ALTERNATIVELY AS SPEAKING
VOL. 4, NO. 2

Notes … on Education

This issue of *Alternatively Speaking* is about education. I am not going to tell you that I am shining a spotlight on education. As any adult who ever supported a child with a severe communication disability through the educational system knows, shining a spotlight on such a vast area would be like pointing a flashlight into the heavens.

As an alternative, this issue focuses on a few specific areas of education. The last issue of *AS* featured guest authors Gus Estrella,[1] Rick Hohn[2] and Mick Joyce[3] talking about work. Their words were from a panel discussion about work and education which they had presented at a United States Society for Augmentative and Alternative Communication (USSAAC) meeting.[4] I thought it was important that I share with you what they had to say about work, and now I want to share a few things they had to say about education. These are three opinionated men who had a rough time getting an education and are hoping others can learn from their experiences.

Mick - On Reading

Reading in schools is often delayed until professionals think kids are ready to read. I give an "F" to parents who assume teaching a child to read is the school's responsibility. I give an "F" to teachers in schools whose students with disabilities are not reading. I give an "F" to therapists who think their sole job is to teach communication. A therapist's job in the schools is to educate themselves, teachers and parents to know that any child is capable of learning and to encourage them to get on with it. No assumptions regarding the intelligence of the child should be made no matter what reports from the past imply. Everyone must make the assumption that the child is capable of learning. The job of the parents and professionals is to tap into how the student learns and what equipment is needed—the younger, the better.

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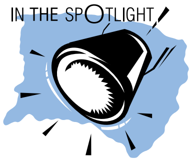


Children must be prepared for life. They must not only be able to communicate, but also be able to read and write. Students must become readers and writers and hopefully learn to communicate verbally with assistive technology.

All children should be given the opportunity to respond when being read to or taught. That's a given. Insist that those who work with one- through five-year-old children with disabilities hold them and read to them and allow them to respond. I would recommend a portion of many therapy sessions and almost every school day, as well as every bedtime ritual, include this. Reading readiness activities

Message from the author

I was the first severely disabled person to attend John Muir High School in Pasadena, California. I didn’t get in without a fight. My mother and I spent a good part of that August trying to find out whether I would be allowed to walk John Muir’s hallowed halls.

The decision came right down to the wire. A week before the start of school, my family and I met with the principal and the school nurse. They looked me up and down real good, and then the principal asked: “Michael, do you REALLY want to go to this school?” The air was tense; we were locked on to each other’s eyes. “Yes, Sir,“ I said in my firmest, clearest voice. To make myself perfectly understood, I nodded my head up and down.

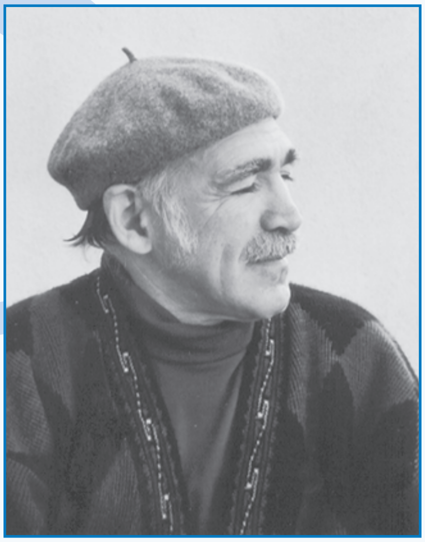
Principal and nurse stepped outside for a conference. My parents and I sat, saying nothing, for what seemed hours. My palms were sweating, and I kept trying to dry them on my knees. I looked down at the floor and shuffled my feet, the ones with the big, ugly orthopedic shoes.

The door opened. The principal walked up to me. "We have reached our decision," he said, towering above me. I looked up at the face above me; the lips started to move, sealing my fate.

"We’ve decided to give you a month’s trial, Michael." Quick looks went back and forth between me and my parents. We weren’t expecting this. Not a yes, not a no, but a compromise.

I passed my trial period with ease. During my first semester, the nurse came up to me and apologized for doubting I could cut the mustard in the real world. In my final semester, I was given a special award for my “significant contribution to the understanding of others.”

All that was long ago. Things are different now, aren’t they?



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Notes ...

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are the responsibility of all the literate supporters of a student. Adults play a critical role in their actions and in their encouragement.

I have three general things to suggest.

- Be creative.
- Run the extra mile.
- Be positive.

And, of course, a good night’s sleep would help.

My last hint is to get acquainted with a child's sounds, grunts and groans. I know of no kid that doesn’t croon to the tune of a fudgesicle.

Rick - On writing

I remember well how left out I felt when my class had a writing assignment. Holding a pencil in my hand was impossible! I would try to hold a pencil, but it went through my fingers like it was water. That is, if I did not throw it across the room from an involuntary movement first!

While my friends wrote an essay, I looked out of the window, and withdrew into my own little world. My teacher misinterpreted my boredom and classified me as mentally retarded.

Things today are much different providing that students take advantage of assistive technology at an early age.

Assistive technology can help with writing in school. Students

... On Education

can use their AAC devices like a word processor to save and print their homework with command buttons. Some AAC devices can be connected to a printer so that a child can print his or her assignment of any length.

Even more impressive is the ability for students to link their AAC devices to a computer through infrared output. They can write or do homework on the computer at any time because no wires have to be connected.

What is spectacular about infrared is that instead of using a conventional computer keyboard, a student can write from the AAC device using the selection method that he or she prefers.

Instead of getting bored and feeling withdrawn, kids can now fully participate in school writing experiences.

Rick - One perspective

Two years ago, when I was teaching an art class for adults with disabilities, one of my pet peeves was seeing someone frustrated by using a picture symbol communication board. They wanted to say so much more than the symbols they had access to and were severely limited. I saw in the person's eyes that he or she was smart, but was somehow given up on somewhere in school.

I can not be sure, but I am willing to wager a bet, that the person was given symbols to communicate with because it was the easiest and the quickest at the time.

I am a strong proponent of word prediction as a primary source of communication, complemented by symbols. To ensure literacy and prepare students for the real world and to maximize their potential, I believe that parents and educators should try everything to encourage children to communicate by typing words out using word prediction. Picture symbols were not around when I went to school, and I am so glad! They might have been easier at the time, but they would have ruined me. I know that I would have taken the easy way out.

As it was, I had a very difficult time learning how to read and write. It was not until I was fifteen years of age, when I typed on the typewriter, that I discovered how words were actually formed, and then I learned how to read and write. I learned from making words.

Looking back on it, the learning process would have been enhanced if word prediction was available so I could see a choice of words to choose from. This would have helped my reading, spelling and writing.

A person graduating from high school and communicating well using an augmentative device stands an excellent chance of leading a full and productive life.

Mick- On Portability

Portability: What a virtue, especially to those with mobility problems. To kids using augmentative and alternative communication, and kids in general, the most important communication occurs, not in the classroom, but in the hallways, the playgrounds and the johns of public schools.

Being aware of this is critical! How many of us asked for a date in language arts class? How many asked for clarification on that math assignment in front of the class? Where was the first time you learned how to wiggle that willy silly ? It wasn't in Miss Mary Tyler Moore's Suds class.

Most effective talking just does not happen in the classroom. If it did, teachers would have control over it. That's the last thing students want, even at a young age. No doubt, some helpful talking occurs in the classroom, but it is in unstructured settings that a child really learns to communicate.

Additionally, the ability to take the communication system home and preprogram planned questions and answers is a must. This is a great habit to get into. If nothing else, The student can gross out his buddies by having the latest version of the power rangers loaded on the hard drive.

For all these reasons, a child's communication device must be a go-everywhere tool.

Mick - School friends

Learning experiences in preadolescence that I enjoyed were few and far between. Of course, I didn't go to school with Barney and his friends so what I say may not be in tune with today's trends. I went to school in the days of crippled kids, segregation and pickled poster children. What I enjoyed was certainly not in the classroom. The quicker we got out of there, the better.

Not too long ago, I watched this movie on HBO called *Stand by Me*. Its conclusion was that eleven- and twelve-year olds have the best friendships. I would have to agree with that completely. It was before the battle over women, before the sports fights and biting off peoples ears to get on the team. As I remember it was me, another guy with CP and the diaper kid. The diaper kid, who was a bit smelly, we called Sandman. Me and Sandman and this other CP ruled the world, for a few months anyway. What we learned wasn't taught in classrooms. We learned compassion, forgiveness and acceptance.

And then along came Mary, my girl, at twelve. Mary had a radio button inside her vocal chords. She could walk and push me into the brush where we'd neck and cry and neck some more. Mary taught me all about the female anatomy. I am not telling what I taught her—most likely nothing she didn't already know.

Those friendships were some of my best school learning experiences.

Mick-becoming a worker

It's very important for students who use AAC devices, as with all students, to get all the work experience they can while they are in school. That goes for both good and bad experiences. Good experiences tell you what you like to do. Bad experiences tell you what you don't like to do.

It's important to start to think about work early in life, no matter how impaired the student, no matter how small the task. Get it in the kid's head that work is a way of life. My work as a small child was learning to read and write. Thanks to my mom and three big sisters, I was reading and writing by the age of five. Not Moby Dick, but some kids' books.

By the way, don't make work for your kids. May I repeat, DON'T MAKE WORK. The kid knows that before you can bat an eye. It has to be a task, part of one, anyway, that needs to be done. Reward work with pay, something that the kid likes. Let's see, what were some of my rewards? In my early years, maybe candy. In later years, it was the latest 45 record or Beatles' music collection.

In our family all anyone ever did was work. Play was a grave sin. A little different mode of thought these days. I got my first real job while still in college. I was the editor of a small newsletter for students with disabilities. I got a whole five bucks an hour, good in those days. In the summer I did other things. One year I worked for a congressman, writing little things. Another year I worked for a professor, collecting poems on old age. He talked on aging and had to have a poem to quote. Later, we made a book and hoped to have it printed. No dice.

In my last year of college, I wrote a grant that funded my position for a year. It was a blessing to go to a college that actively sought out jobs for students with disabilities. I got to know the placement director and he had me over to his house a few times. You've always got to update and nourish those contacts. To this day I always work on that. Some said no to this free service. I said yes.

Again, let me remind you, it is very important to get work experience while in school. Today, we have many more school-to-work programs. Work with them. Be creative. Get involved and be positive. And don't forget, adults are one big, beaming, shining example for students.

Silence is Not Golden

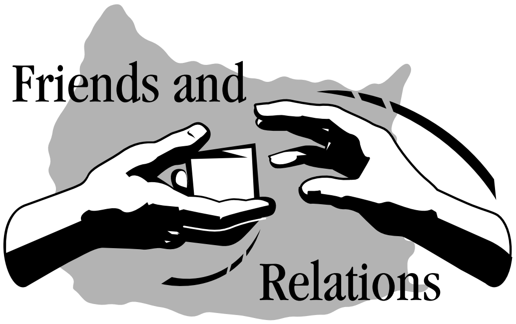
Editor's note: Some of us older augmented communicators who were raised to be silent are finding it a bit awkward to have a voice and to be expected to know how to use it. Mastering the technology is not difficult; it's learning to want to talk after so many years of silence, learning the subtleties of social conversation, and, most of all, finding the long-buried urge to communicate.

This part of Rick Hohn's USSAAC talk explains how a relationship changed after he had access to speech.

By Rick Hohn

Visiting my friend Vicki today and holding a normal conversation with her is completely different than when we were kids. We grew up together, but whenever she came over to my house, we would watch TV in the den while our parents who were best friends visited with each other in the living room. While in the den watching TV, we never talked. Besides feeling awkward around me, Vicki did not know how to communicate with me. So we both kept as silent as possible.

But now, thanks to my AAC device, we talk and make up for lost time! We think about seeing each other as children and compare it to the twilight zone. It was as different from now as day and night.



Assistive technology, especially with voice output, plays a vital role in making and maintaining friends, both in school and out. People depend on hearing each other, and, when someone can not speak, a huge chunk of social interaction is taken away.

Vicki was one of a few able-bodied friends that I had when I was a kid. My friends in the neighborhood were receptive to me because we saw and played with each other everyday, but I found it extremely difficult to be around classmates who had similar disabilities as I. Contrary to some people's belief that we could relate to each other because we shared the same struggles, it was impossible for us to communicate, since none of us could draw out what anyone else was trying to say. So we sat, bored, looking at each other, trying not to be too obvious. We were bored stiff—Is it any wonder that some of us are so spastic?

Children today who have problems with their speech have a much better chance to participate and interact if assistive technology is made available from preschool age. It's never too early to start making friends through technology.

More than a Mentor

By Gus Estrella

Editor's note: Before Gus Estrella worked in Washington D.C., he had a job as a mentor for a student in a public school in New Mexico. The critical role Gus played in making this inclusion experience work seems to be more than a mentor. Whatever the job title, I wish every student had someone like Gus. Readers may want to share this article with teachers and instructional assistants who provide supports.

As a mentor, I would go with a student who used an AAC device into the regular classroom and participate in the classroom discussions, setting an example for the student, the class and the teacher. My going into the classroom with the student had a dual purpose. One was to make the student with the AAC device feel like he was a part of the class and not just the token student with a disability. The second purpose was to show the other students in the class how a person with a disability could function in the classroom just like they were.

I would try to figure out ways for the student to participate in the classroom activities. For example, I would find out from the teacher what the class would be doing the next day so we could program some responses to questions and put in some comments pertaining to the story the class was reading that day. This didn't mean that the student was limited to what we had programmed in his device. He could always formulate a comment that popped into his head during the discussion.

To assure that my student would have an equal chance to participate in the classroom discussion, I would communicate with the teacher and make sure the teacher was aware of him and the possibility of him trying to get her attention.

Also, I would make sure that the teacher understood that a person using an AAC device, despite being somewhat proficient with the device, was still going to take time to formulate whatever he wants to say. I would try to help the teacher realize that it is going to take time for the student with the AAC device to respond and make comments during the discussion periods.

My ultimate goal was for the teacher to take the initiative and include this student in the classroom activities. Feeling included would encourage the student to use his device and participate in the classroom discussion. At the same time, conversations might develop among him and his classmates.

Going Out on a Limb

I was seventeen years old when I took my seat in John Limb's high school English class. It was Mr. Limb's last year of teaching; it was my first year of regular high school. We were both scared as hell.

Mr. Limb had been teaching at various schools since 1911. I had spent my entire academic career in the sleepy backwaters of special education. When our paths crossed in the fall of '55, it was a time of momentous change for both of us.

Limb was one of those guys who had chalk dust in their veins. Latin was not a dead language for him, it lived on his tongue tip ready to spring into action at a moment's notice in the service of praise or damnation. He was also a poetry nut. My fellow classmates and I suspected that he had every poem ever written committed to memory. Frequently—too frequently for the class—something would spin inside his head, and Limb would select a poem at random which he would recite in a loud sentorian voice, standing ramrod straight in front of the class, while beating out the rhythm of

the poem with a pencil. It made for quite an effect. Unfortunately, this recitation often produced a low level background noise of moans, groans and snickers from my fellow students.

My dad dropped me at school half an hour before the start of class. Since English was my first period, this gave me an opportunity to get to know Mr. Limb as few of my fellow students would. He would come in the classroom precisely at twenty minutes before the hour, briefly nod a greeting to me and start writing that day's assignment on the board. When that was done, he would turn his attention to the lone piece of paper sitting on his desk, a piece of flotsam on a vast sea of brown. This was my completed assignment for the day. He would eye it with great suspicion and leap upon it like a mighty vulture on a bit of carrion. He would reach for his weapon and make my paper bleed red with comments. When I was thoroughly terrified, Mr. Limb often would drag a desk next to mine and explain the error of my ways in a soft, calm voice that I found comforting.

As ready academically as I was to attend regular high school, I was in no way prepared to cope with the social rigors I found there. I was shocked by the behavior of my fellow students. I had never seen anyone treat a teacher with anything other than the utmost respect (except in movies, of course, but that didn't count). Most of my classmates seemed hell-bent upon doing almost anything except school work. The beauty of poetry was way down the list of things to think about while in English class. Cars, fashions and what to do on Friday night were more important considerations to the typical teenage mind, outrunning Truth and Beauty by a mile. Oh, there were the people who enjoyed studying, all right, but they were called “grinds” and were immediately written off as not worthy of association.

Then there was me, a stumbling, drooling spastic who communicated by crudely printing things out on small bits of paper. I didn't drive a car, I had no concept of what was fashionable, and I certainly wasn't going anywhere on Friday night unless I was with my parents.

I didn't like my first taste of adolescent culture, but as the semester rolled on in English, and my other classes, I realized this was pretty much the norm in the real world. There weren't going to be any perfect students learning from a perfect teacher in a perfect classroom setting. From that point on, my educational path would be rife with the conflict between academia and teen culture. Much of my education would consist of learning how to handle this conflict. There is much more to education than sitting in class, writing papers and taking exams; one must develop a rapport with ones peers no matter how awkward or uncomfortable. That is why it is so important for people with disabilities to be included in a regular classroom setting. Consider it "on the job training" for the rest of your life.

An Internet Connection

I am excited about a cool new idea for young people who have access to the Internet.

ContAACt [5] is the first listserv designed for kids [6] who use AAC.

A listserv is a group of people who all care about the same thing. By writing to the listserv, your message will go to everyone who belongs to it. It's like having a lot of pen pals, but you only have to write the letter once!

To join ContAACt, all you need is a computer and an email address. [7]

To write to all the members, just send one message to contaact@nmsu.edu

Each month ContAACt will try to find interesting adults who use AAC to write to the listserv. Ask them anything about life and their jobs!

Send me a fax or e-mail and tell me who you would like to talk to.

Who would you like to talk to?

You can write to me: Michael Williams, augmentative Communication,Inc. One Surf Way, Suite 237, Monterey, California 93940.

You can send me a fax at 831-646-5428.

You can send me electronic mail at mbwill@well.com

Sources & Resources

1. Gus Estrella. United Cerebral Palsy Associations, 1660 L Street, N.W., Suite 700, Washington, D.C. 20036. phone: 800-872-5827
fax: 202-776-0414
email: funspastic@ucpa.org

2. Rick Hohn. 1125 Cottontail Road, Vista, CA 92083.
phone: 760-598-8336.
rickstalk@juno.com

3. Mick Joyce. 4 North Allen St., Madison, WI 53705.
phone/fax: 608-238-9549
mjoyce@facstaff.wisc.edu

4. USSAAC, the United States Society for Augmentative and Alternative Communication, is the United States chapter of ISAAC, the International Society for Augmentative and Alternative Communication. www@isaac-online.org

5. ContAACt was created by Dr. Sheela Stuart and Julie A. Webb.

6. Teachers and parents are always welcome.

7. Follow these directions to sign up to be part of the ContAACt listserv:
   - Send an e-mail to listproc@nmsu.edu
   - Leave the subject blank
   - In the message type: subscribe contaact yourfirstname yourlastname (For example: subscribe contaact julie webb)
   - Send your message (You will immediately receive a message letting you know that you have been listed.)