ALTERNATIVELY AS SPEAKING

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Talking About Us

I was raised with the adage, "Sticks and stones will break my bones, but words will never hurt me." I wish this familiar childhood chant were true, but, in reality, words can change our attitudes toward a person and change a person's self image. In short, words can hurt. Fortunately, using care in selecting one's words can also help. The words we choose influence our perspective and our behavior, for better or for worse.

Disability is a social state

Most of the difficulties faced by people with disabilities are not inherent in the disability itself, but in the social response to disability. Joseph Shapiro, a news reporter who wrote a book called *No Pity* about the disability rights movement, was surprised to learn that, "It is society's myths, fears, and stereotypes that most make being disabled difficult."[1] Robert F. Murphy, an anthropologist who recently acquired a disability, carries this argument one step further in his book, *The Body Silent*, saying, "Disablement is at one and the same time a condition of the body and an aspect of social identity."[2] I have heard it said about illness that it is "all in your head," but disability seems to be all in everyone's head.

Internalized ableism

And I do mean in everyone's head. As people with communication disabilities, we experience the pain of cultural prejudices and stereotypes. But we are also members of these cultures, and most of us have internalized these prejudices and stereotypes. When people of color believe they are less than their "white" counterparts, it is called "internalized racism." When we believe we are less than our able-bodied peers, it is called "internalized ableism." (Ableism is defined as discrimination based on ability, especially discrimination against people with disabilities.)

INSIDE THIS ISSUE

I have been fighting this tendency to accept the names others would give me all my adult life. It was not all that long ago that I would introduce myself by saying "I have a speech problem." Now I say "I am an augmented communicator." They are just a few words, but they are the words I have chosen. They make me feel strong and in control of my own life.

Preprogrammed ableism

People who rely on AAC have another way to internalize ableism. The technology that we use to communicate may come preprogrammed with prejudice, ableism or stigma. Many years ago I had a communication aid which had a thousand canned words and phrases. All the basics were supposed to be there, but the obvious phrase which had been left out was, "You're welcome." Apparently the clinician who developed the vocabulary

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Message from the author

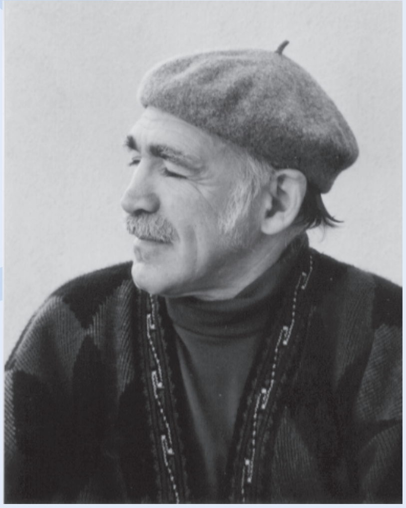
I first learned about the negative power of language from a guy named Pop when I was five. Pop ran the grocery store in the neighborhood in which I lived with my parents. This was in an age before groceries went corporate, before track homes bloomed in the suburbs.

Pop took care of all of our foodstuff needs with an acumen appropriate for a small business person. We could always tell when things were going well with Pop; he handed out candy to the neighborhood kids. This delighted everyone, including me.

One day when he handed me some candy, I decided to say thank you. I had never done this before. I thought Pop would be surprised. He was surprised, all right, but he didn't respond in the way I thought he would. As I said thank you, he looked at Mother, then at me, then back to my mother again. "Hey," he said, "Your kid's got good sense."

A thoughtless remark? Sure, but I hurt like hell. Until that moment, I had no idea that Pop thought I was cognitively impaired. And so my interest in the power of language began.

I want to give thanks to Carole Krezman and Morgan Marchbanks for their tireless research efforts in support of this issue. Without their help, this issue wouldn't be as good as it is.



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didn't think a person who relied on AAC would be thanked often enough to warrant including "You're welcome."

Those of us who can select our own vocabulary have a responsibility to our "brothers and sisters" who can not select their own vocabulary. We must ensure they have access to the kind of words we would want: the words that they will need to become or continue to be strong, self-led people.

A lack of protocol

There are no cultural rules for interacting with people with disabilities. Murphy says, "When the able-bodied are forced into confrontation with the disabled—that is, when they cannot escape—they often cope with the threat by treating the disabled as minors or as incompetent, withholding deference and thereby depriving them of their due as fellow humans."[3] One way to ease these "confrontations" is by using language in a way that reflects the humanity of all people. A respectful vocabulary is the first step in turning confrontations into meaningful interactions.

Even our able-bodied allies aren't sure how to describe people who rely on AAC or which topics might be hurtful or embarrassing. Murphy continues, "People have a hard time deciding what to say to the disabled, and their troubles are compounded by the fact that they are uncertain about what words to use."[4] The box on page three includes some of the words used to describe people who rely on AAC. Most of them certainly are not ones we would choose. It is up to us to let people know what we expect.

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What's in a Name?

We asked people to fill in the blanks on these sentences with words they had used, seen or heard. We hoped that someone would have the perfect words: clear, descriptive and powerful. But as the growing lists jogged memories, it was the oppressive words which came pouring forth. The real question is not which phrases are best or even most popular, but, How can we survive these names?[11]

1) I am a person with ...

dysarthric speech
an exceptionality
a disability
a handicap
a problem
a physical inconvenience
differing abilities
a physical challenge
a speech disability
a speech impediment
a commmunication disability
a handicapping condition
a condition
a speech impairment
a physical and a speech disability
special needs
a physical condition
cp
severe communication impairment
cerebral palsy
a voice that doesn't work

2) I am a person who ...

depends on AAC
relies on AAC
needs to use augmentative communication
can't speak and uses computers to talk
can't speak and needs computers to communicate
speaks a bit funny

3) I use _________ to communicate.

a VOCA
an AAC system
an aug com system
an aug com device
an AAC device
a voice output communication device
an electronic communication device
this device
assistive technology
a communication book
a talking machine
a high tech machine
a letterboard
a communication board
a speech board
a language board
a color coded communication board
a low-tech, self-designed communication board
a low tech board
a Blissboard
that old board
a Liberator
DAC
a Macaw
a Canon
a miniVOCA
"Spot"
a computer
a speech computer
a talking computer
a speech synthesizer
a lap top with speech synthesizer
a speech prosthesis
a communication aid
an electronic communication aid
high tech equipmnt
a speech box
the talking thing
a synthesized voice
my voice

4) I might be called ...

an augmented communicator
a cripple
a handicapper
a disabled person
a handicapped person
an AAC user
a disabled individual
a handicapped individual
an individual who lacks functional speech
a nonspeaking individual
a unique individual
a man of letters
a wheelchair guy
big wheeler
big guy
honey
dear
darling
dearie
baby
pet
little girl
special fellow
handsome
little guy
big boy
brave boy
the mick with no dick, but a lot of balls
handicapped
a non-speaking person
a non-verbal
a non-oral
a non-speaking
blabber finger
tricky Mickey
a human unicorn
physically challenged
retarded
cerebral palsy
a bleeding heart liberal
spasso
spastic
spaz motaze
a drunk
a crazy bastard
a cheap bastard
an irish jew
deaf and dumb
"He"
"Them"
one of those people
that guy in a wheelchair
a vegetable in a wheelchair

5) An AAC professional provides services to ...

consumers
users
customers
clients
patients
people
individuals
people with speech disabilities
people with communication difficulties
people with disabilities
a guy bleeding the system for every damn dime.

Continued from page 2

Words can hurt

We must think about the feelings behind the words we use to describe our disabilities and our assistive technology. Do the words reflect historical oppression? Are feelings of pity, fear, anger or disgust carried in the words we use? If so, those words are likely to hurt.

Where disability vocabulary comes from

Disability vocabulary comes from a variety of environments: medicine, education, rehabilitation, charity, sociology, political discourse and disability rights. Very little of it comes from people with disabilities. Jenny Corbett, a radical disability rights theorist and professor of education from Great Britain, says, "For many years, the voices which reflect the experiences of disabled people's lives have been effectively muted."[5] Rick Hohn presented an example of this by telling me, "[Some] people say that I talk too much after they impatiently wait for me to type a message. In reality, they speak ten sentences to my one, and yet they say I talk too much!"[6] We are expected to be silent.

But they are so nice

Sugarcoated paternalism can seem so innocuous. Everybody is being so nice. How can being called "special" compare to calling African Americans "violent," calling Native Americans "savages" or calling women "girls"? It is the same. All of these examples show the use of language to "justify the unjustifiable, to make palatable the unpalatable, to make reasonable the unreasonable, to make decent the indecent," [7] according to Haig A. Bosmajian in his article, "The Language of Oppression." Use of the word "special" often serves to disempower people. As Corbett says, "If 'special' is so positive, why is it not ... widely employed to define power and status?"[8] Can't you just see presidential candidates arguing over which one of them is more "special"?

What can people who rely on AAC do?

We struggle with a dilemma. The words we choose to describe ourselves and our technology must reflect us as the powerful, multifaceted human beings that we are, but it is hard to think of ourselves that way when our names have been "ugly" for so long. Here are some strategies:

- Talk to other people who rely on AAC about the words we use to describe ourselves. The ACOLUG listserv[9] has been a wonderful venue for this kind of discussion.

- Choose words to describe yourself and your technology that are respectful, clear, descriptive and powerful; then insist that others use them.

- Join policy-making organizations and remind the organizations' leaders to choose carefully the words they use to describe people who rely on AAC.

- Use e-mail to communicate with people all over the world about things that matter to you.

What can allies do?

- Get to know some people who rely on AAC. Socialize with them. Have a beer. Go out in public. Invite them to your home. Introduce them to your friends and family. It is easier to talk accurately about people when you actually know them.

- Do something! Talking and writing are not the end. Try implementing a change in your facility, institution or community.

- It is hard to go wrong describing a person as "a person who ..." or "a person with ...." The professional who thinks of people with disabilities as individual persons rather than "clients," "cases" or "patients" is less likely to use oppressive vocabulary.

- Look at your own vocabulary and try to understand the emotions that particular words and phrases carry. Watch out for words charged with sympathy, pity, disgust, anger, fear or awe.

- Listen carefully to the way people with disabilities choose to describe themselves. Some will choose the vocabulary of the people they respect—professionals, family and friends—without thinking about whether it is oppressive. Others will follow in the footsteps of the anonymous founder of People first of Oregon and say, "I want to be treated like a person first."

In conclusion

In every social interaction we try to make other persons understand that we are not who they think we are; we try to shake off "the tissue of myths, fears, and misunderstandings that society attaches to [us]."[10] We must take charge of our own voices. We must let people know who we really are and what we are worth, using our own words.

This Is Entertainment?

We all hate the media these days. From politicians to Aunt Polly in Peekskill, New York the cry goes up: The media is biased. No matter what you're discussing, be it politics, food, morality or a thousand other things, the media has the wrong slant on it.

I happen to think the media, especially the entertainment media, have the wrong slant on disability. For years, industry people have ground the raw experience of disability into sausage for mass market minds. Television is the worst offender. Its producers have a real knack of finding disability material that will produce extreme sympathy in the average viewer and then tweaking it a bit until it becomes in-your-face bathos.

Here's a perfect example: A recent episode of the popular American TV series *Touched by an Angel* was about a woman who had given birth out of wedlock twenty years earlier. Of course, the baby had a disability. The mother hid him in an institution and secretly visited him weekly. The angel intervenes so that the "horribly disabled" child can be part of the woman's new family. When we finally see the illegitimate child, he turns out to be a young man with mild cerebral palsy. Such horror!

Over the years I have subjected myself to many soggy sentimentalities. I remember watching a kid with a terminal brain tumor stumbling forward to receive his diploma from Harvard and a blind man fighting to get into medical school. How marvelous. How noble. How boring. If these kids had been normal, nobody would have paid any attention to them. Their disabilities made them heroes.

Then there is the silly season. One of the more absurd pieces of schlock Hollywood has produced about disabled people is the TV series *Mantis*, which featured a young African American man with a spinal cord injury who has money, friends, a good job, a great education and an active social life. He spends much of his time in a computerized "Mantis" suit (which hides both his disability and his race) trying to stop crime. The conflict in the story usually consists of the bad guys deactivating the Mantis suit, which leaves the Mantis in helpless agony until he and his friends concoct a rescue.

To be fair about this, the industry has come around on disability a bit in recent years, especially on the issue of mental retardation. The character of Benny, an office worker with mental retardation, became so popular on the series *LA Law* that many employers were calling the show wanting to know where they could find their own Benny. *Life Goes On*, an outstanding family drama, appeared on American TV screens a few years back and featured an actor with mental retardation in one of the lead roles.

But such examples are few and far between. The industry's instinct is still to make us go for the hankies. People with disabilities are seldom portrayed as persons who lead interesting and productive lives. We are too often used as hooks for the general public to hang their collective misery on.

What Hollywood needs to do is to stop using us as fodder for their two-hour freak shows and start treating people with disabilities as people. I'd like to see more of us included in street scenes. We don't have to be singled out as objects of special attention. Just let us do our thing.

Tips from Lenny

Lenny Robbins[12] is the father of ten-year-old Rachel, who uses a miniVOCA. Their family lives in Michigan. Rachel is fully included in public school and Hebrew school. I asked him to tell us about some of the solutions their family has developed for increasing or improving social opportunities for his daughter.

Problem: People often will talk to us instead of Rachel.

Solution: The response to that is, "Ask Rachel."

Problem: People who mean to be sympathetic, but are jerks.

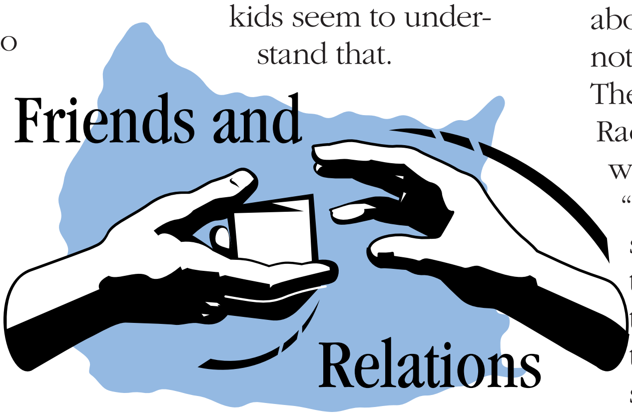
Solution: We just basically ignore them.

Problem: Initiating conversations with strangers.

Solution: The other night after swimming, we were at a restaurant and there was a family at a nearby table. One of the kids said a knock-knock joke, and I asked him if he could come and tell it to Rachel, and he did. Then Rachel switched over to her page of jokes. That whole family joined in listening to her telling jokes, and it was just wonderful.

Problem: People are not patient enough.

Solution:. I put a red light on the back of her miniVOCA screen, and everytime she pushes a switch, the light comes on for five seconds and lets people know she is trying to do something. The kids in her class caught on to it instantly, but I've had to explain the red light to adults over and over again. It doesn't mean that she is necessarily about to say something, or that when the light goes out and she hasn't said something, something is wrong; it just means she is trying to do something, and people should be patient. The kids seem to understand that.



Problem: Encouraging people to interact with Rachel.

Solution #1: When someone talks to us, and they are asking something that could be addressed to Rachel, we just say, "Ask Rachel." Usually we just shut up after that until they begin to talk with her. And people often do.

Solution #2: Once in a while we will say, "Rachel can answer that." "Rachel would you show so-and-so how you say yes, how you say no," and then we just don't let the conversation continue as a conversation with us.

Problem: Dealing with unusual technology.

Solution: People are very curious. When someone sees Rachel's VOCA, and hears her talking, they will ask us how it works. I used to start telling them about the technology, but that's not what they are interested in. They really want to know how Rachel works it, not how it works. What I say now is, "Rachel uses it to speak, and she works it with her feet." If they want more than that, I tell them she uses her left foot to move around on the screen, and she uses her right foot to pick out what she wants to say. People are just fascinated, and we encourage them to interact with her. Both Rachel's VOCA and her turbo power chair (which is also very unusual) are tremendous ice breakers.

Words about Words

We all need to think about the language we use and how it affects us and the people around us. This is not an easy task.

This issue of *Alternatively Speaking* only begins to examine how language impacts the lives of augmented communicators. Here are some choice "raves" by people whose opinions I respect. These quotes are intended to jump-start your thinking about further aspects of language and disability.

Some of these quotes are extremely powerful. I hope they have the same impact on you as they do on me.

"The new thinking by disabled people [is] that there is no pity or tragedy in disability, and that it is society's myths, fears, and stereotypes that most make being disabled difficult."[13] Joseph Shapiro

"People who meet me judge me only by my speech and think I'm incompetent of living in my place."[14] Tom Reed

"It is not enough that we look at the power of oppressive language. We must also take action to address the problem by un-naming and unlabeling in those situations where names and labels have served to limit and oppress people."[15] Morgan Marchbanks

"Through collective political strength, new positive metaphors will emerge to celebrate difference and demonstrate pride and self-respect."[16] Jenny Corbett

"Children need the vocabulary to take the mystery out of the familiar."[17] Faith Carlson

"Language is a virus from outer space."[18] Laurie Anderson

"While names, words and language can be and are used to inspire us, to motivate us to humane acts, to liberate us, they can also be used to dehumanize human beings and to 'justify' their supression ...."[19] Haig A. Bosmajian

"There is close nexus between language and self-perception, self-awareness, self-identity, and self-esteem. Just as our thoughts affect our language, so does our language affect our thoughts and eventually our actions and behaviors."[20] Haig A. Bosmajain

"The power which comes from names and naming is related directly to the power to define others—individuals, races, sexes, ethnic groups, [and people who rely on AAC]. Our identities, who and what we are, how others see us, are greatly affected by the names we are called and the words with which we are labeled."[21] Haig A. Bosmajian

"The decadence in our language is probably curable. ... Silly words and expressions have often disappeared, not through any evolutionary process but owing to the conscious action of a minority."[22] George Orwell

What is Normal?

Most people want to be normal. But what is normal? Normal means that you are like everybody else in ways that count. Are people with disabilities normal? Of course they are.

Some people with disabilities get angry or sad when they are called "crippled" or "handicapped" because those words make people feel like they are not normal. As my friend Mary says,

"If they say 'handicap,' they do not realize I am normal." Mary A., Age 18

Find ways to describe yourself and your assistive technology such as, "I have brown, curly hair, I have blue eyes, I use a communication board, AND I am normal." Choose words that make you feel important and good. If you don't choose words to describe yourself, other people will, and you might not like their choices!

Send me a fax or e-mail and tell me how you describe yourself.

Young Voices

What would make your communication system even better?

The next issue will be about consumer satisfaction. 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.

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

Sources & Resources

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2 Murphy, Robert F. (1990). *The Body Silent.* New York: W. W. Norton. p. 2.

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9 To join ACOLUG, e-mail Graciela Slesaransky-Poe at graciela@astro.ocis.temple.edu

10 Murphy. *The Body Silent.* p. 113.

11 Many thanks to Mary A., Lynne Atanasoff, Sue Balandin, Sarah Blackstone, Doug Chambers, Gus Estrella, Amy Goldman, Beth Haller, Rick Hohn, Hilary Johnson, Paul Marshall, Rosie Miller, Paul Pecunas, Sue Pitt, Semyon Rakhman, Lenny Robbins, Bob Segalman, Ron Sinsz, Graciela Slesaransky-Poe, Jack Tyers and the consumers and speechies from the Spastic Society of Victoria, Australia for working on these lists.

12 Lenny Robbins, 3705 Lansing Road, Lansing, MI 48917. E-mail address: 21675MGR@MSU.EDU

13 Shapiro. *No Pity.* p. 5.

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18 Laurie Anderson in her performance video *Home of the Brave.*

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