

The Monster in the Closet



In this issue we turn the searching rays of our spotlight on the monster in the closet, the boogie man under the bed, the six thousand pound gorilla sitting there right next to your elbow. Name your grimmest specter, it will be a metaphor for what we are talking about in this issue: employment for people who use augmentative and alternative communication.

Next to sex, employment is the least talked about subject in the field of AAC. Up until this year the International Society for Augmentative and Alternative Communication (ISAAC) had no keyword for employment in its research index. I had never heard the subject of employment for users of AAC discussed in a group in more than just an off hand way until the Pittsburgh Employment Conference raised the banner two years ago.

Why Is It in the Closet?

What's going on here? Why is everyone so reluctant to discuss this subject? Is this field so nascent and our information so scant that we don't know what we've doing, or, do we, deep down in our guts believe that most people who use AAC simply aren't candidates for good jobs? Is this the secret we are

afraid will surface if we talk about employment? And how about ourselves—the people who use AAC—do we *want* to work, and do we believe we *can* work?

The Importance of Work

What do I mean by work? I define work quite broadly and include things done on a volunteer basis as well as any paid position.

Employment is a subcategory of work which implies a contractual arrangement between you and an employer. You do x amount of work for y amount of dollars or in exchange for something else you value.

Everybody has an opinion about their job. Some people love their work, other people hate theirs, still others couldn't care less what they do, just so long as they bring home a paycheck. There's no doubt about it, working is an important part of a person's everyday life. Work brings stimulation to the mind as well as satisfaction to the soul in knowing you've done your best for your employer.

Work brings other benefits, too, not the least of which is the opportunity for interaction and socialization among one's co-workers. Having a job may mean you can determine where you live, what you eat, and how you spend your time when at play, how you feel about yourself and how your neighbors and your community see you as a person. In short, having a job may give you more control over what you do with your life.

The Grim Statistics

The employment statistics for people with disabilities are not

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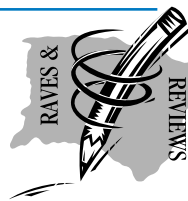
My First Job Interview



Going To Work



Books That Lead To Jobs



What Do You Want To Be When You Grow Up?



Message from the author

This issue has been a very tough one for me to write. Although I began full of enthusiasm just after returning from the Pittsburgh Employment Conference for Augmented Communicators, I soon realized what an emotionally charged and volatile subject employment is for me. Employment is, and always will be, my monster in the closet.

As a kid, I knew two working disabled people, which I bet is a lot a more than most people can say. There was Lloyd, a tall gangly man with cerebral palsy and unclear speech, who ran his own radio and television repair shop. He was the darling of the chamber of commerce and was respected by all the parents of disabled children. Here was a man who had “made it.”

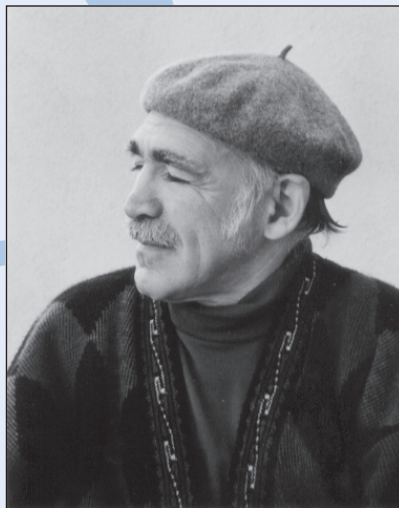
But Lloyd always seemed kind of dull. He never spoke to me other than to say hello. He didn't appear to have any kind of social life. While not tinkering with his customers' broken radios and TVs, he would be in his living quarters upstairs from his shop watching this new entertainment medium with his mother. I certainly wanted more out of life than this.

The second working disabled adult I grew up around was George. He was a co-worker of my dad's in a Southern California defense plant and was unlucky enough to be in the last North American generation without the Salk polio vaccine.

George was one of my father's favorite friends, and he visited our house often. I once built an AM radio from a kit with George's help. Through the years I have wondered if that project was a set up between the two men to get me into the electronics industry.

I'll never know, employment was a dirty word in our house. We never talked about it.

Do you talk about it in your house, or is it a monster in your closet, too?



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Author: Michael B. Williams Technical Editor: Carole Krezman

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good and they are even worse for people who use AAC. When I talked to the co-chairperson of the President's Committee on the Employment of the Handicapped, he indicated the unemployment rate among all disabilities has been increasing over the past five years in spite of the passage of such legislation as the American Disabilities Act. The Committee is now looking into the reasons why this is so. (Jacobson, 1994)

Unemployment rates for people with speech impairments and people who can not speak are grim. About sixty-five percent of people with a speech impairment are unemployed, and the rate of unemployment among people who can not speak at all is seventy-five percent. (LaPlante, 1993) These statistics include part-time as well as full-time work and do not tell us how many people are able to support themselves by their work. In a survey of AAC professionals, Blackstone (1993) reported an unemployment rate of more than eighty-five percent among people of working age who use AAC.

Breaking In

As bleak as these numbers are, some people who use AAC are out in the workplace holding down jobs. Fried-Oken (1993) reported on eight adults who continued to work many years following their diagnoses of ALS. In a survey conducted at Pennsylvania State University, respondents indicated that they were working in a wide variety of employment categories. (Light,

in the Closet

Stoltz & McNaughton, 1993)
These included clerical positions, laborer, trainer, counselor, educational aide, cook, consumer advocate, technical consultant, artist, writer and an AAC specialist, among other things. Other kinds of work that people who use AAC are doing include data entry, assembly work in sheltered workshops, custodial work, self employment and service jobs. (Blackstone, 1993)

Anyone looking for work knows that it is a very difficult and frustrating experience. For the person who uses AAC, it's rather like exploring another planet without a map. You have no idea where you are or where you are going, and you certainly don't know anything about the culture you will encounter sooner or later. In short, you don't know what you're doing.

Are We Workers?

Most able-bodied adults I've talked to during the preparation of this issue have had some sort of work experience in their early teens. The same can not be said of most of the people who use AAC. They are not ready to take charge of the basics of their lives let alone engage in a serious job search. I mean basic things like doing one's own grocery shopping and banking, things that most people do without thinking.

There is a big difference between people who have developmental disabilities and people who have acquired their disabilities later in life. People with acquired disabili-

ties may have more poise and smarts about life. At age thirty I was still having trouble figuring out the basics of buying my food and clothing. Most people with congenital speech disabilities have a similar lack of experiences. Since people who grow up with communication disabilities have not been expected to be independent or employed, they have not had the life experiences needed to become working people.

Planting the Seeds

Can anything be done about this? Faith Carlson, a speech language pathologist from Maine, believes we should begin instilling employment prerequisites in pre-school children. At the 1994 Pittsburgh Employment Conference Carlson ticked off nine areas of development that help prepare children for the world of work. These include development of

- A sense of self and others
- A sense of time
- Interests and desires that reach the outside world
- A sense of money, its worth and its use
- Skill basics that are potentially marketable
- An independent communication system
- Social sensitivity
- A sense of realistic optimism
- A sense of the community in which we live (Carlson, 1994)

These nine areas of development are valid for all children, not just ones that use AAC. All too often,



however, the child with significant physical impairments misses out on opportunities to develop in these areas simply because it may be easier for a busy adult to do a task for the child rather than involving the child with the task. This short term surrender to expediency may have unwanted consequences in later life.

The Future

People who want to work need to get basic skills that will help them in the job market. But what are these skills, and what are the best ways to teach them?

We just don't know enough about AAC and employment. We need research into the types of jobs AAC users with various cognitive abilities might be able to do. We must learn more about attitudes toward people who use AAC. What really goes through an employer's mind when a person who uses AAC comes in for a job interview, and how can one override any negative attitudes?

We must decide if we really want to deal with this monster in the closet, or if we just want to open the door a crack, peek in and quickly shut it again.

A



My First Job Interview

I am a devotee of horror movies. I seem to be immune to their more frightening aspects. When others are quivering in fear around me, I'm able to sit there with a big grin on my face and enjoy the director's blatant attempts to shamelessly manipulate his viewers.

Don't get me wrong, some things do scare me. Take my first job interview for example. Nothing I had seen on the silver screen could have prepared me for an event as frightening as this.

I remember it was an unseasonably hot day in June 1987, the day of my first job interview. I woke up dead tired because I had trouble sleeping the night before. Horrible interview questions blended with scenes from bad television were whipped into a powerful potion of insomnia and paranoia. No wonder I felt on edge.

Well, I was awake now, and it was early; I had at least an hour until my personal care attendant was scheduled to walk through

the door. Would he show in time to get me to my scheduled interview? I had slipped him a few extra bucks a couple of days earlier as a way of insuring his presence, and I tried to impress upon him how important his presence was to me. But would he actually walk through the door at the appointed hour? I had no way of knowing, and this thought kept my mind occupied for the next hour as my body worked up a heavy lather of sweat.

Suddenly I heard a key in the door and my heart leapt for joy. My attendant was on time. As soon as I saw him I became crazed. I started barking orders. "Fruit! Cereal! Coffee! Get a move on, this is no time to waste time. Got to eat. Got to shower." This is the new me talking.

My attendant whirled about my abode like a dervish trying to comply with my requests. Every time I cracked off an order, he looked at me as if I'd gone bonkers. He is not used to my militaristic demeanor; however, there is no time to soothe frazzled nerves today, the clock is ticking on my future and it's late.

I ate breakfast in a rush and jumped into the shower as the orange juice I gulped down at breakfast burned a hole in my stomach. My attendant soaped me up and washed me down. While this was going on, my mind riveted to the interview questions that were sure to come later. My mind fixated on a particular query. "What do you expect to be doing in the next five years?" I don't know what I'll be doing five minutes from now,

let alone in five years. Give me a break! I have enough trouble with the present without thinking about the future.

"Well, my friend, it's time to get corporate." The voice of my attendant jerked me back to the here and now. We begin the torturous task of putting on my suit and tie. This cloth duo is a formidable opponent, and it fights to the death, but in the end, my attendant and I are victorious, and I look great. A sudden thought crosses my mind: "My God, if I get this job I'll have to do this everyday." I shudder at the prospect and hope my attendant can't read my mind.

But there's no room for such foolishness now; it's time to go. I roll out of the house and into the van for the short ride to my destination. Upon my arrival, I check to see if there is any public transport nearby. I'm in luck, there's a subway station right next to the office. As I approach the building, I notice it is ramped with a gentle sloping incline, and I think, "I could work here."

I enter the building and find the office. It occupies a large corner of the building and is guarded by two massive glass doors that look like they weigh a ton. I clang and bang at these portals a while, trying to get them open. The noise alerts someone inside to my presence. The woman at the large desk looks like a tiny dot she is so far away, but soon she is coming at me with the velocity of a major league fastball. She reaches the doors and flings them open with ease. "You must be Mr. Williams," she says. I am expected. "Won't you sit over here;

Going To Work

Mr. Smith will be with you in a few minutes.” She quickly abandons me and goes back to her post, leaving me alone with my thoughts.

Mr. Smith did come and get me after a while. He took me into his office, and we talked about nothing for ten minutes. We literally didn’t speak to each other for ten minutes. Mr. Smith tapped his pencil and looked intently at my resume and said nothing. I watched Mr. Smith tap his pencil and read my resume and say nothing. When I realized nothing substantive was going to happen, I rolled out of there and headed home.

Out on the street, I felt a sense of shame and embarrassment burn into my cheeks. I was knocked out in the first round.

Looking back on this, I realize the whole thing was pretty silly. Mr. Smith shouldn’t have given me the silent treatment, but I shouldn’t have sat there like a dummy either. I should have chatted up a storm even though I knew I wasn’t going to get the job. I had nothing to lose.

I hope Mr. Smith has learned to be more receptive toward people who use communication devices. If not, he may find himself on the receiving end of an ADA lawsuit. If I ever find myself in a similar situation again, I certainly will speak my mind. Fools like Mr. Smith need to be educated. **A**

What does it take to become successfully employed? I decided to investigate this question by interviewing two people who have made it in the job market.

Bob Segalman is a statistical analyst for the State Department of Rehabilitation in California. Neil Jacobson is a vice president of a Northern California bank. In addition, they each do a considerable amount of volunteer work in their communities. Both men have speech that is difficult to understand as a result of cerebral palsy.

Bob has discovered that his speech is clearer if he whispers. He augments his speech with a device on his

wheelchair that amplifies his whispers. If you listen attentively you can understand almost everything that Bob says. Things get a bit tricky in noisy rooms—you really have to concentrate to hear what Bob is saying. This is when Bob pulls out a portable TDD with a LED screen or an alphabet board and uses one as a communication device if he can’t find someone to stand very close to him and repeat what he is saying more loudly. Making telephone calls can be a real adventure for Bob, because he sounds like someone you would hang up on in the middle of the night.

Neil Jacobson’s dysarthric speech is complicated by the fact that he

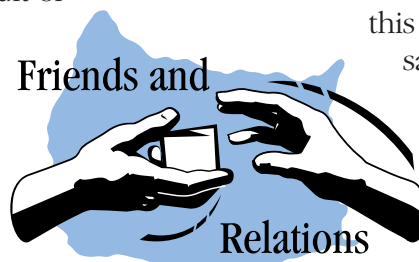
is from New York. Not only do you have to listen carefully to Neil, you must take into account his distinctive accent. Neil has chosen to use no AAC technology. He feels that people will shortly learn to understand his speech. Each man came into the job market in a very different way.

Success via Computing

Neil got a BS degree in mathematics and computer science from Hofstra University. When I asked him why he decided on this particular path, Neil said, “I thought it would be a good career move.” And indeed it has been. It was the mid-seventies and the general

public was just beginning to be aware of computers. The Center for Independent Living in Berkeley, California, the nation’s first independent living center, was starting a computer training program in conjunction with the California Department of Rehabilitation. This nine month program is like intellectual boot camp. People go in knowing nothing about the digital arts, and those who make it to the other side, emerge with a working knowledge of the computer languages used in business. Graduates of the program usually get well paying jobs, helped along by one-on-one mentorships by people in the business community. Neil, who had moved to

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Berkeley from New York, was hired as the program's first instructor, a position he held for about four years.

Neil then decided to test the waters of employment in the private sector. "I wanted to see what it was all about," he said. Neil got his first job in private industry via his former secretary at the Computer Training Project who had gone to work at Wells Fargo Bank in San Francisco. Neil has been climbing the corporate ladder ever since. He is now Vice President in charge of computer operations at Wells Fargo Bank.

I asked Neil what he does when he encounters a person who is uptight about his speech. "There are good days and there are bad days," Jacobson said philosophically. "The bad days really bother me a lot. On the good days I kiss it off and go on. The more relaxed I am, the more relaxed other people get."

When asked what he thought was the most important skill a person needs to go to work, Neil said, "a really good sense of who you are and what you can offer a potential employer. Without this self knowledge and self assurance, you won't get very far in the job market." He also said that the ability to hire and manage personal care assistants, the ability to get around town on your own and the ability to show up on time somewhere are important.

As our interview was drawing to a close, Jacobson said that his parents kept preaching the work ethic to him and that they expected him to make it in the world of work. He laments that

disabled children today have no responsibilities around the home. "This is very important in nurturing the first feelings of the value of work. Young people must get out in their communities by themselves as much as possible. They should go to the store and the library and things like that. They should also volunteer in their communities."

Perseverance Furthers

Bob Segalman espouses the virtues of over-preparedness and persistence as pathways to employment. He has a Ph.D. in sociology and social welfare. Indeed, his resume touts the fact that he is one of two Californians with severe cerebral palsy to hold an earned doctorate.

By his own count, Segalman estimates that he sent out 300 resumes before he got his first job. But he didn't approach this task in a haphazard fashion, he had a plan. First he took a written and oral examination and received a civil service rating from the State of California Personnel Board. This rating made it possible for his name to be placed on the Personnel Board's lists of people who are eligible to be employed by the state. Potential employees may be chosen from the top three candidates on each list. When a person accepts or refuses a job offer, their name is removed from the list and the other people move up. As Segalman's name advanced upwards on several lists, he began to receive inquiries from potential employers. At this point, not being one to sit idly by, he requested a roster of all the state agencies that were hiring people in his particular job classification.

He then sent all these agencies a letter requesting an interview for any vacancies in his job classification. If he didn't hear from them within three weeks, he called them.

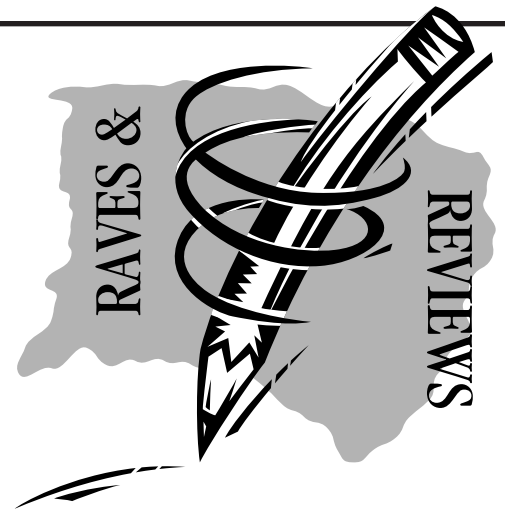
Segalman says the supervisor who finally hired him for his first job did so partly because he was pleased to have a person with a Ph.D. working in a job which only required a Masters degree. This first job was as a psychiatric social worker in a hospital for people with developmental disabilities. After Bob was mistaken for a patient on his first day at work, Bob's supervisor realized the necessity of introducing Bob as a professional to all of his co-workers. He also wore a white dress shirt to work in order to differentiate himself from the clients.

Seven years later he transferred within the civil service system into a state research job. He has continued to aggressively seek out challenging employment opportunities. He currently enjoys his sociological work at the California State Department of Rehabilitation.

In talking to these two people I see they are a lot alike. Both of them have "the will to win" or "that killer instinct." They are not afraid to take risks or accept new challenges. They grab hold of new opportunities when they come along, not accepting that old adage that says "good things come to those who wait." Both men make things happen knowing that if you wait for things to happen, you could be waiting a long time.

A

Books that Lead to Jobs



People spend a lot of time sending out copies of their resume. They busy themselves with the daily classified ads in the local newspaper. Or they while away the hours in public and private employment agencies. Such diligence ought to get a person a job. There's only one thing wrong with it: it doesn't work.

According to Richard N. Bolles, author of *What Color is Your Parachute: A Practical Manual for Job-Hunters & Career-Changers*, over fifty percent of people who use these methods do not get a job. Are you shocked and surprised to hear this news? I certainly was. These are the traditional methods to use when looking for work.

Bolles is no fly by night author who has decided to write a book on how to find a job. *What Color is Your Parachute* first came out in 1970, and the twenty-fifth anniversary edition is just off the press. It is the most respected and beloved job hunting manual around.

Because Bolles updates his book every year, he can keep his finger on the pulse of the job market. What he says about the job

market of the 90's will not be of comfort to job seekers of any type, especially those with communication disabilities. The days of the one career job are over. Everyone will be changing careers every five years or so, taking the skills they have with them and learning new skills on the fly. Scary? You bet, but Bolles shows you how to cope with these realities and details how you really get a job, and that's just the first part of the book.

I can hear people saying, "But Bolles is writing for an able-bodied audience, none of that stuff applies to me. Not true. In fact he is way ahead of you. Bolles has written another, smaller, book called *Job-Hunting Tips for the So-Called Handicapped or People Who Have Disabilities*. This is comprised of material that used to be in *Parachute*, but that book has gotten so large that this material has been broken out into a separate volume by the publisher. A rip off? Perhaps, but the information is great.

Bolles is certainly no disability insider, but he has interviewed some good people in the course of his research and provides

readers with some really good insights about what employers think when a disabled person comes into the room. This can be invaluable when preparing for a job interview. But don't just look at this book, look at *Parachute* too and arm yourself for the hunt.

Another book worth looking into is *How to Work a Room* by Susan RoAne. This is a book about networking at business luncheons, cocktail parties and other functions where business contacts gather. It is aimed at women, but don't let that put you men off. The book is filled with tips on how to wade into a room full of people and strike up conversations. RoAne gives samples of conversation starters, conversation closers as well as how to rid yourselves of bores and other unwanted people. Read this book and learn how to mingle. **A**

Thinking about what you might want to be and do when you are older is important. It can also be fun to imagine. I always wanted to be a mathematician. I talked to some young people about work. They were attending the Bridge School Camp last summer in Northern California. Here's what they said.

“What do you want to be when you grow up?”

“I want to be a teacher.” **Vanessa, age 15**
Fremont, CA

“I would like to be a writer.” **Lateef, age 14**
Lafayette, CA

“Go to to school and study AAC.” **April, age 8**
San Francisco, CA

“I want to be a writer.” **Maricor, age 15**
San Francisco, CA

“Take information on the telephone.” **Chrstina, age 18**
Rifton, NY

“Teacher of computers.” **Nina, age 14**
San Francisco, CA

Thanks to Cassi Sementelli for her assistance.



I want to know what you want and how you get it. From making your dreams come true to getting your parents to buy you your favorite stuff, tell me,

*What do you do
to get what you want?*

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 (408) 646-5428. Or you can send me electronic mail at mbwill@well.sf.ca.us

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