problems, atypicality, withdrawal, attention problems; Functional Behavior Analysis indicated behavior was attention seeking
A Case Study: Educational History

First grade

- Eligibility- Primary: Other Health Impairment; Secondary: Speech & Language Impairment

- Neither district audiologist nor teacher of the deaf/hard of hearing is invited or present at eligibility or IEP meetings

- Mother tells IEP team that Kevin “is easily frustrated...can be bossy...lacks social skills...problems interacting with other children...tends to give up easily when learning something new...temper tantrums”

- SLP responds to mother saying “lots of kids that age are like Kevin”

IEP

- No recognition of hearing loss, no accommodations to address hearing loss
A Case Study: Educational History

- **Second Grade**
  - August- Surgery for bone anchored hearing instrument (Ponto)
  - March– processor activated
  - Fall IEP Annual Review – “hearing aid” discussed but **no audiologist or TOD involved; no adjustments to IEP based on hearing status**

- **Third Grade - No change; met standards on state tests**

- **Fourth Grade**
  - Beginning of school year: Three year eligibility evaluation
    - No additional testing completed
    - Staffed out of special education because goals met, declared “model student”
    - MET noted ADHD disability still present but does not require special designed instruction
  - Grades: mostly B’s & C’s but D in math (F - 4th qrtr)
  - State Tests: Minimally proficient (Math) to Partially Proficient (ELA)
A Case Study: Educational History

Fifth Grade
- Grades: Math - C (D Q3), Reading - C- (D Q2)
- State Tests: Partially Proficient

Sixth Grade
- Discipline issues: 3 reports in 1 month (inappropriate language, threw an object at a student) resulting in in-school suspension
- Mother requests special education evaluation noting decline in grades, behavior issues, and hearing concerns
  - MET does not include the educational audiologist or TOD but notes in audiology report that he has failed hearing screening annually
  - MET states on IEP that Kevin's current difficulties are not primarily the result of adverse impact of “deafness in the right ear”
  - MET determines additional assessments are needed to determine eligibility: general intelligence, academics, communication, social/emotional, and motor/sensory plus FBA to determine function of Kevin's argumentative behavior/noncompliance.
A Case Study: Educational History

- **MET Evaluation:**
  - School Psychologist:
    - WISC-V: overall average ability (working memory – low average)
    - Children's Depression Inventory, Autism Diagnostic Observation Schedule (ADOS), Behavior Assessment of Children -3 (BASC)
    - BASC-3 Finding: “clinically significant”, “emotional behavioral disorder probability”
    - Classroom observation (band) - teacher needs to “constantly remind Kevin to follow along” and has “issues with controlling his anger”
    - Functional Behavior Analysis – behavior is intended to get adult and peer attention
  - Achievement: below average and needs intervention and accommodations
  - Speech-Language: trouble making inferences
A Case Study: Educational History

- Special Education Eligibility Meeting
  - MET present results and determines eligibility again
  - Other Health Impaired (ADHD)
- Mother asks for evaluations related to audiology and hearing impairment and that eligibility include hearing impairment: **Denied**
- Mother asks for Independent Educational Evaluation (IEE) at school expense
  - District denies because they did not conduct audiology or speech/language evaluations that included receptive and expressive language)
  - District grants IEE for psychoeducational and OT evaluations
- Mother files a due process complaint
- IEP meeting is scheduled, mother notifies school she is bringing attorney; **district invites educational audiologist** to attend
A Case Study: Educational History

- IEP Meeting
  - Psychologist: Kevin struggles with controlling symptoms related to his diagnosis of ADHD…symptoms include difficulties with focus and attention…poor listening skills, and being in trouble for not paying attention…is extremely self-conscious about his hearing aid implant which also impacts his mood.

  Social-emotional functioning should be monitored very closely to prevent his functioning in this area from elevating to the point of being considered a disability. Accommodations and interventions should be considered as a preventative measure. Encourage Kevin to discuss his emotions and feelings to a trusted adult who can intervene and provide support. Teach Kevin appropriate ways to deal with and resolve conflict and to gain the attention he desires in a socially appropriate manner.

- Speech/Language Summary: Kevin has ability to understand and use appropriate social language…may need occasional guidance with interpreting situations and body language of others.
A Case Study: Educational History

- **IEP Meeting**
  - Audiologist Summary: Kevin has previously documented right single-sided deafness; he currently wears a PONTO bone anchored hearing aid on the right side. Recent audiological testing at XXX indicates he demonstrates excellent aided benefit in quiet situations.

- **Occupational Therapy Summary**: Kevin has overall typical sensory processing abilities; non-sensory concerns with social participation.

- **ADOS Evaluation Team Summary**: no evidence of characteristics consistent with Autism Spectrum Disorder

- **Needs:**
  - Kevin can increase his communication ability through the provision of assistive technology including a classroom or personal FM amplification device.

- **Not Needed:**
  - Special Considerations: Statement of the Language Needs, Opportunities for Direct Communication with Peers in the Child’s Language and Communication Mode
A Case Study: Educational History

IEP Goals Offered: Social Emotional

- Kevin will follow a verbal direction positively (without arguing, talking back, commenting or making noises) in 8 out of 10 opportunities as measured by teacher data tracking sheets.

- When given a task, Kevin will begin the task within 1 minute and remain on task for a minimum of 7 minutes with no more than 1 adult prompt in 8 out of 10 opportunities as measured by teacher made data tracking sheets.

- When Kevin becomes upset, frustrated, or angry, he will choose to use a self-regulation or coping strategy (i.e., deep breathing, asking for a break/use a break card, ask for help, request a fidget, etc) in 3 out of 5 trails as measured by teacher data tracking sheets.
A Case Study: Educational History

- Accommodations

<table>
<thead>
<tr>
<th>Accommodations</th>
<th>Type</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>Giving advance notice for changes in routine and schedule (privately if possible)</td>
<td>3</td>
<td>A</td>
</tr>
<tr>
<td>Use preferential seating to be near speaking individual away from any background noise (i.e. heating/cooling vents, doorway, etc.)</td>
<td>3</td>
<td>A</td>
</tr>
<tr>
<td>Written schedule and copy of school map</td>
<td>3</td>
<td>A</td>
</tr>
<tr>
<td>Provide an internet disabled tablet or ipad with word processing program and speech to text functionality</td>
<td>3</td>
<td>A</td>
</tr>
<tr>
<td>Allow provisions for physical movement (distribute materials, run errands, etc.)</td>
<td>3</td>
<td>A</td>
</tr>
<tr>
<td>Make certain the student understands the directions</td>
<td>3</td>
<td>A</td>
</tr>
<tr>
<td>Use manipulatives</td>
<td>3</td>
<td>A</td>
</tr>
<tr>
<td>Frequent immediate positive praise for task initiation and completion</td>
<td>3</td>
<td>A</td>
</tr>
<tr>
<td>Allow scribing or speech to text for writing assignments</td>
<td>3</td>
<td>A</td>
</tr>
<tr>
<td>Break down assignments into smaller parts giving interim due dates</td>
<td>3</td>
<td>A</td>
</tr>
<tr>
<td>Frequently monitor independent work</td>
<td>3</td>
<td>A</td>
</tr>
<tr>
<td>Provide close captioning for movies/videos/media when appropriate for curriculum</td>
<td>3</td>
<td>A</td>
</tr>
<tr>
<td>Shortened assignments for writing</td>
<td>3</td>
<td>A</td>
</tr>
<tr>
<td>Provide notes prior to instruction</td>
<td>3</td>
<td>A</td>
</tr>
</tbody>
</table>

Legend for Type and Location Fields

**Type:**
- 1 = Class work/assignments
- 2 = Assessments/tests
- 3 = Both class work/assignments/assessments

**Location:**
- A = All Subjects
- B = Language Arts/English
- C = Reading
- D = Spelling
- E = Math
- F = Science
- G = Social Studies
- H = Health
- I = Electives
- J = Physical Education
- K = Lunch
- L = Transition/Vocation
- M = Library
- N = Title 1
- O = Special/Exploratory
A Case Study: Educational History

- **IEP Services**
  - **Behavior Support** in the general education classroom to include disability awareness training and self-advocacy skills; provided by special education teacher
  - **Audiology** – annual audiogram may be provided by the district audiologist or parent’s private audiologist through private insurance
  - **Speech to Text training** - assistive technology to support initiation and writing activities; provided by para/teacher/staff
  - **FM training for student** - audiological support (FM system) while in the general education setting; provided by the audiologist, 1 hour/semester
  - **Supports for school personnel** - speech to text training and FM system training will incorporate universal application across the campus; provided by teacher/staff and audiologist

- **Behavior Intervention Plan**
A Case Study: Due Process Proceedings

What went wrong?

- Failure to rescreen hearing when kindergarten teacher expressed concern
  - District is required to ensure all children with disabilities are identified, located, and evaluated (Child Find, §300.111).

- Failure to conduct assessment according to IDEA requirements. (Denial of FAPE)
  - A full evaluation in all areas of suspected disability meaning a variety of assessment tools and strategies to gather relevant functional, developmental, and academic information about the child, including information provided by the parent (§300.304(a)(1)).

- Failure to recognize the possible implications of single-sided deafness.

- Failure to identify hearing impairment as a disability category.

- Failure to address the special factors (communication considerations for children who are deaf or hard of hearing) (§300.324(2)(iv)).

- Failure to offer a 504 Plan once staff out of special education even though the district stated that Kevin still had a disability of ADHD.
A Case Study: IEE Speech/Language Evaluation

- **CELF-5**
  - Significant difference in understanding language and ability to express himself
  - Significant difference between semantic knowledge and ability to apply memory to language tasks
  - Summary: Difficulty with the metalinguistic skills needed to interpret and utilize complex language; as a result, we would expect difficulties with both processing and production of language to have a significant negative impact on the performance of the complex academic tasks required of adolescents.

<table>
<thead>
<tr>
<th>Language Indexes</th>
<th>Standard Score*</th>
<th>Percentile Rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>Core Language</td>
<td>107</td>
<td>68</td>
</tr>
<tr>
<td>Receptive Language</td>
<td>105*</td>
<td>63</td>
</tr>
<tr>
<td>Expressive Language</td>
<td>89*</td>
<td>23</td>
</tr>
<tr>
<td>Language Content</td>
<td>116**</td>
<td>86</td>
</tr>
<tr>
<td>Language Memory</td>
<td>83**</td>
<td>13</td>
</tr>
</tbody>
</table>

Mean = 100, with standard deviation of +/-15

*Statistically significant difference
**Statistically significant difference
Test Effort

- Struggled to create sentences: frustration, banging his chin on the table and actually crying.

- Productions characterized by false starts, stopping, restarting, and very long pauses while he reformulated his sentences mentally; frequently made multiple self-corrections including after an item had passed.

- “In a classroom, if Kevin is rethinking things, the rest of the class is moving ahead, and he is likely to be frequently “lost” throughout his school day. Overall, Kevin’s scores may appear to be better than his actual functioning, as a great deal of effort and self-correction was noted, and in a rapidly-paced classroom, he does not have the luxury of time that the testing environment affords.”
A Case Study: IEE
Functional Listening Evaluation

Averaged Results: Common Phrases vs Nonsense Phrases

- **Common Phrases** (able to use linguistic knowledge to fill in the blanks)
  - Effect of Noise – quiet 99%, noise 96%
  - Effect of Distance – close 99%, distant 96%
  - Effect of Visual Input – auditory + visual 98%, auditory only 98%

- **Nonsense Phrases** (ability to understand words without topic knowledge)
  - Effect of Noise – quiet 74%, noise 51%
  - Effect of Distance – close 66%, distant 59%
  - Effect of Visual Input – auditory + visual 66%, auditory only 59%

<table>
<thead>
<tr>
<th>Speech Understanding Nonsense Phrases</th>
<th>Close/quiet</th>
<th>Close/noise Effect of noise</th>
<th>Distant/quiet Effect of distance</th>
<th>Distant/noise Effect of noise + distance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Auditory and visual</td>
<td>70%</td>
<td>65%</td>
<td>75%</td>
<td>50%</td>
</tr>
<tr>
<td>Auditory only</td>
<td>70%</td>
<td>60%</td>
<td>80%</td>
<td>30%</td>
</tr>
<tr>
<td>Effect of loss of visual input</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
A Case Study: IEE
Classroom Participation Questionnaire

- Desirable Ratings: 3.5-4.0, Negative Affect 1.0-2.0
- Available from www.adevantage.com

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Question Number</th>
<th>Questions</th>
<th>1 - Almost Never</th>
<th>2 - Seldom</th>
<th>3 - Often</th>
<th>4 - Almost Always</th>
<th>Mean of the Subtotal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understanding Teacher (4)</td>
<td>1</td>
<td>I understand my teacher.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>9</td>
<td>I understand my teacher when she gives me homework assignments.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>10</td>
<td>I understand my teacher when she answers other students’ questions.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>11</td>
<td>I understand my teacher when she tells me what to study for a test.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mean of the Subtotal</td>
<td>11 / 4 = 2.75</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Understanding Student (4)</td>
<td>2</td>
<td>I understand the other students in class.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>I join in class discussions.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>12</td>
<td>I understand other students during group discussions.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>13</td>
<td>I understand other students when they answer my teacher’s questions.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mean of the Subtotal</td>
<td>14 / 4 = 2.5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Positive Affect (4)</td>
<td>4</td>
<td>I feel good about how I communicate in class.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>8</td>
<td>I feel relaxed when I talk to my teacher.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>14</td>
<td>I feel happy in group discussions in class.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>15</td>
<td>I feel good in group discussions in class.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mean of the Subtotal</td>
<td>5 / 4 = 1.25</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Negative Affect (4)</td>
<td>5</td>
<td>I feel frustrated because it is difficult for me to communicate with other students.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>I get upset because other students cannot understand me.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>7</td>
<td>I get upset because my teacher cannot understand me.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>16</td>
<td>I feel unhappy in group discussions in class.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mean of the Subtotal</td>
<td>10 / 4 = 2.5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
A Case Study: Implications

- Identity as a person
- Identity as a person with hearing loss
- Without accommodations and support, Kevin’s behavior and school performance spiraled
- School never recognized hearing loss as a factor; focus on behavior misplaced the support for his challenges

“An unawareness of the effects that SSD can have on a child’s academic performance can lead to a reactive or “failure-based” approach towards intervention. By recognizing the significant effect of Kevin’s hearing loss, support and intervention efforts can be proactive and can lead to successful academic and social functioning”. (SLP)
Due Process Outcomes

- Mediation Settlement
  - Private school placement
  - Compensatory services

- Kevin in private school placement focusing on students with unique learning needs – 3 other students there with MMUSSD
Kevin’s comments:

- Comparing Classroom Listening
Kevin’s comments:

- Understanding Teachers
Kevin’s comments:

- Advice for Teachers
Reflections

- Identity and social-emotional development considerations are paramount

- Counseling at diagnosis and ongoing support
  - Prior to and in conjunction with amplification

- Peer opportunities for shared experiences and acceptance

- Risk Factor approach
  - Age of diagnosis
  - Age of intervention/ Intervention
  - Other birth or developmental issues
  - Family situation
  - Appropriateness of Assessment – comprehensive, qualified personnel
Educational Audiology Association:
Minimal, Mild, Unilateral HL, and Single-Singled Deafness (MMUSSD) www.edaud.org

- Introduction and Overview
- Educational Audiology Evaluation Recommendations
- Technology Considerations
- Accommodations and Intervention Considerations
- Research citations
Audiologists make the diagnosis; we have to get it right!!!