

VETERANS WITH HEARING LOSS

Lt. Allen Ford

Lt. Ford: Thank you for coming in and especially thank you, veterans, for your service. Over the past four years I have been traveling to conferences like ALDAcon and any other conference related to disabilities and organizations interested in helping veterans returning with hearing loss. The biggest question has been, "Where are they?" Where are these veterans with hearing loss? I have some theories about that.

I'm excited that what I have done over the past four years has changed. How I have interacted with higher education, disability directors, military veteran programs and coordinators has evolved.

Something significant happened to me on October 1st of 2012. *USA Today* newspaper printed a front-page article on the lack of advertising people who knew how to write good advertising copy. Most of you probably like me growing up in the '60s and '70s heard jingles for JELLO and Good 'n Plenty candy. Now with digital technology and visual messages, very little line copy is written. In response to that, *USA Today* set up a competition worth \$1 million in advertising in their newspaper. An idea came to my head immediately to enter this contest with the people I work with at NTID. For this competition, we plan a different panel for each day of the week. Do I think my team or I will win? I doubt it. We are not professional ad writers, but I was so wowed by the first panel, I've become more of an optimist. Our message is that we don't know where the veterans are because no one has asked them where they are. That's the basic concept.

I have gone to many conferences, such as to the Department of Defense, to worldwide education conferences, to Association of Higher Education and disabilities groups meetings. I also research every week looking for where the vets are, using military.com and the American Council on Education. All these groups have great data, a lot of numbers but they are mere numbers, not people. Numbers are not useful to me. Fortunately, during my search, veterans began reaching out to me for information about ways I could help them.

An example of this occurred in May in Rhode Island. A veteran, Ken Smith, had partnered with some other veterans working at Google, using Google Plus to set up a website to promote a veteran's workshop. Kent had set up a non-profit organization, a veteran's workshop to train blind veterans to caption phone calls for veterans with hearing loss. As we were talking on the phone about his work, he said, "Wait a minute, you have a hearing loss. How are you using the phone?" I told him about captioned telephone, the CapTel I was using. He'd never heard of captioned telephone. Now he knows about it. He wanted to find a veteran with a hearing loss willing to help launch this relay service, Veterans Helping Veterans. They wanted to call the Obama and Romney campaigns on Memorial Day. I'm not naïve. "Kent, do you really think they will take your call? Really?" He answered, "They have to. It's a political campaign. They cannot, not take the call"

Long story short, the campaign didn't take the call. And I couldn't locate a vet who wanted to participate with Kent. However, he is still working with his idea.

Another example of how my outreach has offered me opportunities is being invited by the National Council on Disability to attend a one-day symposium, VCOA, this past June. I was one of 22 invited guests. The theme of this all-day workshop was that no matter what one's disability is, it is common ground. At the end of the day, all the people who spoke agreed that their disability enabled them to go places with their lives that they never thought they would go.

I have been saying this ever since I was disabled, that is, got really sick when I lost my hearing and was retired. It was the best thing to happen to me. I don't have the mental capacity I used to have. I don't have the physical capacity but I have a lot of appreciation. My life has been good. I am sure veterans are scared, lost and lonely as I once was. All of us with hearing loss have experienced this.

I was asked to go to the Veteran of Foreign Wars conference in Reno and moderate two panel discussions. Seven of the eight panelists were veterans who had served from World War II on up to Iran and Afghanistan. I thought to myself, I appreciate the thought, but what makes you think I can moderate a panel? I can't process information like everyone else. I can't modulate my voice. How am I going to hear the panelists? I ended up moderating the panel after all and found it was the best veterans-related event I had ever done since I began doing this outreach. The first panel was at 9:00 in the morning and we learned quickly that waiting to communicate on a panel discussion is not a good way to communicate. They had CART, so I was able to read everyone's responses. When we went to the second panel, we raised the microphone and I revised the questions a bit. As it turned out, we stayed 45 minutes beyond the allotted time and we accommodated every veteran in the overflow audience. We answered all their questions and also let people just talk about their experiences. It was just real life experiences coming from the heart while the panelists benefitted from the discussion as well.

I want to talk about numbers. The Veterans Administration says we have 128,000 veterans with hearing loss coming back from our wars. The VA anticipates an annual growth of 20% of returning veterans with hearing loss. That number will stabilize itself at some point. Hearing loss in veterans is significantly underreported because the V.A. data only relates to the veterans registered with the V.A. A lot of veterans do not register with the V.A.

The VA counts any measurable hearing loss but I am pretty sure they are not taking into consideration the slowed information processing in terms of context and meaning. I knew I needed to get back into the V.A. system myself so I could be invited to talk to veterans with hearing loss. Veterans will understand this. I had checked myself out of two V.A. hospitals. That saved my life both times and both times it was against medical advice. I will stop there with that story. It took a lot for me to walk through the V.A. door. Five hundred thousand veterans are known for having hearing loss who are not in the veteran administration system. That number was originally given to me in 2010 in an interview with a researcher working with the Marines.

It wasn't until last fall that an article by AHEAD (the Association of Higher Education and Disabilities) published the number at 350,000. I asked this researcher, why the disparity? Why is there a range between what the V.A. says at 128,000 and the 500,000? It depends on who is doing the research and it depends on the agenda of the people doing the research. So we know the 500,000 figure is more accurate than the V.A.'s data but that's about all we know. What makes counting so difficult is we can't see a hearing loss veteran. We can't find them because we can't see them. So where are they?

Again, the V.A. system has the statistics. They have numbers but they can't show who or where the people are. ACE, the American Council on Education, publishes a lot of research related to veterans. They actually survey veterans. They did a survey in 2009 or '10, and recently finished one last year. What do the numbers mean? What does the research show? The research focuses on higher education, such as what private colleges have vet programs and which are the better programs. They are not getting any information useful for me. I was really frustrated with the D.O.D. also when they cautioned I use the data carefully. For me, they didn't have enough solid information to make any judgments. The data is useless. This is all coming back to that *USA Today* competition.

Before I get to that, can we all agree that hearing loss is an invisible disability? Yes? Traumatic brain injury, TBI, is an invisible disability, correct? PTSD is also invisible, correct? Pretty much all three are invisible; however, they will have different visible manifestations. People with hearing loss tend to avoid conversation. The articles on recovery or rehab are rarely about veterans with hearing loss. In a rare case, HLAA in October 2010 published an article about Captain Mark Brogan, a soldier who lost half of his skull that resulted in hearing loss. Another vet I know is a quadriplegic from the war and for both him and Mark, the most inconvenient disability is their hearing loss. They say, "Quadriplegic? I can get around, I can get out there and talk." What they couldn't do is hear.

The difference is veterans with visible disabilities have sports leagues. They are playing games; they are interacting. How many of you saw the Olympian with the prosthetics? This is enabling and visible. Everybody in America has a heart and we are touched by the bravery of these vets. We admire them and thank them for their service and we mean it. But there is no reciprocity for veterans with hearing loss. While their buddies are getting recognized privately and publicly and socially, veterans with hearing loss are barely noticed.

So what do we do for this TBI hearing loss, IED's, noise, processing issues, PTSD? I call this the trifecta of disabilities. Vets with these invisible disabilities are out there in numbers that we can't count because we don't know who they are or where they are. This is coming back to the *USA Today*. If my team can produce those five panel ads, we will raise an issue that has not risen to this level of public conversation before.

First, I'm working with educational researchers who already work with deaf and hard of hearing students in the classroom. We have been trying to launch two separate proposals to get grant money to work with other institutions collaboratively at no cost to them. The grants would fund my travel and outreach. Although we have the numbers to justify it, how do we

find out where these people are? I have already worked with my ad competition team to develop a survey that we display in the fifth panel. The concept is to invite veterans with hearing loss and anyone who knows of a veteran with hearing loss to participate in the survey. Tell us your story.

Second, I contacted the Associate Director of Military Programs and the American Council of Education. I wanted her to help us develop this survey. She said that she was thrilled by the idea but what I am proposing is so large, it is beyond the scope that anything any researcher has done. Nobody has done this, nobody has asked the veterans with hearing loss, or given them an opportunity to tell us who they are or where they are or what they want or what they need. I'm aware, it may not happen. It may implode. It may just be embarrassing but that is not going to be for lack of effort or motivation. I'm very optimistic about finding those vets with hearing loss.

I hope you are too. I hope you spread the word. I would really like to stay in contact with people interested in this project. I am even confident that I have to come up with a concept for a research project. Even if the survey concept is rejected on the first draft, I know through the people I'm working with, I will probably have access to the Gates Foundation and some big spenders willing to support veterans. If you have any thoughts or ideas or concepts on how we can go forward and actually have a conversation with veterans with hearing loss, I would fully appreciate hearing from you

The survey will be tiered. That is, if you respond to certain questions, you are asked if you would be interested in taking another survey related to these questions. The survey asks about the needs regarding employment, education, training, social support, family support, things of that nature.

The five ad panel starts with visibly showing the isolation of hearing loss. Then we move that to the inability to socialize and about the trifecta--TBI, hearing loss, PTSD. Third panel shows the kind of attention the enabled warriors are getting, that they are being recognized in comparison to the veterans with hearing loss. The fourth panel addresses employers and family members. And the last panel addresses the entire population that reads *USA Today*. We ask them to take action by taking the survey.

Audience Member: It seems like the survey would have to get the information that's missing. I mean, working for Sprint CapTel, I go to the V.A. and they won't even let me put brochures for captioned telephones in the V.A. You know that's where you know they are going to see thousands of military or even prior military that need help hearing. They have no knowledge of it. The bases don't have individuals going to the TAP seminars giving them the data they need so when they separate or retire they have the information. They don't give it out. I went through it myself. You don't get anything. Civilians are offered more than the military.

Lt. Ford: This is related to the dilemma about "are they going to take the guns away?" After this accessing conference in Denver, I read an article about how the Command was systematically finding ways to boot out decorated warriors for small infractions to save the

army \$770 a month in pay. On the strength of that, I went directly to the hospital on base to talk to that chaplain at the hospital. Figured if the Chaplain saw me when I was in the hospital, he sure is visiting these warriors as well. I told the Chaplain what I was doing. He connected me with the people who are in charge of out-processing warriors because of their disability. One of the panelists at the Reno conference is a retired chaplain working with veterans with hearing loss. I have some connections that I will exploit. I definitely will ask them for feedback on both these issues.

Audience Member: Maybe five or six years ago, some vets emailed me wanting to know how many veterans with hearing loss there were. I went to the V.A. hospital and started asking questions and they told me they didn't know. I didn't find any information.

Lt. Ford: That represents the worst data yet.

Audience Member: I didn't know where to go.

Lt. Ford: The V.A. is huge. Some people are more helpful than others.

Audience Member: The vets wanted to do a story on veterans with hearing loss. I couldn't find anything. I'm still trying. I will succeed one day, you watch.

Lt. Ford: I hope so. That's my frustration, too. You can find isolated articles here and there. I think vets just need a place where the conversation can start. For example, in 2009 I visited every Seattle community college campus and at every one of them, first thing: the interviewer sought out the Disability Director. Some campuses had a veteran rep person. I knew immediately when that rep was not a veteran because they had no idea what I was talking about. The ones who were gave me the good scoop. "Yeah, we have a lot of veterans on campus with hearing loss, mobility loss, breathing issues." I asked what they were majoring in. He said, "Majoring? They are taking courses. They are biding their time, they are in the water, they are drifting." They don't have goals that they think they can achieve. So how are they going to get in the program?

Audience Member: They are in college for the stipend so they actually have income while they are taking a class. They need the stipend because they need to survive. It is not necessarily about the school. They will sit in school forever and take classes.

Lt. Ford: That typical story about veterans in colleges has been repeated. I know that's one place disabled veterans are. Once we can identify institutions that are willing to identify that issue, I think we would be making inroads. Again, a survey can get at that. Right now ACE surveys universities and colleges in America, the V.A. does a study of veterans themselves, I think, annually. They update few of these. So they come back with stats that report 80% are doing four-year degrees. Or some other percentage is going for two-year degrees, but they don't say where. There is no demographic information. That's why their information is useless to me.

What really bothered me about the V.A. and ACE surveys is they don't know where the for-profit colleges are or how many vets they serve. I'm showing in my personal interviews and

conversation are telling me that veterans in higher ed. at the bachelor level are tending to stay in the environment from where they were deployed. Fort Carson soldiers deployed from Fort Carson are returning to Fort Carson. That's where their families are. You can't get that data from any ACE reports. Therefore, I am targeting 13 military installations on six regions in the U.S.

Audience Member: Can you get federal congressmen interested where you can make them do a survey?

Audience Member: You have an uphill battle, I see. There is so much pride being a service member and then when they are injured, they don't want to acknowledge it. And so they go almost into hiding or denial and change things around so they can survive and even still stay in the military and get by with it. So they won't tell you stuff.

Lt. Ford: I have also heard from others who are taking advantage of the V.A. counseling system. There are different stories, different experiences, different situations. The uniqueness of the combination of PTSD, TBI and hearing loss, says you can't make general statements.

Audience Member: I did 22 years of counseling. It wasn't with the V.A. It was Veterans Helping Veterans. When I tried to going to counseling with the V.A., it cost \$200 a month. I mean, I served my country, and I'm screwed up, and I needed help. Illinois Vets helped me. Got my head screwed on right.

Lt. Ford: I actually think the Veterans Administration is cognizant of the value of veterans helping veterans and I think that's going to be a growth area in the counseling. I have credibility on campuses as a veteran with the veterans who recognize me. The civilian's view is I'm just another veteran who wants something from the school. Kind of cynical, isn't it?

We can't let all that cynicism, a reality of the day, predict what is going to happen in the future. Someone was telling me, "You know, you are crazy for doing as much as you are doing because you can't make an impact. You are going to lose your sanity." I have nothing to lose here. I am not going to get fired from my job. And if it came to that, I don't really care. Relatively speaking, it is a small thing to me. My life would be inconvenienced without a job, no doubt about it. But it is a small thing. Small things are big things for others. It depends on where you are in your life.

So...I'm so optimistic, and hopefully next year at this time, the deadline for this *USA Today* ad campaign is the third week in November, we will have something to submit. Ultimately, I believe the ACE will see the value in this survey because we are not tethered to ACE's very restrictive higher education focus. We can go beyond the boundaries that they are comfortable with and we are willing to collaborate with them. I think they are actually going to sign on. Especially once we start collecting the data. I see a bright, bright future over the next six months on this topic.

Audience Member: The V.F.W.'s, who goes there?

Lt. Ford: Veterans of Foreign Wars, one of the major social groups, support groups for veterans.

Audience Member: No hearing loss vets go there?

Lt. Ford: Well, I have a love/hate relationship with the VFW and with the individual I interact with in Reno. They are fantastic, real people with real stories. And they really appreciate the deaf holistic hearing health panel. However, when I went through the headquarters table and got contact information for North and South Carolina, specifically to help recruit veterans to speak here today, I was stunned by the indifference and apathy.

The VFW said, "You want me to do *what* for you?" Actually, they are not doing it for me. I think based on what I saw at their national conference, at least 100 people benefited by a presentation on hearing loss. It opened their eyes to the available technology, if nothing else. They also saw they weren't alone. There was a group of them: a hundred veterans with hearing loss in one room.

The VFW is asking me if I think they are helping me? No. The VFW is helping its membership. They are not helping if they don't care. I was asking for e-mail addresses. I tried phoning others and there was just apathy. It is discouraging and it is really difficult to find current information in terms of the leadership within the VFW. I definitely will get the information when the survey is developed but I haven't had a lot of success with them up to now.

Thank you for your attention. I have email if you would like to stay in contact with me:
amfntd@ntid.rit.edu

Lt. Allen Ford was commissioned a regular Army officer, Military Intelligence in 1979. In 1980 he retired with a service-connected hearing loss. Since then, he has earned an MFA in Fine Art Photography and an MSSE, Deaf & Hearing, from RIT, Rochester, NY. He currently is Assist. Prof. NTID Business Studies, RIT, Rochester.