

LEARNING TO SELF-ADVOCATE:

Why Active, Early Parental Involvement is Key

By Steven J. Wright

Self-advocacy is not something that happens naturally. *Advocacy*, defined as “one who supports” (Merriam-Webster, n.d.), is an art form. Like many deaf or hard of hearing individuals, I learned the art of advocacy through a trial-by-fire process in which my parents and I struggled with the teachers and administrators of my public school. Together, we fought for and achieved programming that allowed me to experience more than we would have received had the educators and experts determined my programming alone.

I grew up in western New York, a hearing child born to hearing parents. I became deaf at age 4 from what my mother suspects was a high fever, though my audiological file lists the cause as an “unknown.” I was enrolled in an oral mainstream setting, learning and communicating with the use of residual hearing, FM systems, and hearing aids in keeping with the belief that deaf children should be able to produce measurably intelligible speech and recognize a measurable amount of spoken words; this would allow children like me to develop the skills to socially assimilate into hearing culture within postsecondary settings.

There are two problems with this approach:

1. Educators too often drive the educational ship, and parents are not empowered to make informed, educational choices.
2. Educators too often are immersed in a single educational ideology, often to the detriment of the deaf or hard of hearing child.

Photos courtesy of Steven J. Wright

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Right: Wright with his mother.



This combination can lead to the conundrum of missed opportunities, language deprivation, and inappropriate programming that puts an undue burden on the deaf or hard of hearing child. Further, it stifles deaf or hard of hearing students' development of a skill they will require throughout their lifetime: the skill of self-advocacy.

A Lesson from Life **Teaming up with Parents**

During the winter of fifth grade, my classmates—all hearing students in the school in which I, equipped with an FM system and speech therapy, was mainstreamed—began preparing for a spring concert in honor of St. Patrick's Day. As the concert took shape, a tangible excitement permeated the classroom during each rehearsal. I would watch as the other students performed. There were

various skits and songs and a rudimentary version of the Irish jig, but what fascinated me most was the limerick competition.

Although *limerick* is defined as “a structured five-line verse” (with aabba rhyme), we used the term in accordance with its earliest definition (i.e., poetry that originated in gatherings of partygoers in a certain region of Ireland (Oxford English Dictionary, www.oed.com). In the limerick competition, students practiced reciting a poem again and again, seeing who could repeat the words with the most speed and precision. What fascinated me was how the students would face off against each other, each exclaiming faster and faster, until a winner was announced. Lunch immediately preceded rehearsals, and as we gathered in the cafeteria students would “slam limericks” at each other

until they were out of breath. I so wanted to participate, but rehearsals were scheduled during chorus, and chorus was scheduled during my speech therapy. Finally, I went to my teachers to ask that the schedule be changed, but they were resolute. Speech therapy was required. More important, they pointed out, “There is no point in you attending chorus ... you cannot sing.” I was crestfallen. During the long bus ride back to my house, I fought back tears. When I arrived home, I ran inside, found my mother in the kitchen, buried my head against her chest, and sobbed. She got down on her knee, clasped my head between her hands, and asked, “What is wrong?” My father, hearing the commotion, appeared. Through tears, I explained what happened. My parents told me that if being in the spring concert was something I really wanted to do, we



Left: Wright as a young child.

when my turn on stage came, I caught sight of my parents among the audience beneath the blinding spotlight and the butterflies quickly abated. I went to the microphone and spat out what I had been practicing. I spoke rapidly, firing the words as if from a machine gun. I still remember what I said:

*Shake hands with your Uncle Mike,
me boy
And here is your sister, Kate
And there's the girl you used to swing
Down by the garden gate
Shake hands with all of the neighbors
And kiss the colleens all
You're as welcome as the flowers in
May
To dear old Donegal*

*Meet Branigan, Fannigan, Milligan,
Gilligan, Duffy, McCuffy, Malachy,
Mahone, Rafferty, Lafferty, Donnelly,
Connelly, Dooley, O'Hooley,
Muldowney, Malone, Madigan,
Cadigan, Lanihan, Flanihan, Fagan,
O'Hagan, O'Hoolihan, Flynn,
Shanihan, Manihan, Fogarty,
Hogarty, Kelly, O'Kelly, McGuinness,
McGuinn*

As I finished, the audience cheered. I did not win, but even today I remember the sense of accomplishment I felt. The meaning of participating in such an event with my peers was monumental—so monumental that I am able to detail it richly here nearly 30 years later. They say hindsight is 20/20 and in my adult years, I look back on this moment with the bittersweet sensation of pride.

I was proud to engage in an activity from which I would have been excluded had it not been for the joint advocacy of myself and my parents. Part of me admires the bravery I had at such a young age to defy school administrators and speak before an audience in an auditorium. Perhaps I did not perform perfectly, but the payoff was worth its weight in gold for confidence and the knowledge it gave me. After that, I felt

would make it happen.

This must not have been easy for my parents. They faced an educational system replete with confusing laws and a maelstrom of complex information to be parsed. Like so many parents, they tended to defer to educators and to acquiesce in what the school's experts told them was the best educational plan for their deaf son. Perhaps they also accepted the implicit message of the school and the surrounding culture—that the most important aspect of my education was learning speech and assimilating into hearing society.

The principal and speech teacher had not wanted me involved in the spring concert, but my parents insisted. The following week, we met with teachers and school administrators. Although I did not entirely understand the discussion, I felt the tension in the room, the friction between the adults. I also felt a sense of empowerment and solidarity. For the first time, somebody seemed concerned about what I wanted to do, not what the professionals thought. For the first time, I felt that

my needs were important, too. My parents and I were a team of three, and we were standing up against a slew of hearing educators who simply believed that people like me did not belong in school activities in which singing and dancing took place. My parents asserted that if a child wanted to sing, a child should be allowed to sing. The skill of the singing was not the issue. After all, it was unreasonable to expect that every hearing child in music or chorus classes would sing well. The issue was the opportunity to participate in the least restrictive environment to the extent allowed. Further, my parents wanted to know why spitting out words at rapid-fire pace could not be a natural part of my speech therapy.

In the face of our joint advocacy, school experts and bureaucrats backed down. I practiced the limerick slam with my speech therapist three times a week while attending chorus twice weekly. I sang badly, I'm quite positive, but nobody seemed to care. Spring rolled around, and it was time for the competition. I was a ball of nerves, but

that young deaf children could participate in whatever their hearts desire.

From Student to Professor Advocacy Remains Critical

Looking back, I see that this experience—my parents respecting me and coming to my defense, and the teachers, administrators, and deaf education specialists eventually supporting our decision—taught me the importance of advocating for what I knew was best for myself. It was a critical moment in my education. I learned the importance of advocacy, and I began to learn how to advocate. From that moment forward, my parents and I realized the importance of our involvement in my education. We came to consider our involvement especially important at meetings to discuss my IEP. The IEP can be a source of great benefit if and only if parents and their children are involved. After what we considered a victory, my parents encouraged my continual involvement in the IEP process, not just as a student, although that was important, but as a member of our family team.

Yet advocacy for me did not advance in a smoothly rising curve. Some decisions continued to occur without our input. For example, as a restless child, I longed to go outside every day for recess with my peers. I wanted to be in the sun. I wanted to exercise. I wanted to get my hands dirty. Instead, often I was pulled out of recess. I would be sent to speech therapy or another resource room meeting with an itinerant teacher. This led to unhappiness at home. I was lucky that my parents encouraged me to speak openly about what was working for me, what was not working for me, and what struggles I experienced at school. Since my parents encouraged me to engage in continuous dialogue with them, they were able to garner a more complete picture of what I needed and what I did not need.

In high school, I would engage in self-advocacy again, this time when I

convinced my parents that I did not need more speech therapy. Although they initially resisted—claiming that I was simply being a rebellious teenager—our discussions led to their realizing that I had passed the point where the rote work of repeated pronunciation was beneficial and, in fact, would conflict with other opportunities I wanted to pursue—like Advanced English Composition, Writing, and Literary Studies. Again, my parents and I made our position known, and speech therapy was removed from my IEP as a freshman in high school. This allowed me time to take classes that reflected my love of literature. As I progressed, my own desires were increasingly considered—both in conjugation with



Above: Today, Wright is a professor of Deaf Studies and Deaf Education.

my day-to-day programming and in alignment with my transition goals.

I ended up graduating with a Regents diploma, the college preparation degree for which New York is known and sometimes envied throughout the nation, with a concentration in English. In my case, succeeding in removing the supports that the experts initially recommended allowed me the necessary time to pursue the appropriate credits that led to a Regents diploma. It was

not until I matriculated at California State University, Northridge, however, that I was introduced to American Sign Language (ASL) and Deaf culture. From that day forward, I accepted myself as a Deaf person. Once I finally embraced who I was truly meant to be, I fell in love with my community, the language, and the shared experiences of other Deaf people—and I incorporated this love into my own sense of self. While I maintained my love of English literature, I adopted ASL as my language of preference. As an undergraduate, I learned to believe that a deaf or hard of hearing child can have the best of both worlds. Spoken English, speech therapy, and the ideals of the days of my childhood have a place, but they are only part of a successful approach, and one size does not fit all deaf children. In hindsight, I wish that a bilingual environment, in which deaf and hard of hearing children had access to ASL and English, had been available to my parents when I was enrolled in school.

Today, I have a bachelor's degree in English literature, a master's degree in organizational development, and a doctoral degree in critical studies. I am a professor of Deaf Studies and Deaf Education at Lamar University, where I teach research design, statistics, and methodology on the doctorate level and law and advocacy and ASL literature on the undergraduate level, a dual focus that fuels the passions I developed as I navigated public school while a child. I tell my deaf and hard of hearing students—young undergraduates who are coming into their own just as I did all those years go—that “being your own staunch advocate is the key to success.” I encourage them to recognize that neither teachers nor parents are always correct about what is right for the child in their classroom. Parents need to have meaningful dialogue with their children, and teachers need to engage in meaningful dialogue with parents. The risk parents take when accepting without question the advice of school personnel is that they may rob

their deaf or hard of hearing children of other ever-present opportunities. Especially in high school, discovering and putting together the best educational experience should be done together—with family, the child, and school personnel.

Every deaf and hard of hearing child deserves to be protected, allowed to participate in events with their peers and able to make their needs known. They rely on us—parents, caretakers, and educators—to be their advocates. As children navigate the K-12 years, watching and assisting in IEP meetings and other discussions, experiencing their parents' advocacy, they are empowered to become their own advocates. The young adults who are my deaf and hard of hearing students will go on to become advocates, counselors, IEP team leaders, and teachers of deaf and hard of hearing students all over the United States. Most have already found that the

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world too often discriminates against deaf and hard of hearing individuals, inhibiting access to education, employment, and recreation, and that the art of self-advocacy remains critical even as they move through their adult years and their professional lives.

Self-advocacy is an art. It requires diligent, unwavering knowledge of law and policy and the tempering finesse of soft skills in social graces. If they are fortunate, the first place children begin to learn this art is in school—and their first teachers are their parents.

Reference

Merriam-Webster. (n.d.). *Advocacy*. Retrieved from <https://www.merriamwebster.com/dictionary/advocacy>

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Through partnerships with their host institutions, the Gallaudet University Regional Centers (GURCs) share Gallaudet's undergraduate and graduate programs and the Laurent Clerc National Deaf Education Center's resources and expertise through training programs, workshops and conferences, youth programs, technical assistance, and consultation.

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Assistance for Child Advocates: A Few Clicks Away

By Steven J. Wright

Research indicates that deaf and hard of hearing children are not present for their IEP meetings (Calderon, 2000; Luft, 2014), a troubling finding that confirms my own professional experience. Too often, I find that parents view the IEP solely as a way for determining the academics of their deaf or hard of hearing children. Yet the IEP affects life in the home as well as in school. If a child is organically integrated within a mainstream program, it has a dramatic effect on life at home and on the child's social and emotional development.

Younger students may have a difficult time articulating their needs; however, this does not mean that they cannot express desires, dislikes, and dreams. Parents can help their children simply by supporting them. They can buttress their children's expression and perhaps help them overcome shyness while serving as a communication intermediary to members of a professional IEP team.

Parent attendance and advocacy are critical to the child's well-being. Becoming an advocate for deaf and hard of hearing children may seem daunting to you as parents, but you are not alone. Advocacy is a skill that is supported by a wealth of online resources. Information necessary for advocating has never been easier to find. In this digital age, it may be just a few clicks away.

Here are places to start:

- **National Association of the Deaf** (www.nad.org)—NAD has a website that spells out key components necessary for advocacy, including the laws that relate to specific accommodations in educational settings for deaf and hard of hearing children. The website explains and offers guidance on the use of Section 504 of the Rehabilitation Act, which concerns employment rights, and the Individuals with Disabilities Education Act, which concerns educational rights, including how to establish an IEP team for your child. Further, NAD trains Education Advocates who can assist parents and families.
- **Laurent Clerc National Deaf Education Center** (<http://clerccenter.gallaudet.edu>)—The Clerc Center, located on the campus of Gallaudet University, offers valuable information and resources on its website. For example, *Odyssey*, in which this very article is printed, is published annually and offered free online as well as in print. Further, valuable resources for parents can be found under the New to Deaf Education tab, which offers resources on literacy strategies, early intervention resources, and includes a helpful guide on classroom interpreters for students in mainstream settings. Parents and paraprofessionals may also want to check out the 2019 Education and Advocacy Summit: Deaf Education that was held in February.
- **Lamar University** (www.lamar.edu)—Lamar offers a bachelor's degree through an advocacy track in education with some online options. Students from all backgrounds are welcome to take or audit courses. Parents, educators, and paraprofessionals are encouraged to explore programs and contact faculty or instructors for resources in their specialized areas.
- **Online collaboration** (www.redefiningacademiccollaboration.com)—Lamar University, Gallaudet University, Western Oregon University, and Towson University have developed a free website for parents, professionals, and paraprofessionals that explores a range of topics concerning individuals who are deaf, deafblind, or hard of hearing.

References

Calderon, R. (2000). Parental involvement in deaf children's education programs as a predictor of child's language, early reading, and social-emotional development. *Journal of Deaf Studies and Deaf Education*, 5(2), 140-155.

Luft, P. (2014). A national survey of transition services for deaf and hard of hearing students. *Career Development and Transition for Exceptional Individuals*, 37(3), 177-192.