ALTERNATIVELY AS SPEAKING

VOL. 8, NO. 2

Who is that Masked Man?

IN THE SPOTLIGHT

We are going to take a look at ourselves as a stranger might. Why do most people who see our disabilities and the assistive technology we use proceed to make snap judgments about who we are? What can we do about it?

This issue of *Alternatively Speaking* discusses rejection, something we have all experienced and been frustrated by. Many people get confused when we act or look different from what they expect. Some know that babies drool and people who can't talk are deaf, yet we are not deaf babies! What's going on, here?

It's more than confusing. I feel like a competitor and they see incompetence. I feel powerful and they see someone who is helpless. I feel sexy and they see child-like innocence. I feel like an equal and they see me as a burden. There is a burden here, and we are carrying it. It is not enough for us to have the usual attributes (determination, skills, education, resilience, interest) to succeed; it is not enough to give 110% to every endeavor; we also must be willing and able to carry the burdens of ignorance and low expectations.

Rejection based on disability can take many forms. Sometimes rejection is straightforward and direct. Sometimes it may look or even feel like protection and support. For example, false praise, excessive permission and low expectations are insidious forms of rejection that take away the opportunity for honest feedback. Rejection can also take the form of insincere friendliness, pushing away authentic interactions and opportunities for success. Sometimes a real need for help in doing the tasks of daily living leads to the false impression that people who rely on AAC are child-like, asexual and dependent. Children don't work. Children don't have adult relationships. Children aren't relied on to make their own decisions. Thus, a paternalistic pat on the head or a juvenile nickname is not harmless. It steals away our opportunities for adult roles. However rejection occurs, it can become a virtual barricade to participation and success.

INSIDE THIS ISSUE

AAC-RERC
SPREAD THE WORD

Most rejection is not based on hatred, bias or prejudice. Those who reject people with complex communication needs may be oblivious to the consequences of their actions and may even be unaware of their actions. Plenty of cues from role models, elders, the media and the medical field serve to set people who rely on AAC apart. These cues come with social labels that remind everyone that people who rely on AAC are "different" and thus, not included in "our" group.

Continued on page 2

Message from the editor

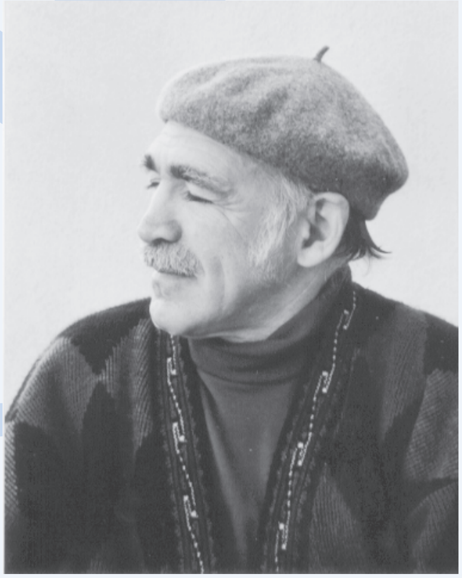
If jealousy is the green-eyed monster, rejection is the monster with the small, beady eyes that can pierce your soul with a quick glance.

I first experienced rejection's painful gaze as an eight year old when I wasn't invited to a playmate's birthday party. It hurt like hell not to be included in the fun and games and I cried about it for days. The birthday boy's mom thought the decision not to invite me was all quite logical. When asked about it some time after the event, the woman said without a hint of regret, "Oh, there were some activities that we knew Michael couldn't participate in. We thought it best not to invite him. Wouldn't want to hurt his feelings, you know."

Yeah, lady, we know, it's been over fifty years since this incident, and I still remember the sting of those hot tears of shame as they rolled down my face.

And that's why this issue of *Alternatively Speaking* is looking at rejection from a multiplicity of angles. We have some of the best augmentative communicators in the business doing the looking.

Perhaps after you finish this issue of *AS*, you'll be ready to look into those beady, little eyes of rejection, stick your tongue out, put your communication device on full volume and yell, "Nanny, nanny, nanny!"



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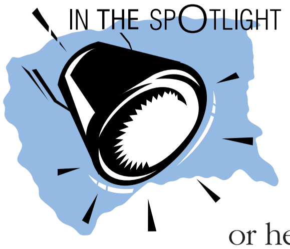
Continued from page 1

The front

Irving Goffman is a sociologist who has a paradigm that he refers to as the "front."[1] The front is an individual's public face—the way each of us look and present ourselves, the roles we play, the way we behave. Other people see our front and can quickly figure out "who" we are. According to Goffman, giving social labels to strangers is a survival tactic and helps identify friend or foe, potential mate or rival, neighbor or foreigner. Human beings seem to be hard wired to give newcomers social labels rather than to take the time to make fine distinctions about each person's uniqueness. By understanding this ancient behavior, we may prepare ourselves to respond to rejection.

We wear clothes, hairstyles, jewelry and tattoos that help others label us. Sometimes we wear the labels themselves, whether "Tommy Hilfiger" or "Fubu." Our transportation methods, our addresses, our dialects, our manners, as well as our body language help people figure out who we are and how we might fit into their social world. A potential girlfriend or boyfriend looks for certain behaviors, manners and appearances, and so does a prospective employer.

Needless to say, most people who rely on AAC have an atypical front, or as Mick Joyce would say, *a unique physique*. We may initially pay the price by being labeled crippled, dumb, retarded or special. While each of us has his or her own unique front, we also take on characteristics of the groups we identify with so we are recognizable as familiar to others. For example, looking at football



fans leaving a game, you can see that each person has his or her own (probably boisterous) personality and style. But you can also clearly tell that each of them is a football fan and you can probably also tell which team each fan supports by watching and listening for a few minutes. The following morning, each of these fans will have on a different front in preparation for his or her role at work. We are all individuals within groups.

Comfortably familiar

Not surprisingly, most people prefer to be around people who understand and accept their differences. How many fellows have you heard say, "I want to work for an AAC manufacturer"? It would be great to work for a company where almost everyone understood the idiosyncrasies and potential of people like us. Then there is that tech support. Can you imagine there always being at least one person on site who could make minor adjustments on your assistive technology?

Looking honestly at social matters, haven't you wished you could find a best friend, sexual partner, colleague or mate who understood what makes you tick as well as that wonderful nurse, PT, SLP, attendant, doctor, or AAC consultant? Most people who work in the AAC field do make distinctions among individuals who rely on AAC and can see us as the individuals we are.

Wanting to work and socialize with people who understand, respect and support you makes sense. One way to open up possibilities is to surround yourself with others like you. Over the years, there has been a history of social clubs, recreation centers, athletic groups, workshops and group living situations for people with similar disabilities. The difficulty with this solution is that more of your relationships and activities become disability-based. Unfortunately, this can narrow your world. On the other hand, even when we don't want our disabilities to determine with whom we work and play, we must admit that going to disability conferences where most of the participants can see more to our front than "there's an AAC user" is a very enjoyable experience.

Another way to open up the world is to have an advance team who paves your way. A boss at work or an administrator at school can create a receptive corporate culture and be an example for everyone on site. In the social world, a friend whom everybody looks up to can do this. Sometimes an enthusiastic family member can prepare others to look further than the disability. Another advance team of sorts is money. Lots of money can make almost anything happen. The downside of relying on someone to pave the way is that someone else is paving the way for you. The direction might not be exactly as you would choose. Also, it puts you in the role of follower as opposed to leader.

Education is another popular solution to systemic rejection because the cure for ignorance is education, right? Who is going to do this education? The answer is, we must and it is a constant unpaid effort with intermittent success. It seems unfair to lay the responsibility of educating the public in the laps of those already disadvantaged by the problem, but, that said, no one else has the motivation or the experience to do it. From time to time, we may relax in one of those comfortable worlds of acceptance, but eventually we will want to take up the challenge again—by trying something different or meeting someone new—and part of every new challenge will be educating the strangers we meet.

Conclusion

Rejection is a major barrier to full participation in society. It is powerful because it is painful and can destroy our self-confidence, making us feel weak, insignificant and alone. But we are not alone on this sea of trouble. Rejection is something that many people in many walks of life have dealt with successfully. We can't change the fact that we have disabilities, but we are not prisoners of our disabiilities. Who we become is largely about the choices we make and how we define ourselves. While it is difficult to face and overcome rejection, it can be done. "The fault, dear Brutus, is not in our stars, But in ourselves, that we are underlings," as Shakespeare nicely summed up the situation in his play *Julius Ceasar.*

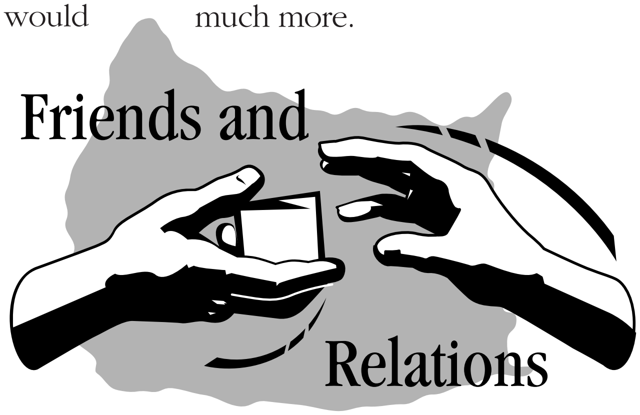
Being Yourself

by Jon Feucht

Why should we be ourselves? If everybody would be themselves, then this world would be a truly interesting place to live. There are so many interesting characters in this world. I love going out and seeing all the different, unique people. You know what I mean, people who don't dress like other people, and the people who dye their hair funky colors. For many, having a group of people who rely on AAC sitting around talking would be out of the norm. To them, we would be the interesting characters.

Sometimes you come across a person who thinks you're too different or too disabled to talk to. These people don't see you as a regular person. It all has to do with social norms. Social norms can be dangerous for people with disabilities because society doesn't have a positive view of us. Most people in society can't see individuals who rely on AAC as the whole person that each of us is. They often treat us like children because that is how they see us. That isn't right, of course, but people still do it because they don't know better.

We are all unique beings who change and grow over time. It's never too late to try something new. If you want to do something, then go for it. People who rely on AAC can try to do anything that able-bodied people do; we are capable people. I mean doing things like going to college and obtaining meaningful employment, if that's what you want. You can be whoever you want to be. There are an infinite number of achievements you can seek. Take mine, for example. I have done so much in my life: finishing college, getting into graduate school, starting Authentic Voices of America AAC camp, traveling around the United States, and so much more.



Being yourself doesn't mean always acting the same way. You don't handle a business meeting and an evening out with friends the same. You're more professional in meetings. You don't walk into meetings cracking jokes and not taking things seriously. I know people who don't care about having a professional side. They just want to be themselves all the time, without restrictions. I think these people are never taken seriously. And why should they be? They never take anything seriously themselves. There are a lot of times in life that you need to be serious. During these times, you should be yourself, but more refined.

To be honest, it's really hard to be true to yourself, especially when it isn't what other people want. I find the hardest thing is doing something I really want to do when other people don't want me doing it. It's hard because people are trying to talk me out of doing something that I truly want to do. If I do things I don't want to do, just to make others happy, then it's very likely that I won't be happy myself. I try to focus on making myself happy first because I have to always live with myself, while other people might come and go throughout my life.

It is important to live life on your own terms. Stop and say to yourself, all right, I know what they want, now what's best for me? If you can always remember to do this, then I think you are going to be successful at being yourself. Being yourself truly takes work. You will always have outside forces influencing you. It's perfectly fine to take people's advice and get all the knowledge you can before making a decision. The most important thing is to make decisions that are consistent with your personality and your set of beliefs. If you do that, then you are learning to be true to yourself, which is very, very important.

Jon Feucht adapted this essay from a "Straight Talk" he gives at his Authentic Voices of America AAC Camp.[2]

Rejection

by Mick Joyce

Having a unique physique such as mine brings about different reactions from people. My head bobs and weaves, my hands don't go where I want them to go and my legs don't either. My speech is hard for many people to understand, and I'm in a wheelchair. These and other anomies generate rejection from all directions and distract from my true personality. This I call the "fear factor." It is like looking though bent mirrors. Everything is out of proportion. Without intervention, such as me talking or taking some other insightful action, things become more bent and the "fear factor' increases, making me more of a "monster." This increases my level of rejection as I appear even more "bent" and the cycle continues.

For me the sources of the trouble are from

- Perspective employers
- Women I'd like to get to know
- Persons I have to work with
- Churchgoers
- Rehabilitation professionals

Most dogs and many children under five years old seem to have more common sense than the above groups. When I pass by a dog, I look it in the eye, and the dog wags its tail and wants to rub up against me. [Why can't women be the same way?] Small kids react similarly. They make eye contact. I smile. They smile back. I wave. They wave back. I say, "hi." They say "hi" back. That is, if they aren't swept away by their mothers. If only they would grow up unchanged and become human resource professionals.

Perspective employers

I don't claim to understand much about this gigantic iceberg, but I'll offer a few foghorns to meditate on. Many perspective employers (and their representatives) are not minding the store. They don't bother to learn about assistive technology and never want to rock the boat. Some think that most people with disabilities receive large government checks and wonder why we even want to work.

With these misconceptions floating around, the government might be better off spending more money on public education. I say put the human resources people on a cruise ship, feed them fresh fruit, fish and seaweed. At one port, load a lot of friendly folks who have unique physiques. Then, let everyone ride the seven seas together. This may work better than hiring Vocational Rehabilitation counselors or providing large federal grants to promote systems change that keep the "fat cats" at universities happy but haven't done a lot for the workforce of people with disabilities that continues to dwindle dramatically. May I suggest a radically new way to change the system? Hire people with disabilities!

Women I'd like to know

One must use extreme caution here not to bite the hand that feeds thee, but I gave up on understanding women long ago. Both men and women use a rigorous form of cost-benefit analysis when picking whom to hang out with. Sometimes, when persons with physical conditions are involved, the perceived benefits are not evident for some time, artificially tilting the cost side higher. I am in full agreement with Tina Turner when she asks that rhetorical question, "What's love got to do with it?"

Persons I work with

People I've had to work with over the years have been, on the whole, pretty friendly. It's those peripheral people in peripheral places that give me trouble. They think I'm the mail boy, or a lost soul looking for the bathroom, or something out of cloud nine. Unfortunately, I am usually there to ask a tough question about conflict in public policy and what impact that might have on consumers. I never expect to get a straight answer because usually,

Continued on page 8

RAVES & REVIEWS

The Big Box Incident

by Michael B. Williams

Traditional grocery stores are slowly disappearing from my part of the country and being replaced by concrete warehouses packed to the rafters with a multitude of merchandise. Shoppers from all over come to these big box emporiums to buy anything from large quantities of toilet paper or beer to the latest popular books and DVDs at low, low prices. Shopping at one of these places can be an overwhelming experience, especially when you're a newcomer to the big box universe.

Walk in the entrance of one of these joints and you're confronted by row upon row of stuff. As you work yourself deeper and deeper into the place, you find yourself immersed in brands you never heard of and things you never knew you needed.

Need something specific? Forget it. There is no service at these stores. You can wander the aisles for hours in search of someone to guide you to the area you're looking for and not find a single employee. The only place you'll find a human is at the check-out counter where they are happy to take your money and speed you on your way.

Now you may be wondering what all this pseudo socioeconomic claptrap has to do with anything. Hold on , dear reader, there's a point to all this.

So, I was in this big box store the other day when I heard somebody say, "There's my little buddy." Call me paranoid, but I immediately got the creepy feeling that she was referring to me. It only took a glance to confirm my suspicion. There was my unknowing tormenter, a store employee, smiling sweetly as she glided past me.

The employee's remark puzzled me at first, because a) even though I use a wheelchair, I don't look particularly diminutive and b) I was definitely not this person's buddy. Oh, I had been through the woman's checkout line, flashed a few brief smiles, and exchanged mundane pleasantries with her, but I did nothing that would make her think we shared a common bond of buddyhood together.

And here's another puzzling thing about the incident. Even though I feel youthful most of the time, age has deprived me of most of my hair and put considerable gray in my sideburns and beard stubble. To put a finer point on it, I in no way look like a kid; in fact, I'm probably old enough to be the employee's grandfather.

I let this incident eat at me for several weeks before talking it over with my wife. She asked me if I wanted her to talk to the store manager about it. I said that would be good.

Well, this wasn't the best idea in the world. When presented with the facts, the manager didn't see anything particularly wrong with the employee's behavior. She was just trying to be kind, he said. Further discussion of the matter proved to be fruitless.

Since this incident, I have noted a change of attitude on the part of the staff. They are attentive to me, perhaps overly so, and they are very formal and icy. If I won't play the part of their little buddy, no more smiles or cheerful small talk for me.

And the employee who unknowingly started this whole mess? The next time she spotted me in her line, she immediately went on her break.

AAC-RERC
SPREAD THE WORD

Visual Scene Displays

Visual scene displays (VSDs) are a new technology that uses digital photographs of personalized scenes rather than icons to represent language and support communication. A display may consist of one or more photographs of images to create a familiar scene, such as a child playing with a favorite toy or a family eating a meal.

The primary advantage of visual scene displays is that these displays replicate the real world to a high degree. For instance, "Mother" on a VSD could be represented by a photograph of the person's mother in a familiar setting engaged in a familiar activity. Pointing to actual images on a visual scene display is a natural extension of familiar communication methods. Even very young children can have immediate success communicating with this assistive technology.

Young children

Past research by Janice Light and Kathy Drager at Pennsylvania State University[3] revealed that very young children have difficulty using features of existing communication devices, at least in part because of the way vocabulary is represented and organized on their displays. This research showed that many generic line drawings, known as icons, may not be meaningful to beginning communicators. Also, very young children have trouble relating to the layout of traditional displays. Rows and columns arranged in categories is not how children think about the world. Light and Drager concluded that most very young children have difficulty learning to use speech generating devices as they are presently designed.

A new alternative

Visual scene displays are a new alternative for some young individuals and for those with cognitive and linguistic challenges. AAC-RERC researchers are currently researching SGD designs that would be more appealing and easier to use for young children, adults with aphasia, children and youth with autism spectrum disorders and adolescents and adults with significant cognitive and linguistic delays.

David Beukelman and his colleagues at the University of Nebraksa have developed VSDs for adults with aphasia. Their results show that these adults enjoy and can use technologies that support the use of digitized photos in ways that enable communication partners to co-construct communication without having to rely solely on their residual language skills.

Visual scene displays may soon offer children and youth with autism more access to communication and language. For example, at Children's Hospital Boston, Howard Shane is developing software that uses visual scene displays to support language learning and use. Drager and Light are also beginning to work with individuals with autism using visual scene displays.

Low-tech or high-tech

Visual scene displays can be implemented on both low-tech communication boards and high-tech speech generating devices. When used on communication boards, the individual manually points to the desired photograph or items within the photograph. A communication partner then provides the speech output, co-constructing messages. Currently, VSDs are not widely available on SGDs, so AAC-RERC researchers are working with a communication device manufacturer to further develop this approach.

To learn more about visual scene displays, read the August 2004 issue of *Augmentative Communication News,*[4] go to the AAC-RERC website (www.aac-rerc.com) to view recent webcasts by Drs. Light and Beukelman on the topic and to read Bill Geluso's article[5] in the e-newsletter or contact these AAC-RERC researchers directly.

Bill Geluso contributed to this article.

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Sources & Resources

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2. Contact Jon Feucht for information about Authentic Voices of America and the “Straight Talks” Jon presents there.

3. Drager, K., Light, J., Carlson, R., DSilva, K., Larsson, B., Pitkin, L., Stopper, G. (2004) Learning of dynamic display AAC technologies by typically developing 3-year-olds: Effect of different layouts and menu approaches. *Journal of Speech Language Hearing Research*, 47, 1133-1148.

4. *Augmentative Communication News* is published by Augmentative communication, Inc., www.augcominc.com, 831-649-3050.

5. Bill Geluso previously published some of this material as “Communication Aids for Toddlers” in the *AAC-RERC e-newsletter*, Vol. 1, Issue 4. http://www.imakenews.com/aac-rerc/

To subscribe to the AAC-RERC e-newsletter go to www.aac-rerc.com/pages/news/e-newsletter.htm

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Thank you to the guest authors.

Continued from page 5

they don’t know. But I start the wheels a-turning. My speech generating device comes in real handy in these situations. I can have the basic question typed in and additional information about me, my job, (if I have one) under a pop-up window. This puts some people in shock. But when they are in that state, it is easier to get information out of them.

Churchgoers and rehab professionals

The last two groups of people, churchgoers and rehabilitation professionals, I (sort of) put in the same boat. They both wear shining armor. They say stuff they ought to say like, “Jesus loves you; you’ll be walking in heaven; you’re doing so much better today; you’re speech is getting much easier to understand; you operate that device so well; there is a job out there just waiting for you; or you really ought to get into some kind of exercise program.” I usually agree with them, grunting out a “yes.” I am short on time and they are too. In reality, this is sort of an underhand rejection like a pitcher throwing an undetected spitball. They eventually get real annoying like a not so distant lawn mower on a Sunday afternoon. They are buzzkills.

Rejection hurts

All rejection hurts. I get tired of trying to laugh it off. I think about it a lot at night.

Many of my poems are about the topic. The psychologist’s advice, “Don’t take it personally” doesn’t hold water with me. You’re damn right I take it personally. I’m Irish. Professionals also say that if one is bothered by rejection s/he needs to work on “self-esteem.” Bullshit! It’s the professional’s self-esteem that should be in question.

It helps to have a family grounded in love and acceptance. It helps to have a few friends I can tell about anything to. It helps to know my needs and effectively advocate for them. But most of the time, it’s a waiting game—waiting for puppy dogs and smiling face of children, waiting for those one or two moments during the week when I really connect with a person. Then, the colors of the rainbow fill my mind.