Week 4 Journals

Janet Marcous class visit (April 21, 2011)

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(authors names removed)
I truly enjoyed hearing Janet Marcous recount many of the pivotal events in her life— for an individual who has been dealt quite a challenging hand, Janet is remarkably poised and comfortable being herself. Aside from her academic and professional achievements, Janet seems to have learned how to take advantage of many of the simple pleasures that life has to offer. From hiking outings with her husband, to long walks on the beach with her loyal canine companion, Janet shows how persistence and trust in others has allowed her to live an exciting and fulfilling life. I was particularly struck by Janet’s discussion of her time in California following her completion of college. Not only did she live independently during this time, but she put in the effort to reach out to those around her and initiate relationships. I think I’ll always remember her anecdote about the Sunday morning breakfast club that was a tradition for Janet and her friends. In a similar vein, it is truly incredible how she sought out opportunities to participate in community activism during this time. It seems that many Deaf and Deafblind individuals dedicate a lot of energy to activism to their own causes of equal opportunities for the Deaf and Blind; on the other hand, it seems that Janet has remained true to various outside causes that affect her on a direct or indirect level.

Ultimately, I think that Janet Marcous serves as a wonderful example of how Deaf, Blind and Deadblind individuals can flourish even with various “limitations.” She showed us how she is not defined by her deafness or blindness, and has been able to actively pursue her individual interest and passions throughout her life.
This week we had the pleasure of meeting Ms. Janet Marcous. Although we were told in advance that Janet has Usher’s Syndrome, I was not sure what to expect. Prior to the class, I tried to imagine her perspective and all I could think about was darkness, and total sensory deprivation. Thus, I was curious to meet Janet and better understand how she copes with this “darkness” I couldn’t get past in my imagination.

Upon seeing Janet, I was instantly impressed. Although I still couldn’t understand how her world worked, I was surprised by how well she could express herself with both her face and body language, and her general disposition. Here was someone who was not totally lost in darkness. Even just seeing her stand up to introduce herself to us, I could tell that she had a vivid personality despite her difficulties in receiving information from the peripheral world.

I found her request to hear our first thoughts on the Deaf-blind experience to be a bit awkward at first, mostly because if you boiled down what each member of the class said, our collective response to her inquiry was that deaf-blindness sounded really difficult and horrible. I really enjoyed how Janet went through each of our concerns, and explained how her perspective was different. She was right. We all rely on others to get by, and asking for help always takes courage. Yes, she needs to ask for more help, but she is proud of herself because that takes more courage that the average person must rely upon.

It was quite obvious to me that she is in fact an independent being with her own personality. I am very sad to see that such a wonderful person has to cope with such immense difficulties, but I was inspired by her positivity. I appreciated her honesty about her hardships – that she has bad days and moments of weakness. It became clear to me that through her hardships, she has found meaning in her life and ways to have a positive outlook toward the world. Although I consider myself to be a positive person, I can also be cynical and pessimistic. It amazed me to hear about how she has matured through needing to trust more, and learning that there are more safe people than we realize and that the world can be a good place. It seems that we are often hearing the opposite – that the world is becoming worse all of the time and that we are all contributing to some demise, and it is inspiring to hear optimism from someone who is coping with what are for me unfathomable difficulties.
Thursday, Janet Marcous came in to share her life story as a deaf-blind individual. I don't know what I expected to see as I walked into the classroom, maybe someone who looked crippled, who was hunched over and looked like they had the weight of the world on their shoulders. This, however was not what I witnessed, and as I sat down and listened to Janet's story, my perception of her changed drastically. She is a normal person, she is deaf-blind yes, and throughout her life she's struggled especially with her mother, which I found disheartening, but it did not get her down, and as she continued to tell her life story she morphed into a strong, independent, individual in my eyes; the fact that she was deaf and blind became trivial. Janet asked us some thought provoking questions, one in particular asked us to think about and discuss what it would be like, or how we would feel if we became/were deaf/blind. One of the responses was that we would be completely dependent on others and lose our independence. For some reason I did not agree with this reply, and what Janet said aligned perfectly with what I was thinking but could not put into words. Janet said that she is in fact independent, its just that she has to "trust" people more, she said that hearing and seeing people are not completely independent as we all like to claim, we all do in fact depend on each other. We depend on our professors to teach us correct information, we depend on family to be there to support us, we depend on classmates and tutors to help us succeed in school, we depend on authority figures to protect us and inform us. We are ALL very dependent people, so its not so much the "dependent" factor that would change if one were to become deaf/blind, its, like Janet said, more of a trust issue, you have to trust that people will help you, be there for you, guide you correctly and not do you wrong. "I still keep dependence inside," is what Janet said, "I still have a sense of spirit...it takes strength and courage to be someone who is deaf/bind..." Janet did not consider herself weak, saying that "vulnerable does not mean weak," every time this woman spoke, she transformed before me into more of a strong independent woman, my first impression of someone who would look blind and deaf, whatever that was supposed to look like in my mind, completely vanished, she said some really profound things that definitely made me stop and think. After she spoke I reconsidered my initial response to the prompt and the only change I would make would be that if I ever did become deaf/blind, I would not be sad or devastated or whatever, rather I would take it and run with it, considering it to be a new way to experience the world.
She was sweet and more blind than I would have guessed. Was that a hearing aid in her ear even though she can't hear much? I loved hearing her talk about two things: her dancing and her lip reading abilities. It made me think so much about her, and actually, how I envied her (if I could say that). When she asked us to think about how it would feel to lose your eyesight and hearing in one day, I thought of nothing good. I responded with something like, identity would be lost, loneliness would ensue, independence would be lost, all of my physical activities like tennis and rock climbing would be gone, my family and friends would become distant, it would be hard for me to meet new people, etc. I couldn't even read, which is always something I can do when I have nothing else to do or people to be with. I couldn't watch movies, I couldn't listen to music, see landscapes, etc. More importantly, the burden to communicate with someone would be on them, and not on me. Right now I could go up to a stranger and start a conversation. But Deaf-blind, I could not; interpreting is not the same.

But now that I have thought this over all day, I have come to realize that some good can become of it: being Deaf-blind all of a sudden. After a few years adjusting I feel like I would know people (perhaps fewer in number) a lot deeper. In order for a friend to stay close friends with me they might have to learn sign language, and when they do, I would be experiencing it with them. I would get to know them so well, like only best friends could. And the second thing that is good, is that I would learn to trust people, like Janet said. Trust would be a central part of my life, whereas individualism is a part of my life now. People in this world do not trust each other enough today, and perhaps I would see a different side to the world if I became Deaf-blind.

I talked her husband after class, and we talked mainly about how the non-Deaf-blind world sees him and his wife. When they are walking down the street, people are drawn to look, because there are not that many people being led by seeing-eye-dogs. Given the chance, anyone will try to pet the dog, which is not good for the dog at all. And that is why they leave the dog at home for social gatherings, or else people will pet the dog all night. People don't realize that they should not pet the dog. When they go to restaurants, the owners will say that the dog cannot come in until the husband explains that he cannot refuse them service because of a seeing-eye-dog. When they go to dance clubs because she likes to dance, she cannot take the dog because the loud music would be torture to the poor creature. And she doesn't like leaving the dog alone for more than 4 hours, so they usually have to leave the dance clubs early.

I got a glimpse into the Deaf-blind community today for the second time in my life. The first time was reading about Helen Keller in elementary school. But I think that being born Deaf-blind is different from becoming Deaf-blind. In class someone said that becoming Deaf-blind would be better because they would have already have seen the world, and known about music and such. I disagree. I think that becoming Deaf-blind would be worse, much much worse. To someone born that way, each new success is inspiration for more, but to someone who has become Deaf-blind, nothing can ever be the same (perhaps as good) as the past.

I wish I could lip read.
I thought it was going to be really depressing to meet someone who is deaf-blind. Before meeting Janet, it was really hard for me to imagine someone being both deaf and blind and leading a full life. Janet Marcous amazed me; meeting her was exhilarating and enlightening. She is funny, honest, open and courageous. Meeting her gave me hope that there is nothing that the human spirit cannot conquer.

When I was sixteen, I was blind for four days due to a neurological condition, so I can imagine what it is like to be blind, but it is hard to imagine what it is like to be permanently blind. When I wasn’t in the hospital, I was trying to find my way around my house and getting frustrated at everything. Why hadn’t I counted how many stairs there were when I could see, or figured out exactly where doors were? Why didn’t I take full advantage of my capacities to observe the world around me, when I still had the chance? Of course, at the time I didn’t know for sure that my vision would come back, and I was very depressed. I regretted not having prepared in some way to lose my vision, yet I’m not sure I would have preferred knowing it was going to happen, the way Janet did. I was scared when my world disappeared. I wasn’t well-adjusted or brave or thoughtful—I wasn’t like Janet.

When Janet asked the class how we would feel if we were deaf and blind, I immediately thought about how I could still interact with other people. It didn’t even cross my mind that if I were to lose my sight and hearing, I would not be able to have the job that I wanted, or the future I had chosen for myself, that I have spent my whole life preparing for. All I thought about was other people and how I would feel disconnected and isolated, which I suppose speaks to my priorities. It is remarkable how much you learn about yourself when someone asks you very thoughtful questions, as Janet did.

Janet taught me a lot—it seems almost everything I thought I knew about being deaf-blind doesn’t apply to Janet. I’m not entirely sure whether she is a particularly amazing person or if I had the wrong impression of what it is like to be deaf-blind, but it’s probably both. She doesn’t appear isolated; she did say that at times being deaf-blind depresses her, but she is remarkably connected to other people and her surroundings. Janet has an extraordinary ability to sense emotions and sort of read people. It makes her very empathetic, exactly how I wish to be. She knows when something is funny to other people, or awkward, or puzzling. She perfectly understands what others are thinking; this was demonstrated when she analyzed our misconceptions of deaf-blindness—she knew the class was hesitant to really introspect and also to say something that might be considered offensive. She reassured us without anyone even needing to say anything. Janet is incredibly wise. She talked about how silly it is that we as a culture (especially young people) are so concerned with our image—not merely our physical appearance, but what others think about us and how we’re being judged. She’s so right—it is incredibly refreshing to forget about who others want you to be, or who they think you are, and just be. This lesson is invaluable. Janet also taught me that it takes maturity, courage and trust to ask for help, and that vulnerability does not mean weakness. I came to the class thinking that being deaf-blind was basically akin to helplessness, and I left with a completely new perspective on deaf-blindness, and well as a few precious life lessons that only really sunk in when offered by this extraordinarily wise, understanding
and compassionate deaf-blind woman. Janet is one of the most admirable, inspiring people I have ever met.
Janet Kyricos Marcous, the founder of the Deaf Blind Community Access network and the winner of the University of Massachusetts' John F. Kennedy Award for Academic Excellence, came to speak to my class about her experiences as a deaf-blind woman.

She began her aural autobiography by describing her experiences as a Deaf child. She explained that she was "without a language" during those years. The term that Patrick Graybill so often mentioned, *allingualism*, came to mind. I wondered how it felt to be without a voice. Her speech is astounding; she enunciated every word clearly and I could barely distinguish her dialect from that of a hearing individual. Her mother's early intervention and insistence on oral education paid off, or so I thought. Marcous stated, "My mother did not want a Deaf daughter. She wanted a hearing daughter". I believe her parents must have spent a fortune perfecting their daughter's rhetoric and ensuring that she assimilated into a culture that disdained her. And then *class* hit me. Had Marcous been born today, her parents would have exploited the new technology of modern hearing aids and cochlear implants. Would Marcous' life be significantly different had she been born 40 years later? Our guest's upbringing reeked of privilege, specifically since she was raised in a time when people considered deafness a disability. Save her inability hear and the taunts that followed, I believe Marcous' childhood somewhat normal. She grew up in a nuclear family with a protective older brother and immigrant parents.

During her early adulthood, Marcous refused to allow her parents to control her life. Persistence must be in the bloodline, because she never expressed a degree of helplessness as she discussed her rejection from Emerson, society's disdain towards her, or the loss of sight in her early 30s. We were paired off and asked, "How would you react if you became deaf-blind?" For many of us, Marcous was our primary experience with a deaf-blind person. It was difficult to fathom the self-tragedy. Many of my classmates felt that they would be forced to abandon their ambitions if faced with the obstacle. Marcous then stated two very important things. First, deaf-blindness does not lead to dependence; rather, it leads to interdependence--a trait that all successful people share. Marcous' state allowed her to cultivate a genuine relationship with her now-husband, for example. Secondly, Marcous explained that people are nice than we think. Someone will always be there to help us as we navigate our way through this game called life. I appreciate her wisdom. By the end of the discussion, I no longer thought of Marcous as an upper-class, lucky woman, but a *class act* who we can all benefit from.
Janet Marcous’ visit to our class was both truly inspirational and simply astounding. Everything about this lecture, from the setting to the visitor’s biography, provided me with sincere, personal insight about the world of the deaf-blind. I honestly can say that Janet Marcous’ lecture was the best lecture I have ever attended at Dartmouth!!! IT was not only didactic, but insightful and intimate-I felt every word she said and in my mind I envisaged every experience she related. While listening to her talk, I honestly forgot that she was deaf-blind because before me, I saw a strong, happy, charismatic woman. The minute I entered the classroom I noticed the change in setting: the black screen covering the windows around the space in which Janet and her interpreter sat, the dimmed room, and the bright lamp situated in the middle between Janet and the interpreter. I was intrigued to see this setting and since I had never ever seen a d/Deaf-blind person before, I became excited about the lecture. I’ve seen many blind people in the past and it was amazing for me not to notice visually that Janet was blind. She carried herself out very properly and comfortably and her overall demeanor was absolutely mind-boggling. Janet began by introducing the students to her earlier days as a child. She emphasized how much her mother has always wanted her daughter to be “normal”- a hearing child just like any other. I was profoundly touched by the fact that she spoke so candidly, though I felt how agonizing it must have been, of her days in public school. Janet related the frustration and anger that she felt as a child when her mother forced her day after day to speak vocally and always criticized her until the age of 18 in order to perfect her speech. The intensity of the emotions that Janet had felt during those years could remarkably be sensed in her words-it was as if her experiences and the emotions they evoked were speaking, not her. I could never imagine myself in her shoes-
to have my own mother whom I boundlessly love criticize me and be so tough with me simply because she believed that maybe, just maybe if I spoke vocally, despite a neurological disability, I would be become “normal”. How could a mother estrange her daughter from her own identity?!!! And most importantly, how did Janet find the courage and strength to relate such experiences?!! Janet is not only proud of who she has become but also strong and well-aware of the fact that if words don’t hurt you, they will make you.

Another inspirational aspect of the d/Deaf-blind culture that Janet mentioned is the notion of TRSUT—that word that we all demand as and say all the time without ever understanding what it means to actually trust someone. I never knew nor understood trust until the day Janet spoke about it; the idea of trusting anyone and sometimes everyone around you without ever being able to listen to them or see them—simply trusting people in darkness. This idea of trust was unfamiliar to me and made me realize that I may never ever be able to trust anyone to that extent; maybe I’ll never be able to really know how to trust unless I’m forced to do it. With trust Janet did a remarkable job explaining to us that just because you trust people doesn’t mean you’re dependent upon them, and just because you need them sometimes doesn’t mean you’re weak. In America, I noticed that vulnerability is ALWAYS linked with “weakness”, but Janet proved to me and honestly to everyone who had ever met her that vulnerability NEVER equates weakness. She taught me a personal lesson that I will never forget: that I can be dependent on those I love because I deeply trust them, but also be an independent, strong, relentless woman inside. I am only dependent when “I suck people’s energy” as she stated, and well truth is she is far more courageous than any of us for the faith she demonstrates in people around her. I not only admire Janet Marcous for
being able to overcome her Usher’s syndrome, but for becoming a woman; someone
whom you can look at as an example, someone you can accompany as a friend, and most
importantly someone you can talk to when the world become dusky in your eyes.
Strength = Courage ⇐ Vulnerable ≠ Weak ⇒ Physical

This was one of the last things I noted from our class with Janet Marcous and something that, I believe, nicely summarizes the gist of her message. Janet redefined many words for me, including those in the “equation” above. While her questions gave us an opportunity to reflect and to try to imagine what it would be like to be Deaf-Blind, it was her stories of determination and trust that truly struck me. What does it mean to trust? How does each and every one of us fit into the web of interdependency in which we live? These were questions that she raised, and that ultimately proved that while being Deaf and blind presents numerous unique challenges, societal views are what isolates these people from others. “Society is too much about the image of independence”, Marcous pointed out, when the fact of the matter is that each one of us relies heavily on other people. Dependence is taking those that help you and “sucking up their energy”. In contrast, courage and maturity are knowing how to ask for help while maintaining a sense of self and a personality inside.

Marcous also used the word “courage” in many other contexts, linking it to trusting in oneself and others and associating it with having the strength to cry. After all, “life is too short” not to do so. This idea of courage certainly seemed to be a theme of her presentation, and a concept that she exemplifies. I felt honored to have been in her presence, to have heard her life story and to have had the opportunity to benefit from what I’m sure is a very small portion of her wisdom.
For the past week I have continued to dwell on Janet Marcous’ visit and the questions she posed to the class. To be perfectly honest I think I would feel overwhelming frustration if I were to become deaf-blind. I would feel a loss of independence. This is not to say that deaf-blind people cannot be independent – Janet is certainly proof of this – more that I would be personally dependent upon others to do routine tasks for me until I relearned to do them myself.

In many ways I believe I would be less adept at navigating the world if I became deaf-blind at this point in my life. I have relied on both my hearing and vision and I would be utterly incapacitated without them until I overcame a (very steep) learning curve. However, I would have some advantages if I became deaf-blind at this point. I have a grasp of the English language which would make it easier to learn to read braille or raised print. I could also speak, although I would not be able to understand speech.

I admire Janet’s courage and strength. While I would like to hope that I would persevere if I became deaf-blind I think that in reality I would become depressed over the loss of my imagined future (one where I continue to be non-blind and non-deaf). Janet’s confidence regarding the general goodwill of people was somewhat surprising to me and I am attempting to remember her sense of pervasive optimism and trust each time I encounter negativity.
Janet Marcous

I had some difficulty getting started on this journal. Janet Marcous' class visit brought about quite a lot of emotions and thoughts that I've always had, but never took the time to actually think about. Putting all of that on paper is a bit difficult...but I'll start from the beginning.

Her first question: what would you do if you were deaf-blind? What a loaded question. From taking this class, I have thought about what I would do if I were deaf and having to deal with that seems difficult enough. But to be deaf and blind, I couldn't even fathom what that would be like. When we discussed this in class, a lot of people said they feared losing their independence and I completely agree with that...but even beyond that, I thought if I were to become deaf-blind...I would be so lost. It would be like losing a part of myself, my identity, because everything I knew up to that point is suddenly taken away from me. I would feel such anger and despair because the dreams that I aspired to achieve, the little things in life I enjoyed doing, and the people I loved being with – none of that would be possible or the same anymore. Having to deal with that would require a lot of inner strength that I don't know if I would have.

With that being said, I was amazed with Janet's story. It surprised me how well she spoke. Granted, I have never heard a deaf person speak before, but I was in awe of how well her spoken English was in terms of pronunciation, as she has never been able to even hear herself speak. When she shared with us her childhood experiences, I felt such sympathy and frustration for her. Janet said her mother had the mindset that, “if my speech were perfect, I wouldn't be deaf.” I couldn't even imagine what kind of life that would be like to not have your parents accept you for who you are, and to be criticized constantly for something that isn't even your fault. It must have been so difficult to live under the constant judgment of her own mother, let alone the peer pressure of the students at school. When at 18, she finally said she was done to her mother, I was relieved and amazed by her strength.

This was honestly the best guest lecture that I have ever been to. I am just amazed by how strong and wise Janet is. It is so inspiring listening to her wise advice regarding things that I’m sure a lot of us have never even sat down to truly think about. Her emphasis about trust, for example, resonated within me. Do you realize “how much courage it takes to trust someone you don’t know?” Yes, that takes a lot of courage and modesty. Humans have a lot of pride, and I feel that it's particularly true at Dartmouth. She said that society is too crazy about the individual, and I completely agree with her. We are all stuck in our own
goals, dreams, and beliefs, and sometimes we don’t take the time to consider the bigger picture. That people around us matter, that at the end of the day, your friends and family are the ones who you love and would spend your time with (or at least for me). She said that so many people want to have an image and I think she hit the nail right on the head. When we become too concerned about our own image, when we don’t trust enough, this mistrust passes on to the people around us and we accumulate self-pride in focusing on ourselves, and then we don’t have the courage to ask others for help, even when we need it the most sometimes. It’s good to know that from her experiences, this world has a lot more safe and helpful people than we realize.

“The way I ask for help, I can still keep my independence inside”....“life is too short to pretend things are fine.” Most importantly of all: “I didn’t quit.” To me, this was the most inspiring thing she said, because it truly amazed me (and still amazes me) how someone can be so strong and so wise and so resilient even in the face of losing so much. It astonished and saddened me, because I think it is people like her, people who don’t have as much as others (whether that is in terms of senses, money, material things, etc), who come to the realization that life is really not about what you have....it’s what you make of it. So you may not get that A you really wanted in class, so you didn’t get that job, so you got into a fight with your best friend – all of that, is insignificant when you look at the bigger picture. Because it is then that you know, life is really not about the material things – it’s what you make of it, and it’s saddening yet inspiring to know that this was expressed so eloquently by an individual who doesn’t have as much as others, and has gone through so much, yet manages to rise above it all and make the most of what she has. It is these types of people who are the most genuine and incredibly wise, and it saddens me yet inspires me at the same time.

What would I do if I were deaf-blind? I’d be really angry, depressed, probably take quite a while to figure out what I can do and where I can go with what I have...but life sucks sometimes and it’s certainly not fair, and that’s something we have to accept....it’s just our job to make the most of it.

Also, as a sidenote – I thought it was so precious that she and her husband have such a wonderful connection with each other. They must love each other so much to be able to formulate such trust between each other... it was wonderful and endearing to see their dynamic.
Never having encountered a deaf-blind person before, I found the unique perspective offered by Janet Marcous during last week’s class fascinating, not to mention informative. Through choosing to run the class as a dialogue between herself and the students rather than as a lecture, I believe Ms. Marcous increased everyone’s comfort level in the class and effectively lessened the potential barriers to communication. It appeared that she was as interested in hearing our perspective on Deaf culture and deaf-blind issues as we were in her life experiences. From the start, Ms. Marcous set the tone of the class to one of frankness, asking each member of the class to elaborate on how they would feel to be deaf-blind. It was this exact level of honesty that Marcous reciprocated when she bluntly described many of the unsettling components of her childhood and adolescence, such as her mother’s repeated correction of her speech or the isolation she felt as a deaf student attending public school. It was apparent that such experiences served as a personal motivation to succeed in a society ill-disposed to her success.

This tactful method of presentation allowed me and my peers to take away the inspiring message that the deaf-blind are not individuals that need to be side-stepped, or handled paternalistically. Rather, they are individuals just as capable of doing great things as “hearing” people, as Janet’s life accomplishments demonstrate, and are dependent upon the support of others like the rest of us, just in different ways.

To close, Janet Marcous was an amazing guest lecturer for the class who really opened my eyes to the issues of a societal group about which I previously knew very little.
I really enjoyed meeting Janet Marcous in class last Thursday. It was the first time I had met a Deaf-blind person, so I was not sure what to expect. Professor Polansky told us that Janet loved to dance, but even so, I did not really imagine that she would radiate the vitality and vigor that she clearly has! I admit, when I first entered the classroom, it probably took me a minute or so to figure out who was Janet and who was the interpreter.

Like everyone else in class, I was deeply impressed and inspired by Janet’s courage, charisma, and confidence in her own abilities and in humanity. Although many of us stated that we feared our “loss of independence” if we became Deaf-blind in the future, she reminded us of the importance of “trust” and “codependence.” Many people have a hard time trusting the people around them, let alone complete strangers, so I was somewhat amazed that Janet was so optimistic and felt such faith in the kindness of other people. I agreed with her point that people have to be mutually dependent and supporting, but I hadn’t previously considered it in the context of letting other people see your vulnerabilities. I think that particular lesson will stick with me for a long time.

One lingering thought that remains with me is her childhood experience with speech training under the oralist method. She stated that her mother forced this therapy upon her against her will, and that she was thrilled to call it quits in her young adulthood. However, it seemed like this speech training did have some benefits, in that her speaking voice was nearly impeccable. In fact, it was easy to forget that she was Deaf-blind while she was talking aloud to us. Janet did argue that parents should not force oralism upon Deaf children as the only means of communication, but I wonder if any Deaf child would really choose to go through speech training in addition to learning ASL. That raises the question if Deaf children should even bother trying to learn how to speak. Rather, does it matter if they learn or not? This returns to the enduring controversy over oralism, but that is another matter altogether.

Lastly, I’d like to thank Janet Marcous for coming to class to enlighten us naive students about having courage in the face of obstacles and understanding the Deaf-blind experience.
Having Janet come to class was a treat. She was inspiring, not because she just lives a happy life as a deaf-blind person, but because she seemed so optimistic and honest about life, irregardless of being deaf-blind. I really appreciated her honesty in everything. I was a little bit scared to admit that one big reason that I was in the class was for the distribs, but she seemed to like my honesty, and she deserved it considering how open she was to us.

I really liked how she talked about dependency. Mostly everyone mentioned that being dependent others would be the hardest thing for them if they became deaf-blind. Although I felt that my biggest fear of becoming deaf-blind was that it would set me into a deep depression, I too thought that this was a huge issue. I really hate asking people for help, and I thought that the way she said that it takes a certain kind of courage to ask for help was interesting, and true. I don’t ask for help out of fear, not pride, usually. A fear of what, I don’t know exactly, but fear nonetheless.

I also found it really interesting that she dances. I can understand that she can hear some low range sounds, but I personally don’t enjoy heavy bass. Speaking through the close-range interpreter was difficult, but not too bad. It makes me realize that Janet spends a lot of time in close contact with people. I like close contact, but I know a lot of people don’t know how to deal with someone they don’t know well touching them or being right in their face. I think that having to be so close to people have shaped Janet a lot. She seems incredibly personable and comfortable, which I think is cultivated from spending time in close quarters with people. There was a study I once read about people who didn’t get much or any physical human contact and how impersonal they were, so I think it works the other way too.
From the moment I walked into the class I knew that this class would be different. Everyone was dressed in black and huddled around two women, one under a very bright light. A sweet yellow dog lay silently at the other woman's feet. As the class started and Mrs. Marcous went around asking each of our names, I was immediately struck by the difficulty of communication for her. Signing to her was a long process, she had to constantly readjust the position of her signer for light, and feel her fingers for the hand shape. I wondered how hard it must be for her if communication was this difficult.

Her demeanor completely unmatched this conception I had of a lonely world. She was warm and charismatic. But what struck me most was what she had to say, especially on the subjects of trust and reliance. Especially as someone who find it very hard to trust new people I was astounded by just how much she had to trust others and rely on them. She said that her Usher's syndrome has taught her that there are more good people in this world then we think. I never had really thought about that dimension of deaf blindness. Though there is this sense of perceived removal from the outside world, as sound and sight are less accessible, she is perhaps more attached to other people then many of us are, as she must rely and trust so many people.

Another distinction that she made that was very interesting to me was one that she made between dependence and reliance. She stated that relying on someone means that you receive support from them, while dependence means you are a drain on their energy. I had never thought of that distinction. I never like relying on people, but I suppose that is because I have never made that distinction. I am not entirely sure where that line lies and
I wish that she had elaborated on that more.

I guess what interested me the most about her talk is how much of her talk applies to all of us. Dependence versus reliance and trusting other people, these are concepts we all work with each day. So as corny as it sounds I don’t think we ended up not really talking about Deaf culture at all, but what Janet showed us about humanity.
One of the things Janet asked us to do was to think about what we would do if we woke up one morning and found ourselves deaf and blind. Thinking about it, almost every single thing that we aim for in life takes for granted the use of these two senses. We all want to get nice jobs, make a lot of money, and buy great things. Great things? Yes, things like a nice television, sleek laptop, a house with a nice view, etc. Just how great would those be if we lost hearing and sight? And what would we do for fun? We won't be able to watch movies, read books, play sports, or travel. What a frustrating world it would be! We're so dependent on sight and hearing for livelihood that it's so hard to imagine life without it.

1. I found some other people's reaction to Janet's question interesting. Many students seemed more concerned about what their loss would have on others rather than themselves. I just couldn't bring myself to think the same way. All I was thinking was about how much my life would absolutely turn upside-down. Maybe I'm too selfish and think about myself more than other people do? Or maybe the other students felt obligated to provide a more mature response because it was a classroom environment? And Larry's response was rather unexpected. He said he would be "relatively" ok with it since he was older and had already done many things that he wanted. But if I was his age I don't think I would be saying the same thing.

2. I think it's also important to address the topic of happiness, since happiness is probably the scale we most often use to measure our satisfaction. I want to start with the average person, using myself as an example. I am sometimes happy, sometimes unhappy, but generally content. But during the times when I am happy, I feel like nothing in the world could be better. When my favorite team wins a big game, or when a romantic interest works out, or when I reach a particular goal, I feel great! In fact, I find myself often using the phrase "There's nothing more I could want right now." But what about a deaf-blind person? Can Janet ever honestly feel that way? They might think they are happy, and to them it may be the happiest they can be. But how happy can that be if there is always that lingering thought gnawing at the back of your mind that everything would be so much better with sight and hearing? I can't help but think that everything would feel so fake. If someone else was to say that they were "happy for me," would they really? Is it all relative? I just think that by losing sight and sound, the high range of the "happiness spectrum" become unreachable.

3. Another thought that popped into my head during Janet's visit. Maybe the reason that I can't even begin to fathom what it would be like to be deaf-blind is simply because humans just weren't meant to live like that. If we think in evolutionary terms, a deaf-blind person simply would not be able to survive. Maybe we just don't come with the ability to cope with that kind of a personal disaster.

4. With everything that I said, I find Janet's determination and honesty amazingly admirable. She was able to come in and speak about many things that for her probably were, and always will be, painful to think about, given her current situation. I appreciated her visit, and wish her the best.
I’m not exactly where to start for this journal, so I think I’m just going to go through some things that we discussed with Janet that struck me, and really made me think. I spent a lot of time after this class thinking about what we talked about and discussing with my family and friends.

One of my favorite parts of this class period was when we had to imagine what it would be like if we suddenly became deaf blind. I remember when I was younger (probably around the time we learned about Helen Keller in school) my friends and I would play the “would you rather be blind or deaf?” game all the time. It seemed to me back then that either condition would be horrible, and that I would never really be able to live a happy life if I became deaf or blind. Back then, I never even considered what it would be like to be both deaf and blind, so it was an interesting experience to think about it in class. To be honest, when Janet asked us what the most significant impact would be if we were suddenly to become deaf and blind, my first thought was that I would no longer be able to read (at least not in the way I am accustomed to now). I have been an avid reader since I was very little (my mom jokes that while most parents had to beg their kids to pick up a book, mine had to beg me to put mine down) and I honestly couldn’t imagine not being able to get that thrill of picking up a new book and devouring it. Of course, not being able to read is a relatively silly impact that becoming deaf blind would have, but it was my first thought non the less. Once I began to think about what would really impact me, I came up with three basic responses. First, I would be terrified of what my relationship with family and friends would be like. I am extremely close to my family. When I thought about being deaf-blind I thought about how hard it would be to continue having the same relationship with my family that I have now, both for me and for them. I fear that I would get engulfed by loneliness if I was neither able to see nor hear the people I love so much. It would make me especially sad that I wouldn’t be able to physically watch my little sisters grow up. However, I think that becoming deaf blind could also offer the opportunity of becoming even closer to my family. We would have to learn to communicate with each other in such new ways that it would force us to really get to know each other better. Second, if I suddenly became deaf-blind, I would have to
pretty much rethink my life goals. I am currently a pre-med student wishing to go to medical school after I graduate. I do not think this would be possible if deaf-blind, so I would have to reevaluate what I want (and can) do with my life. Finally, if I became deaf-blind I would really have to get better at not being in control, and trusting other people. Janet made a strong point about how much trust it takes to live like she does, and I know that would be a challenge for me. I am naturally inclined to be in control of my situation, and I don’t like not having control. To be deaf-blind would put me in many positions where I would need to trust everyone around me to keep me safe. These are some of the impacts that becoming deaf-blind would have on me.

Lastly, I just want to say how impressed I was with Janet, and her attitude about life in general. She is certainly a very accomplished woman and she seems to have such joy for life, even in the face of all of her struggles. As she was talking to us, it seemed to me that she really has life figured out. She manages to find such joy in her life, when honestly all I can imagine about being deaf-blind is a sort of loneliness and sadness. I felt absolutely amazed at her attitude about life and feel so fortunate to have met her.
Having Janet come to class was a treat. She was inspiring, not because she just lives a happy life as a deaf-blind person, but because she seemed so optimistic and honest about life, irregardless of being deaf-blind. I really appreciated her honesty in everything. I was a little bit scared to admit that one big reason that I was in the class was for the distrib, but she seemed to like my honesty, and she deserved it considering how open she was to us.

I really liked how she talked about dependency. Mostly everyone mentioned that being dependent others would be the hardest thing for them if they became deaf-blind. Although I felt that my biggest fear of becoming deaf-blind was that it would set me into a deep depression, I too thought that this was a huge issue. I really hate asking people for help, and I thought that the way she said that it takes a certain kind of courage to ask for help was interesting, and true. I don’t ask for help out of fear, not pride, usually. A fear of what, I don’t know exactly, but fear nonetheless.

I also found it really interesting that she dances. I can understand that she can hear some low range sounds, but I personally don’t enjoy heavy bass.

Speaking through the close-range interpreter was difficult, but not too bad. It makes me realize that Janet spends a lot of time in close contact with people. I like close contact, but I know a lot of people don’t know how to deal with someone they don’t know well touching them or being right in their face. I think that having to be so close to people have shaped Janet a lot. She seems incredibly personable and comfortable, which I think is cultivated from spending time in close quarters with people. There was a study I once read about people who didn’t get much or any physical human contact and how impersonal they were, so I think it works the other way too.

Walking into class on Thursday, I was struck by the darkness and how the room was rearranged. I recall seeing a very bright light at the front of the room and black curtains on either side. As I took my seat, I noticed William on the floor by Janet. He looked tired and very mellow, sitting right by Janet’s side. I saw Janet’s husband Charlie in the corner. Then I took notice of the two interpreters in the room. Melody was so expressive and seemed to be able to sign in such a small space. Then I saw Leanne signing across from Janet. It was interesting seeing two interpreters for one individual.

As class began, we each began to say our names to Melanie and the translation process began. Despite them remarking that the process was slow, it seemed incredibly fast and efficient to me, seeing as how three people were communicating at the same time.

Then Janet began to address the group in sign. She first asked us to think of the
first time we had heard the term deaf and blind; I remember in third grade hearing that term when reading a small story about Helen Keller’s life. I don’t think at that age I really appreciated the senses as much as I do now, because at the time, it didn’t seem like a bad thing or a disability; it just seemed like something different. To me, I remember thinking, some people are deaf and blind, others are not. There was no negative connotation in my mind at that point. I think only after many years of constant reminders on how much I rely on my senses now do I realize the significance of living without them.

Janet then asked us to imagine ourselves being deaf and blind. The first thing that I remember thinking of was the idea that parents would have to deal with a deaf and blind child. As far as I know, my family has been hearing and seeing, so to have a child so different would be a scary thought for any parent not familiar with the community. How to raise the child? What is best for the child? And probably the most worrying for the parent, how will the child be able to cope in society? I also remembered music; music has been such an integral part of my childhood and my identity growing up. It was the one thing I found myself always wanting to do: perform in front of people. I don’t think that I could even begin to imagine what life would be like if I were to lose my hearing and sight now. But I suppose, if I had lost both senses from birth, my life would be very different, because I would not have experienced an alternative; I would be deaf and blind, and the world around me would always be a mystery. It made me think also about which would be worse: to be born without being able to see and hear, not ever seeing the world; or to lose these senses later in life, when you have already had a chance to use and live with these senses.

But the most moving and absolutely awe-inspiring moment was when I heard Janet speak to the class. I literally had to put my pen down, and stop taking notes, as I heard her speak. She spoke with such eloquence and honesty. I remember thinking the entire time that in that speech were memories of constant correcting by her mother, so many speech therapy classes, so many harsh memories. And then came this beautiful voice, this strong voice, of a woman speaking in a language foreign to her but somehow familiar to the class. And yet it was so surreal, because I felt that even thought I don’t understand sign language very well, I could understand the feeling behind Janet’s language better in ASL. I was just mesmerized especially by the fact that Janet even felt comfortable enough to use her voice in front of the class. I thought to myself, how hard Janet must have had to work to speak when she was younger. After all that hard work and difficult times, here she was speaking to the class, to me, about her life and the lessons she has learned being deaf and becoming blind. I can say without a doubt that it was one of the most moving speeches I have ever witnessed in my life, and one I will never forget.

Then Janet began speaking of her life. Janet’s life story was absolutely fascinating. I was most surprised by the fact that even though I could probably never relate to Janet’s deafness and blindness that I could relate to life story. I remember especially feeling I could understand Janet when she began to describe her relationship with her mother, and how her mother would constantly correct her speech mistakes, wanting her to “appear” hearing. It is such a hard thing to deal with for both the parent and the child I would imagine, because the parent believes they are actually doing what is best for the child, when the child only wants to be able to express himself or herself freely, not in an uncomfortable language. I had such respect for Janet when she said that
she stopped the criticism and decided to live her own life. I remember thinking that that was the true independence. I saw this even more with what Charlie said of Janet and how she never feels bound by her deafness or blindness. We all spoke in class of how being deaf and blind would make one more dependent on others. But here, I saw Janet become more and more independent right before my eyes in her life story.

I remember also relating to Janet when she spoke of the cruel kids she encountered in school. While I am not deaf or blind, I have been teased a lot in my school career, mainly for being as Janet said, “different or weird.” And growing up, any difference is seen as a threat to others. I could really relate also to Janet’s love of dance to get her through high school; for me, it was music and performing that really helped me through my tough teasing times. But I know, just from hearing Janet speak that the level of “deeper maturity” she spoke of having acquired from her trying experiences is only one that can be learned through actually living through such difficult situations as dealing with Usher’s Syndrome. As much as I can hope and wish and try, I am pretty sure that my culture has been so ingrained in me to value independence and not taking help from others that I can never truly wholly trust others the way that Janet can. The maturity in dealing with others and dealing with life experiences that Janet has achieved is only one that I can hope to even come close to.

I also remember one specific comment Janet made regarding life: “There are a lot more safe people in the world than we think there are.” Being a very cynical person, this has probably been one of my biggest life concerns, and to hear Janet, a person who has probably relied more on her trust in others than anyone else I have met in my life, say that life is a lot more “safe” than we imagine, was very heartening for me as a young person in thinking about the future.

I also remember thinking it must have been so much harder for Janet to lose her eyesight than for most other people, because being deaf, she probably relied on that sense a great deal more than most, especially with lip-reading. Lip-reading was incredibly important and a very developed skill for Janet, so to lose eyesight was, I can only imagine, a very difficult thing to deal with.

While there is much more I would like to say that I took away from Janet’s visit, I will close with this remark. I saw Janet Marcous that day as an incredibly intelligent, cultured, hard-working, and resilient individual, who optimism about life and about independence and trust in others astounded me and will never leave me. Janet mentioned especially that there is a big difference between the terms vulnerable and weak. She said that weakness was physical, not mental. And that weakness did not refer to taking help from others. At some point in everyone’s life, we need to take someone’s help, begrudgingly or willingly. And Janet said that she will always ask if she needs help. Taking help is not weakness; in fact, the person who asks for help is much stronger, for that person has the strength of mind in humility to realize that another can do something that he or she cannot. From this lesson, Janet’s visit has greatly affected my world outlook as a young person.
What can I say about my experience with Janet Marcous? I can tell you she's a very interesting person whose willingness to move beyond herself and use her experiences as first, a deaf individual, and secondly a deaf-blind individual to help others, is commendable. Before our afternoon with Ms. Marcous I'd never given much thought to what she described as "the courage to trust". Much like sitting with a counselor, her comments were insightful and therapeutic. Her message was universal and could be applied to any of our lives, after all, no one likes to feel vulnerable. Yet it is this vulnerability that allows us to discover each others humanity. What a powerful lesson.

Ms. Marcous' discussion also veered into the realm of parental child rearing tactics. I couldn't help but think of the infamous *tiger mom* when she mentioned her mother's draconian methods used as Marcous underwent speech therapy. Sometimes parents go too far in their efforts to force children to learn. It seems as though some parents think that its their job to create a person. They have an idea of what a person should be and hope to mold their child into this image. Unfortunately, you and I don't have the power to create people, we can only offer assistance as one becomes his or herself. I think much like Marcous' mom, these tiger moms can benefit from appreciating their child's humanity before any attempts to teach.

Another aspect of our discussion with Ms. Marcous' was its focus on interactions of deaf-blind individuals with their families. I think its amazing that Ms. Marcous is so aware of her familial relationships. In our busy lives, its easy to overlook the needs and sentiments of those around us. Maybe because of her loss of sight, she is more aware of the need to sense how individuals close to her feel. Its kind of ironic that a lot of people with vision can see but aren't receptive to the sentiments of their family and friends.

Overall, I would say that sitting with Ms. Marcous was like having lunch with someone I greatly respect.