COMMUNITY CONVERSATIONS
AN OMA/CPGC COLLABORATION

LIVING WITH DISABILITY AT HAVERFORD

POST-CONVERSATION TRANSCRIPT
Living with Disability at Haverford

[re]ACT: Community Conversation Series
Sponsored by the Office of Multicultural Affairs (OMA) and Center for Peace and Global Citizenship (CPGC)

Friday, March 25, 2016  Multicultural Center, Stokes 106

SESSION OVERVIEW

In collaboration with OMA, CPGC, OAR and Athletics, this is an interactive student panel discussion on disability. Students will share their experiences, challenges, and successes living with a disability and talk about disability as an identity.

[re]CC COMMITTEE

- Stephanie Zukerman, CPGC Program Coordinator
- Tamar Hoffman ‘16, CPGC Intern
- Benjamin Hughes, OMA Program Coordinator
- Oluwatobi Alliyu ‘16, OMA Intern
- Clara Abbott ‘18, OMA Intern

COLLABORATIVE PARTNERS

- Sherrie Borowsky, Coordinator, Office of Access and Disability Services

FACILITATOR
SESSION NOTES

Who are you and what do you struggle with?

- I am a senior here at Haverford. My condition is chronic headaches that I have had since my senior year of high school, as a result of concussions suffered from football and brain surgery to remove a benign tumor. I basically have a headache 24/7/365 for the past five years.

- I am a biology major and fine arts minor. I was diagnosed with generalized anxiety disorder and manic depressive disorder when I was about 8 or 9 years old. Recently, within the last four years, I started having some aspects of panic disorder.

- I am a sophomore. I have ADD (Attention Deficit Disorder) as well as anxiety and depression. The ADD is a more recent thing that I have acknowledged and the anxiety and depression I have dealt with since I was little.

- I am a sophomore. I have a mild form of executive functioning and processing disorder, which is when I have to take in information at a slower rate and I also have planning and organization skills that I need to work on.

- I am a senior here. My condition is really blindness caused by retina detachment in both eyes from a very young age about less than a year old. I have no memory of any light perception or anything of the sort.

What is something that comes to mind when you are on campus or living here at Haverford? What are some of your experiences, challenges, successes? Things you go through? Things you navigate?

- Everyone knows what it is like to have a headache, but having one all the time makes it somewhat more problematic. So, I would say a majority of what affects me the most is when I have a big essay to write for instance and it is obviously stressful and sometimes its just... when you are under stress, you think about it all the more. It is an obstacle and something you can't really ever truly get around. It is always there. So, yeah. It is a disadvantage to have to start thinking in really deep profound ways in order to create that essay and also about that throbbing.

- I once heard someone describe anxiety to me as the feeling of when you are leaning on the chair fooling around and then all of the sudden you feel the chair going backwards and the instance you feel like you are falling back. When I heard that for the first time a couple weeks ago, I was like, that is pretty damn accurate. One of the issues that I have had especially recently with anxiety is this feeling, again, of falling. Like, you are in danger, even though there is no apparent cause or reason for it. A couple of months ago, my friend texted and say, hey, you want to get together with a couple of friends from high school and I had a panic attack for absolutely no reason. It is just this sensation of things kind of building up inside and kind of feeding off one another.
Just this sensation of intense discomfort and fear. It is almost like a mortal fear. You feel your heart rate increase. Hyperventilated and it is just an uncomfortable experience and the only thing you can think about is not breathing. I have also have a lot with the depressive aspect of things they feed off one another. Feeling like both of these things have kind of been a constant struggle to stay on top of them and make sure that, you know, something minor isn’t worming its way in and it becomes a huge problem later.

- It is really hard to communicate exactly how depression feels. And oftentimes, it draws me have inward and I don’t want to interact with anybody. I don’t feel like doing anything. It has just been difficult to communicate that with people and convey to them that is not something I can just will myself to get over what people don’t realize is that there is a physical aspect of the condition. I have been trying to educate my friend and bring to light this general lack of awareness and passive stigma against individuals with disabilities.

- I was getting testing for accommodations in high school for my anxiety and they were like, oh, by the way, you also have attention deficit disorder. That was something I didn’t know, but made sense. I take anti-depressants and anti-anxiety. I also take stimulants for my ADD. I take them every day. If I didn’t take them, I wouldn’t be able to get my homework done. If I don’t take my medication, a one hour assignment takes five to six hours.

I constantly have people saying it is not a real disease or not a real thing you don’t need that medication and it is incredibly frustrating to have someone say that. That also carries over to the anxiety and depression aspect. Just work through it, get over it, or go for a walk. You don’t need to take these medications, it is not natural. But if I didn’t have my medication, I wouldn’t be able to be at Haverford or function at the level I am and I need them to be at the level that all the other students at Haverford are at. I think one of the big issues is that for me, I think it is harder in terms of how it affects me.

It is an invisible disability. It is sometimes not seen as real. For me, the way anxiety and depression affect me often times is I just shut down. I am a very social, active person, but when I am feeling anxious or depressed I don’t want to get out of bed. I want to lie in bed, and maybe watch Netflix, maybe just do nothing. That is not easy to say to a professor.

- Last year, my freshman year, we read a book that had photographs throughout it and one photograph with somebody with deliberate cuts on their body and it really was upsetting. It brought up a lot of stuff and having a warning for that would have been so important. It would have been so nice and changed how I had experienced that. We were in class and I turned this page and I shut down. Trigger warnings are there for about knowing what is coming. I would have still read the book, but at least I would have known that that picture is there that I was going to have to come up against it. And, yeah, that is something that is really difficult. You are coddled, you need to toughen up; I can’t help it that this is something really hard for me.

- I think I am one of the first blind students Haverford has had maybe in over fort years according to what I have heard. As a student, I have to do things a bit differently as I have not a physical disability, but a sensory disability. People sometimes ask me if I need to take an elevator to go to the next floor. I can walk perfectly as long as I have my cane. I am certainly good at it at this point. After having been blind all of my memorable life at this point. I lost vision when I was less than a year old. I have no memory of any degree of light perception or being able to see anything. There is sort of this idea that hearing smell taste
and touch get elevated when you are blind and I think it is a myth more or less. You just
train these other senses.

As for working here at Haverford, I know I have to use special technology and the professors
have become aware of that when I send emails to them before I have classes and I get my
accommodations from the office of disabilities services as well. I meet with them I talk
about the ways that they can accommodate me in the class. I have to always sit near the
front of the room.

- When I was a sophomore I was trying to take a Computer Science intro class. The
  professor did not accommodate me in the class really... I was with an assistant who
  was supposed to be taking notes for me and I was told you “shouldn't be whispering
  between with your assistant.” I couldn't hear her well, partly because I was sitting
  behind everybody else. Before fall break that semester when I had other classes, I
  had to complete a proof in lab, which was due on the day right before the break. I
  asked for an extension of the assignment past the due time and I was told no you are
  not allowed to extend this, it is due right at the end of class right before the break
  and I sort of completed it and gambling on what grade I would get on it. In the end, I
  just decided I was going to drop the class...

How has the residential side of the college supported your experience(s) and how can it do better?

- My sophomore year when my friends I have a friend that has a heart condition that makes it
  really difficult to climb stairs and it was impossible to get accommodations or prior to with
  the housing services to get her on a first or second floor. Thankfully we were rising juniors
  and were able to get a second floor spot in comfort, but it was generally very stressful for
  her and disheartening between choosing getting a single in a random dorm or with her
  friends.

- In my opinion, the housing lottery is kind of a nightmare if you have really bad anxiety
  because it is kind of like — you have no idea. For me, living in a dorm is not conducive to
  anxiety. If you are living with a lot of people around you, it is really hard to get away and be
  alone if you do that. My friends and I were going to get an apartment, but everybody wanted
  the apartments last year. We got put on summer housing and that was so stressful because I
  had no idea where I was going to live until July.

- I have housing accommodations now to get an apartment because I know that is
  what I need to have a better experience when I am not feeling great.

- I have been keeping that same exact room due to the strategic location and to get there easily
  and get around that area of the campus and make sure that my [braille] equipment stays
  where it is. My problem is there aren’t many people around; and when there are, they end
  up studying in other places and the common area seems deserted. Especially in the situation
  where, say, you have to evacuate the dorm where there is a fire or emergency. I am by
  myself and I have nobody to reach out to. I’ve been trying to establish a buddy system
  between me and a neighbor, but they may not always be there at the time of the incident.
Also, [moving around on campus] there are places where I could easily get sidetracked off the path because I am using my cane a certain way and I go on a wrong path and there is nobody out there and I have to basically shout, excuse me, to be heard across hundreds of feet to campus and nobody comes to me, my last resort is calling safety and security. I would like to avoid that. I try to use my hearing and good judgment.

Can each of you think of an example of what has been most helpful to you?

- One of my friends was a Peer Awareness Facilitator (PAF) last year. She knew that I identified as having a disability and asked me if I would come speak at their training session on disability. I was initially like really scared. I don't do well talking in front of people. I remember going in there and sitting in front of a group of students and seeing people I had known at that point for three years and being really scared. After settling in, I realized that it was an audience looking me in the eye and taking everything that I said seriously. I got more comfortable and I felt like people were understanding as much as they possibly could- trying to take it all in and respect my words and giving me time to kind of go through everything.

- That experience really changed my own personal advocacy and solidarity. I feel like after that experience, I reach out a lot more and am a lot more of an activist. I am not as afraid to talk about it, I didn't feel as shameful.

- I think people listening is really important. Listening without trying to help unless someone is asking for help. When I say to somebody I am feeling really depressed right now I don't want them to say why don't you go for a run. I don't want them to say you should practice a lot of self care or just try to make yourself get out of bed I know all of that I have been in bed for years I know somebody is trying to help but it is not helpful it seems patronizing and it seems honestly like you are trying to understand and you can't because you don't know, you are not me. People who will just sit and listen without putting themselves onto it, that is really important. Just offering the emotional support and not trying to fix me, but just being there.

Have you found more supports or as you've gone through Haverford and think back to where you started and came to campus, where you are at now?

- This is my second year, I haven't seen a lot of change. But I thought it might be nice to have a support group because there is something about talking to somebody who knows what you are going through that is really important.

- I think there needs to be more awareness about how to serve people in a wider variety of ways, because I think in this program now is a little small. I don't think it is able to reach everybody in the right way. Honestly, I think there just needs to be more awareness of how the pressures of being at school can really kind of have a negative effect on people.

- Just the general, the culture of disability needs to change. I feel there is a lot of stigma with disability- your body doesn't work and that is inherently bad. I think a lot of people feel like
that and are ashamed. You sent out an email twice asking if there would be people who would want to come and talk about their disabilities in front of a panel and there were only four of us that responded out of 1200 people here and I know for a fact that ten percent of students here seek accommodations.

AUDIENCE REACTIONS

- I am on the faculty. I want to, first of all, appreciate you coming forward and this is really helpful. I am happy to be an advocate or support what you do. Sherry knows how to get in touch with me. I think I would suggest from my time here on the campus that your participation would be appreciated so I would encourage you to talk to us. I think the mission of the college is right in line with what you are asking that is why everybody is here. Sometimes we don't know. We don't know exactly the mistakes [we] professors are making. We really do want you to succeed. Most of the mistakes I have made are out of ignorance.

DISCUSSION CONCLUSION(S)

1. [Sherrie] The purpose of this discussion really was to educate. When someone makes a mistake or doesn't understand the accommodation, I look at it as an opportunity to explain and educate. I never tend to blame someone, “why didn't you do this..?” It is just another opportunity to get information out there and educate. That is why I thought this was so important to hear and educate everyone around these issues.