

Tawny Holmes

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Education Advocates: A New Frontier of Advocacy

By Tawny Holmes Hlibok

I never had anyone understand my feelings [or] what my deaf daughter had gone through ... I so appreciate your putting all your knowledge and energy into changing the school situation and finally giving her a bright future. With your support, now we don't have to put up with the school assigning her menial tasks like sorting mayonnaise and mustard packets for two and a half hours every day. ~ Parent of a 19-year-old deaf daughter

For parents and teachers, Individualized Education Program (IEP) meetings can be stressful. Worse, they can be ineffective—with parent, teacher, and student feeling that words were exchanged and passions ignited—without meaningful discussion, let alone effective development of or change in the student's educational program. One way to reduce the stress, expand the discussion, and perhaps improve the environment for a student is to bring to the meetings an Education Advocate, a person trained in federal law, familiar with IEP language and committed to working for the deaf or hard of hearing student. A trained Education Advocate can help teachers and parents understand important issues and support parents in understanding the IEP process.

As the need for such trained advocates became acute, the National Association of the Deaf (NAD), the civil rights organization of, by, and for deaf and hard of hearing individuals, stepped up and sent invitations to its state associations asking each to send a representative to be trained to the 2012 National Biennial Conference in Louisville, Ky. Twelve states sent individuals to this first training, and other states immediately joined the campaign. By 2018, all 50 states, plus D.C., Guam, and Puerto Rico, had joined, receiving an Education Advocate handbook with information about the role of the Education Advocate and the program itself.

Every NAD Education Advocate is deaf or hard of hearing, and most have a master's degree in deaf education and experience in teaching or working with deaf and hard of hearing students. They attend online trainings and at least one in-person training every year. Training sessions include everything from in-depth updates on

Photos courtesy of Tawny Holmes Hlibok



Left: Holmes Hlibok at one of her many education advocacy presentations with students, this one at the California School for the Deaf, Fremont.

Below: Felice Marcus, one of the Education Advocates in Florida, engages local deaf and hard of hearing children in a storytelling session at an education advocacy event.



relevant legislation—including provisions specific to deaf and hard of hearing children—to the role of deafblind intervenors, to ways to develop and apply negotiating skills. Education Advocates host events and workshops for families, advocate for legislative changes on the state or federal level, and meet with school administrators or government agency heads. In addition, they attend IEP meetings with parents and teachers.

In their role as IEP advocates, these trained individuals often sense the occurrence of imbalanced language dynamics and misunderstandings due to cultural issues. For example, at one IEP meeting, an Education Advocate met the student for whom she would advocate only a few minutes before the meeting began. As the meeting got underway, one of the student's teachers, who was a teacher of the deaf as well as a certified interpreter, announced she would function as both.

Immediately, the Education Advocate realized that she was in an ethically questionable situation. How could a student express herself freely about her experience in the classroom when she was dependent on her teacher for interpreting? When the meeting began, the ethical dilemma deepened. The student was asked to name her current goals, and the teacher/interpreter turned to the student and, instead of signing the words that had been spoken (i.e., "What is your current goal?"), asked a whole different question: "*You want to finish school and go work with your friend, Sheila*, right?*" The student, smiling perhaps at the mention of her friend, nodded tentatively. Appalled at the twist in the question, the Education Advocate interrupted. She asked politely if she could take over the questioning, and once this permission was granted, she turned to face the student. Her questions were designed

to be neutral, to allow the student to be able to give a clear sense of who she was and what she wanted. "*What do you want to do?*" she asked the student. "*Do you like school? Do you want to finish school, or do you want more school, which? Do you want to learn more or go to work?*" The student said she did not want to work yet; she wanted to stay in school and learn more. The Education Advocate followed up by asking her in which subjects she wanted support, and the student responded, "Both English and math." This was what the student's mother had shared earlier with the advocate, so the advocate ended her questioning and the meeting continued. The IEP team members were unsure how to proceed, and later



Left: Members of the Education Strategy Team discuss education advocacy strategies. Pictured: Donna Valverde-Hummel, Dr. Melissa Herzig, Kim Bianco-Majeri, Onudeah Nicolarakis, and Susanne Scott.

it was learned that the school's administrators felt they had run out of classes to offer the student and wanted to see her graduate and leave the school. With the family's permission, the Education Advocate noted that the family was considering other schools and the tension in the room visibly reduced. She reminded the IEP team that placement (e.g., in which school) should not be discussed until goals and services were decided based on the individual student's needs (Individuals with Disabilities Education Act, 2004). The meeting ended with the IEP focused on what was best for the student, and after an independent evaluation and some paperwork, the student transferred to another school. She is now in a postsecondary educational program in which she is doing well, learning more English and math to assist with her dream of eventually working at a jewelry shop.

In another situation, the IEP team was skeptical of a deaf student's request to sit at a distance from an electronic speaker in the classroom. Sitting so near to the speaker gave her headaches, the student said, a claim that her teacher flatly did not believe. In fact, the teacher had accused the student of faking headaches and established her seat

permanently next to the speaker. With the support of an Education Advocate, the parents brought her audiogram to the IEP meeting and showed that the student had some hearing, was sensitive to vibrations, and, therefore, her request to put some distance between herself and the speaker should be honored.

In still other cases, Education Advocates have stopped situations in which students were misdiagnosed due to professionals who could not communicate with the student whom they were supposed to evaluate. In these cases, expectations were often placed lower than they should have been, which not only diminished the school's ability to serve the student but also the student's ability to learn grade-level information due to lack of exposure.

Low expectations are the bane of deaf and hard of hearing students, as too often hearing educators consider being deaf or hard of hearing a reason to expect low academic performance. When an Education Advocate was contacted by a mother concerned that her son's school was combining Total Communication and oral programs into one program without adequate planning or resources, the Education Advocate agreed to attend the upcoming IEP meeting by videophone. She was

surprised to see the IEP team discussing third-grade goals for a student in eighth grade. She asked the IEP team why the student, who had been exposed to language since birth and who had no other disability except Attention Deficit Hyperactive Disorder, was so far behind. When no one on the team could answer, she explained to the student's parent as well as the other IEP team members that being deaf should not warrant lower academic expectations. She further provided national resources on how they could adjust their programs and receive professional development and training to more effectively accommodate students who were deaf or hard of hearing. A recent Supreme Court case affirmed that services should be calculated to provide progress appropriate to the child's circumstances; for students who are deaf or hard of hearing, this includes the student making a year's progress in a year's time (Endrew, 2017).

NAD Education Advocates have also been effective in supporting students in private schools. In one private arts program, a student received a sign language interpreter only two days a week. The mother, a recent immigrant who was still mastering English, sought the assistance of an NAD Education Advocate. The advocate came to the meeting, explained the effective communication requirements of the Americans with Disabilities Act, and provided new guidance from the U.S. Department of Education and the U.S. Department of Justice on the appropriate protocol for ensuring deaf and hard of hearing students had language access (U.S. Department of Justice Civil Rights Division, 2014; U.S. Department of Education and U.S. Department of Justice, 2014). Upon

learning about those requirements and guidance, the private school immediately approved the student's request much to the happiness of the student and her mother.

Families have appreciated the assistance of Education Advocates as these advocates often assist not only at IEP meetings but also help families benefit from the advocates' experience and cultural knowledge as members of the Deaf community. Parents have reported that they are thrilled to finally have someone that understands their children's situation.

Now Available: A New Tool for Parents

A wonderful new tool, the Parent Advocacy app, developed collaboratively by the Laurent Clerc National Deaf Education Center, NAD, the American Society for Deaf Children, and Hands & Voices, is now available both in Android and Apple versions. This free app includes videos, tips, resources, and checklists to prepare for school meetings, including IEP meetings, 504 plan meetings, and other related school meetings. Developed especially for parents of deaf and hard of hearing children, the app was released in May of this year.

Don't hesitate! Get ready to download

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Below: Hiwote Denu, one of the clients most impacted by NAD's direct IEP advocacy, and her family gave an award to Holmes Hlibok to thank her for making a difference.



the new app and seek an Education Advocate to provide you with information or support. For more information, including the qualifications of advocates and website contacts, visit www.nad.org/educationadvocates. Also check out the annual National Deaf Education Conference (www.deafeducation.us), during which Education Advocates, teachers, other professionals, and families receive training.

Note: Sheila is a pseudonym.*

References

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CONSIDERATIONS WHEN DEVELOPING AN IEP FOR A DEAF OR HARD OF HEARING CHILD

When developing a deaf or hard of hearing child's IEP, consider the child's:

- Language and communication needs
- Opportunities for direct communications with peers
- Access to professional personnel who meet the child's language communication, academic, and social-emotional needs
- Access to direct instruction in his or her language and communication model
- Need for assistive technology

Adapted from the Individuals with Disabilities Education Act, §300.324(a)(2)(i)-(v), at the Center for Parent Information and Resources.

References

Center for Parent Information and Resources. (n.d.). *Special factors in IEP development*. Author. Retrieved January 18, 2019, from <http://www.parentcenterhub.org/special-factors>

Individuals with Disabilities Education Act. (2004). §300.324(a)(2).

Tips for Education Advocacy

By Tawny Holmes Hlibok

- ✓ **Know what you and your child want and need.** Bring your notes and suggestions to the IEP meeting.
- ✓ **Check the state curriculum standards.** See if your child is on grade level or has age-appropriate expectations. For example, if your child is in third grade and has no additional disabilities, he or she should be learning third grade subject matter, and his or her IEP goals should be aligned with the Grade 3 standards in academic subjects.
- ✓ **Gather as much information as you can.** Talk to other parents, your child's teacher, and other service professionals who work with your child. Observe your child in the classroom after making arrangements in advance.
- ✓ **Be as calm and collected as possible.** If you are frustrated, seek an Education Advocate or other support—perhaps a counselor or other family member—to figure out the situation and what can be done to ensure the legal rights of the child.
- ✓ **Figure out a win-win situation.** As often as possible, look for ways the school itself can save money or benefit from your request. For example, if a school has difficulty finding an interpreter, offer school representatives assistance with networking or positioning advertisements or finding other students in the same category of grade or age who have similar interpreting needs.

