

A new paradigm to rally round people with aphasia

by DON WEINSTEIN on MAY 21, 2014

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God knows my speech therapist worked daily, Monday to Friday, attentively and conscientiously, to help me get my limited speech, by stages, back; I will be beholden to her every day for the rest of my life. She was in the trenches with me and the rest of my aphasiacs sweating out each letter, syllable and word fifty weeks a year. I valued her and her colleagues at Transition of Long Island and the hundreds of other hands on speech therapists and the people with aphasia who shared their experiences, as limited as they were. Over the years I spent more time in rehabilitation centers, hospitals, universities, and other types of community aphasia groups listening, speaking and Skypeing.

The worst assembled group programs for aphasiacs and caregivers were those who were presented my therapists who didn't have daily hands on experiences in the trenches presently or people who didn't have aphasia but had a script about aphasia; the chutzpah, the audacity, the presumptuousness and pretentiousness when they wring out words that say that aphasiacs are bright but the organization somehow couldn't find one person, one person, with aphasia to present the program and the other speakers who have aphasia.

In juxtaposition to the fact that some organizations still have no aphasia presidents, presenters or master of ceremonies for programs, they are good, competent organizations, yet, they dream of an aphasia global association; they have not worked out the relationship between the different aphasia group, agencies, organizations and the problems in each state in the United States. These people have chutzpah; they dream the dream, their dream of an aphasia global association, a daydream, like Happy Talk Lyrics, "You gotta have a dream, if you don't have a dream, How you gonna have a dream come true?" Who can argue, no, who would want to dispute Hammerstein and Rodgers? Not I. But is this dream a prophetic vision or a nightmare? Is it for management types, in the United State, even though they haven't gotten all universities, hospitals, medical staff, therapists and aphasiacs on board? Hell no they have to go miles and miles so why are they pushing for the global association?. And who will control this organization, therapists or people with aphasia? Is this a top bottom or bottom top association? Is it to help people with aphasia in the United State? How will this help a person with aphasia? Is it meant to be a pot of gold of jobs, grants, recognition awards and government charity?

Stop thinking that the aphasiac community wants charity or that we can get along by afternoon teas and crumpets and government doles; the Ivy leagues are just another group of costly good schools, the Episcopalian church is just another church, those Ivy leagues and Episcopalians together with the CUNY and SUNY noble prize winners, in every state university, and the Native Americans, Latinos, African American, Irish, German, Norwegians, Swedes, Jewish, Italian, Poles, Indian, Chinese, and the other immigrants that made this country great also have people with aphasia. Instead of talking to other academicians in their annual conventions find out where people with aphasia live and go to their houses and talk with them, there is no simply way but it is a sure way; stop cursing hard work and make use of the lessons learned by businesses, politics, governments, and universities; make use of high schools and colleges students.

I have a dream also; aphasiacs must own their organizations, an organization of aphasiacs, controlled by aphasiacs, for aphasiacs, headed by a person with aphasia with an abiding respect for the need of transparency, with some kind of a annual shareholder meeting, so that the people who give money can hold the board, director and staff responsible for the organization's programs.; these groups will be supported by families members, employ speech, occupational, emotional and physical therapists; they will get help from grassroots marches, protests, boycotts and civil disobedience; and if needed they can buy other talents. That was a lesson learned from the time of the abolitionist movement, National Rifle Association, unions, Alcoholics Anonymous and the wide range of substance-abuse and dependency problems, African American movements and the NAACP, the oldest and most widely recognized civil rights organization, Woman (NOW), National Council of La Raza and the Vietnam, Iraq and Afghanistan wars organizations and other groups.

Fredrick Douglass understood the ludicrous events when white and black abolitionists, well meaning, introduced him to the audience and then interpreted Douglass' words and used him as an object, one that was told to follow the scripts of the activists. Douglass was literate, understood the details and horrors of slavery; he had been a slave. There was no reason for him to be only an example; he rallied against the fact that his was an object, it was degrading and infantilizing; he was in a moral prison, constructed by the abolitionists; he became free when he spoke his words and thoughts in his tone. Unfortunately, this absurdity still goes on today when a puppeteer who doesn't have aphasia comes out to talk about aphasia; he show off his bullpen of aphasiacs, and limits their time and thoughts; it was unbecoming, morally lazy and a mockery of brightness of people with aphasia.

There are therapists that should be honored by their professional organizations as therapists not as Ms. or Mr. Aphasia. The aphasia movement is a movement for people with aphasia; remember the poster woman or man is a person with aphasia.

Please give me some feedback especially if you want to form a new aphasia organization with aphasia management.