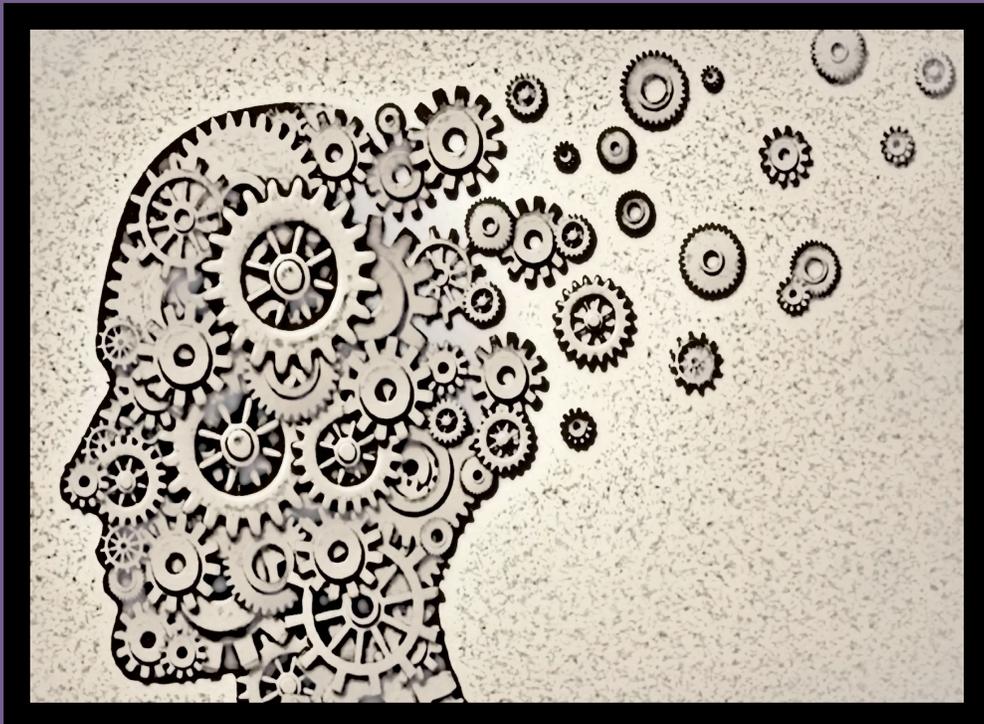


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ACCESS. ABILITY.
LIVING WITH DISABILITY AT HAVERFORD



POST-CONVERSATION
TRANSCRIPT

COMMUNITY
CONVERSATIONS

AN OMA/CPGC COLLABORATION

Access. Ability.

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, Mar. 24, 2017

Multicultural Center (MCC), Stokes 106

SESSION OVERVIEW

How does (dis)ability show up in our lives at Haverford? What does it mean to consider (dis)ability as a marker of identity? How can we all be more present to the ways ability shapes our community? Join a panel of students living with disabilities as they share their experiences, challenges and successes while exploring these questions.

[re]CC COMMITTEE

- Stephanie Zukerman, *CPGC Program Coordinator*
- Benjamin Hughes, *OMA Program Coordinator*
- Maia Williams, *Student Activities Office Graduate Assistant*
- Ananya Kumar BMC '18, *CPGC Intern*
- Riddhi Panchal '19, *OMA Intern*

COLLABORATIVE PARTNERS

- Sherrie Borowsky, *Access and Disability Services* FACILITATOR

GUIDING QUESTION(S)

- How does (dis)ability show up in our lives at Haverford?
- What does it mean to consider (dis)ability as a marker of identity?
- How can we all be more present to the ways ability shapes our community?

SESSION NOTES

OPENING REMARKS FROM SHERRIE

- I am Sherrie Borowsky, the coordinator of Access and Disability Services. This is a panel of students here at Haverford who have graciously agreed to share their experiences, successes, and challenges and just information about what it is like to live with a medical condition, physical condition, or psychological diagnosis.
- They are going to be talking, and one thing that I want to mention is some of their experiences might be personal, and if you feel anything they are talking about is a trigger, please take care of yourselves.
- First, we will just have our panelist introduce themselves and talk briefly a little bit about their disability, and whoever wants to start first...

OPENING REMARKS FROM PANELISTS

- *My name is RED, I am a junior at Haverford.* Just a few, um, disabilities to talk about. One I have had since I was a kid, I was diagnosed with ADD and ADHD when I was eight or nine. So that is something that I have dealt with for awhile. In high school some psychological conditions like depression and anxiety. A new diagnosis is bipolar disorder which I was diagnosed with within the year-- since [bipolar disorder] is new, it has been effecting me pretty dramatically in school.
- *My name is ORANGE, I am a sophomore,* and I was diagnosed with Crohn's disease and rheumatoid arthritis when I was 13, in the 7th grade. And I don't know if you know about Crohn's disease, but that is an auto-immune disease that attacks the lining of your intestine and causing damaging to the lining of your intestine. And rheumatoid arthritis is attacking your joints, so the inflammation of your joints.
- *My name is YELLOW, and I am a first year.* I was diagnosed with Celiac disease about a year ago. Celiac disease is an autoimmune disorder, which, it effectively means that I can't eat gluten, which is in a lot of things.
- *My name is GREEN.* I was identified with ADHD when I was about six, and throughout the years have added on a couple other fun stuff like depression, anxiety and whatever. But, yeah, that is what I am here to talk about today.
- *My name is BLUE, I am a first year here.* I was diagnosed with ADHD when I was about 13 years old. At 15, I was diagnosed with functional abdominal pain syndrome, fibro myalgia and more recently, endometriosis. All of those are kinds of pain disorders. And that's what I am here to talk about ADHD and how they interact with my other conditions.

COULD YOU DESCRIBE YOUR CONDITION(S)?

- **RED:** With depression, that is more of a disorder than people like to think. Not like, oh, I failed my test, I am depressed. Or oh, I was dumped, I am depressed about that. It is a lifetime struggle of being unable to get out of bed or enjoy things that were once enjoyable.

But then, anxiety, which for me is more like panic attacks which can come on unwarranted, as opposed to an anxiety attack which is a build up of, um, being overly stressed and things like that.

And then the bipolar disorder, since it has only been about a year now, I am still learning so much about it. So I don't want to say anything incorrect. But there is bipolar one and two. Bipolar one focuses on mania, or usually a couple of weeks of highs and lows. Bipolar two, which is what I have, that is more focused on the lows, and depressive. And hypomania is shorter periods every couple days of rapid cycles, not being able to sleep, talking too much, saying things you don't want to say, having a bad memory, being over energized, not energized, eating too much, not eating. And not just like screaming and crying, what you might think initially.

- **YELLOW:** My learning difference is really the thing that affects me most, the ADHD side of my diagnosis and that manifests itself, for me, in a really, really short attention span. Impulsivity, so social things are really difficult, like sort of just -- I tend to dominate conversations, things like that. That tends to push people away and then it is very, very difficult to do many, many pages of reading for classes. Because unless it is the most fascinating thing to me in the world I cannot focus on it for more than -- 30 minutes to an hour -- at the most. So yeah.

HOW DOES YOUR DIAGNOSIS IMPACT YOU AT HAVERFORD, AND HOW IS THAT DIFFERENT FROM HOME/GRADE SCHOOL?

- **YELLOW:** For like most of my senior year [of high school] I was feeling sick, like, a lot of the time. I would miss like a few days of school every now and again. But even when I was in school, I had just a lot of headaches, and like muscle fatigue, more than just from tiredness, although the fact that it was high school and I had to get up at 5:45 a.m. certainly didn't help with that. And so, that was pretty significantly impacting my ability to get things done, both with my classes and in the leadership roles that I had taken on. So, when I didn't know what was going on, I thought that, um, that I was just being incompetent and like, I really came to sort of despair at my ability to do things, and to dislike myself in that regard.

So, it's been a lot better at Haverford, simply because now that I know not to eat gluten I feel better almost all of the time. But, it is still a really significant part of my life, because it is a difficult thing to avoid. Like, it seems like gluten is just in breads and bread like things. But in fact, in the Dining Center, it is in all sorts of stuff that you might not expect it to be. Flour is used as a thickener in soups and sauces all of the time. Even though in a lot of circumstances when it totally doesn't

have to be. And also, when there are events for students that they want to try to get people to come to, they entice people with pizza and insomnia cookies -- and neither of them I can have. So, I have learned to like never expect when people say like food is provided at this event, to never expect that I am actually going to be able to eat.

And, it's still -- it is good though that I am feeling okay, almost all of the time. Except that occasionally lack of labeling of things that have gluten have caused me to get briefly sick.

- **ORANGE:** So, I have been sick since the seventh grade, so I had a good rhythm when I was at home with my parents and I lived right next to the hospital. So coming here -- I mean, I live in (X), so that is scary to be that far away from my parents and doctors and stuff.

But the hardest thing for me was to like figure out how to talk about it with people. Because I didn't have to tell people from first through seventh grade, everyone was just kind of there when it happened. And like they all were just like, okay, this is happening to ORANGE, and that is like an incurable disease so, it is there now. So it is hard to tell people without making it seem like it is not a big deal, because it is a big deal. But also not make people think it is this thing that controls every aspect of my life and that they need think about it all of the time.

And another thing about school is fatigue. Because -- a side effect of Crohn's is anemia. So I would be so tired that I would fall asleep sitting up like at dinner and stuff. So I get infusions when I am at home. It is hard to be -- to get people to realize that just because I said I would hang out with them in the morning and then I start feeling sick, like my stomach is not good or whatever, it is hard to tell people that yeah, I felt fine this morning, but now I can't leave my room. And there was a time I couldn't walk because of the arthritis in my knees. So that was hard. I worried about what to tell people. Because people in school were like why could ORANGE walk yesterday and not today?

So that was a thing I worried about and trying to talk to people and get them to understand. It is not a day-to-day thing, sometimes it is an hour-to-hour thing and hard to get people to understand, especially if I don't feel comfortable sharing every detail of my personal health with them.

- **BLUE:** I think that is interesting how you went to the same school for so many years. I was also like that, and I didn't think about it in that context. But also in terms of professors, it is hard to feel like you need to explain yourself. So let's say I didn't do this assignment or I'm 10 minutes late to class because I could not sit up and get out of bed, the balance between feeling like you need to explain yourself (even if the explanation doesn't always seem valid) and then not knowing...

I know that the Office of Access and Disability, as well as the professor, at least in my experience, have been really great in saying you don't need to disclose anything you are uncomfortable with- "I am not here to get a diagnosis of every excuse possible of what may happen, which is great." But then I feel invalidated

sometimes like I need to explain. Like here is the outline for the paper, I haven't been able to work on it for two days because I haven't been able to focus or function in the way that I had hoped.

- **GREEN:** I have joined an organization of people with learning differences and ADHD, so like dyslexia, dyscalculia, stuff like that- learning disabilities or as we call them, learning differences. The fact is that I just learn differently from someone who doesn't have ADHD. I am not less intelligent or anything like that. I just learn more visually, which is like one of my classes right now, that is workshop based -- and I love that! Not everything has to be an essay. Sometimes I feel like writing an essay, but I might feel like writing a song or something like that. And that is perfect for me because I am very creative minded- not built for basic college. Like some people can sit down and study for 10 hours. I am not one of those people. So it is so nice to have opportunities to have workshop style classes.
- **BLUE:** Yeah, going off of this idea about being more vocal about your disability in the situation you are in. I remember I was diagnosed with all of my pain conditions throughout high school, but I was never vocal about any of it.

I went to have very academically intense high school. And I thought I was very good at managing stress, because I wouldn't experience stress. My friend would say I am so stressed out, but I would say to myself I don't feel the increasing heart rate. I feel like I am handling this really well and then by the sophomore year of high school I started feeling very sick all of the time. I couldn't eat food without vomiting. I couldn't sleep or make it through classes. When I went to the doctor, it took months to actually get a diagnosis. But it turned out that these chronic pain conditions are brought on by stress, anxiety, and depression. And because of my high school, I was shunning those things and suppressing them and it manifested itself in a different way because of that.

So now that I am finally aware of that, I think it is really important to acknowledge when I am stressed otherwise I will feel sick, and that is very important for knowing how to navigate in an academic environment like Haverford. Pluralism was very helpful for me, because it was the first time that I actually spoke about my conditions. Even my good friends in high school knew I got sick, but I never talked about it, because again the environment of my high school was everybody thought everyone else was perfect- you kept to yourself about things that were wrong with you. So I found that starting with Pluralism, I can now be much more open about my condition and how everything isn't perfect all of the time, and that is important for me to acknowledge.

WHAT ADVICE DO YOU HAVE FOR OTHERS ON HOW TO SPEAK WITH YOU ABOUT YOUR CONDITION OR FOR OTHER STUDENTS LIVING WITH CONDITIONS?

- **ORANGE:** Um, I would say just trust what the person is saying. Because it is really frustrating when you feel fine in the morning or the day before and you are trying to tell people about it. And they are like well, you can still go, you will feel fine. Or just do this, you will feel better. And I just feel like that is -- that is not the other person's decision to tell you what you can do, particularly if they don't know that much. Because you can't really tell that I have two incurable diseases -- like you can't tell what is going on. There is stuff that I am physically not able to do, so I just won't be like I don't want to hang out with my friends I will tell them I don't feel good because I don't want to. So that is frustrating when people try to make assumptions about it. So I would just say to trust the person.
- **GREEN:** I think with professor also don't be afraid to really share, like don't hold back if you don't want to. You don't have to meet with them every week and share everything that happened to you, but if there is something you want them to know, this is the place to be. This is a school where people care.

Although sometimes the word “accommodation” gets me. It’s a great word, I guess... but the fact that I need it, or that people think I am using my disorder as an excuse, I don't like that. Because -- I also can't always be proactive about it.

Also, if you haven't met with Sherrie -- even if you don't think you have something to meet with her about -- just meet with her anyway.

WHAT IS AN “ACCOMMODATION ANYWAY?”

- **SHERRIE:** So in higher education, an accommodation is based on a student's documented mental, psychological or physical condition and how their diagnosis presents.

For example, they might take medication that makes them really tired. So, they have difficulty getting up in the morning, and may need to schedule classes a little later in the day. They may get an accommodation around scheduling classes. Students who have slower processing may get longer time to take an exam, because it takes longer to process the exam.

It is support-- to get a student with a diagnosis to the same level as someone else who doesn't have that, they get an accommodation. So accommodation can be academic, housing, it could be with the materials you get for a class, it could be dining, etc. It is giving access to courses, programs, events, anything offered on Haverford's campus.

I would never say to someone, take your glasses off, you have to read without your glasses. You need your glasses for 20/20, because RED might have 20/20 vision without glasses. So that is the best way to explain it, to have glasses or not.

I am also happy to talk to faculty about it. I don't think that any faculty want to

give someone an education that doesn't work for them. I think everyone is on board, but if we can have continued guidance from you, and what your needs are from the faculty, that would help.

One thing that I hear from faculty, and RED touched on it, when I meet with students and they need accommodation, it is the student's decision which classes they want to use accommodations in and then speak with the professor and give them the letter. And I tell students, you only have to share what you feel comfortable sharing. But from my understanding of the faculty, the more you express about how you learn, the more they understand what your needs are and how the semester will go.

WHAT ADVICE DO YOU HAVE FOR OTHERS ON HOW TO SPEAK WITH YOU ABOUT YOUR CONDITION OR FOR OTHER STUDENTS LIVING WITH CONDITIONS? (*Continued*)

- **RED:** And talk to the professors at the beginning of the semester, or now. Talk about what the assignments are going to be, okay, two essay, one presentation -- is that a set? Do we sign up on the fly? Just be prepared. But then, at least with bipolar disorder, did the professor recollect that it is not obvious when highs and lows will come..?

So I can't say okay, a paper due next Friday I will probably feel like crap Wednesday, Thursday, Friday so it won't be done. So Monday I am not as focused on it, because I have something due that Wednesday. So it is sometimes hard to say okay, Thursday do I email the professor and say, sorry I wasn't proactive about it I didn't know this was going to happen, I didn't know I was going feel like this, but at the end of the day, the worst that can happen is they will say no, you cannot have an extension. And I don't think that will happen, because we want each other to succeed- the deans, faculty, we want us to be successful.

- **YELLOW:** For me, in those situations the hard part was not getting professors to give me what I needed, but getting myself to understand that this is something that I need. This is not just me being not determined enough. And that this is something I should go and ask for. And that's been particularly impactful in trying to figure out dining and housing stuff. And I really struggle with how to figure out what is something that would just be nice, and what is a need that I have?
- **BLUE:** When you have a disability that no one can see, I find that for myself to be very isolating, especially a chronic pain condition where no one would know. I have gotten good at pretending -- as my parents tell me. No one will know I am in pain unless I tell them. So I can feel isolated and I have often felt that I -- I just don't fit in with the world, because the world keeps going and I am here, in a catastrophic amount of pain and why does that happen.

So because of that, I have felt that it is hard to ask for accommodations because I feel like what help can it do? Especially for stuff that is well established. Like I am in the stem field and I have labs where I have to stand for three hours. Everyone else can manage to do it, but on some days I don't think I can. But I feel like if I

were to get a job in the lab, that's what it would be. And that is something that I don't know if I can -- I don't know if I can change that, I don't know if there is a way to accommodate myself for that. So I often just try to push through it and then it affects me for the next day or two afterwards.

CAN WE TALK ABOUT TREATMENT?

- **GREEN:** So it feels like there's a solution to fix things that not necessarily can be fixed. But there are ways to help. At least with some of the things that I dealt with in the semester. I did an IOP (Intensive Outpatient Program) therapy, so three days of therapy a week. I got an accommodation to take three classes. I scheduled them only on Tuesdays and Thursdays, and then I have therapy Mondays, Wednesdays, and Fridays. And then practices. And it worked out really well.

Medication is another thing I wanted to mention, because I think medication gives people on the outside a reason to think that the medicine fixes someone. So like you have a headache, take Advil, no headache. That is not true with a lot of things. If it was that easy -- many people would not be in this room right now, many people would not have jobs because they are therapist -- whatever.

- **RED:** Yeah, if I could sort of also speak about treatment. So, I've basically as soon as -- I was a bit of a -- let's say crazy kid. Like the first therapy I did was occupational therapy, because I used to walk into a walls. I kid you not. So ever since then I have gone through therapy, tons of therapist, every single kind of therapy from DVT to -- all sorts of stuff.

So I had a lot of supporters throughout my education and throughout my growing up. I also take medication and things like that, and speaking about forgetting medication, I do that all of the time. Here I am, somebody who has to remember to take this at this certain time of day, and every day I get up at a different time for different classes... So you are asking somebody who is horrible at remembering things to remember something at a different time every day. But that medication is really essential.

And, you know, too, I really don't like when people make it seem like using it is a crutch. Because the fact is that medication doesn't work unless you put effort in. It is not a fix all. I have to have a quite a large dose of a stimulant to help me focus and I still can't focus for very long. So, you know, I am proud of the fact that I am in treatment, because it is -- I am showing progress and things like that. But just as a thing that I look for from everybody is not to never, ever shame somebody for having to be in treatment. Because the fact is, if they -- whether they want to be or need to be, there is no reason for someone to feel bad about the fact that they are going and getting help. Because asking for help is probably the number one most difficult part of dealing with a disability, or, you know, any difficulty in your life. So yeah, that's what I wanted to say about that.

HAVE YOU HAD PEERS OR MENTORS WHO HELPED YOU FEEL OK WITH HAVING A DISABILITY OR LEARNING DIFFERENCE?

- **YELLOW:** I think everyone is different, especially with youth. So I don't think there is one universal way to help each child or person. But just, being a support and being able to like adjust also. Like maybe this week they needed someone to listen, but now they need be told they are doing something dangerous or starting unhealthy trends, things like that. Being able to adjust and don't try to fix it. Or -- yeah.
- **GREEN:** Yeah. So, I was very lucky and I was able to meet someone that runs this organization I was talking about earlier that basically became a mentor for me. So last summer, right before coming to Haverford.

I have had this sort of shift. I went from thinking that I wanted to be like some sort of medical researcher and things like that, to now realizing I am best set up to help people like me.

The experience that I had that really changed how I viewed my learning difference was learning how to say learning difference instead of disability. Because for so many years people told me I have a disability, which is really -- you know, just scientifically not true. The way that I learn is just different.

And figuring out that I can help other people like me become vocal about it. Because the fact is that right now as great as things like accommodations are, they are really just band-aids for a really outdated education system. Realizing that it's not my fault, it is that the system is really not set up for me, that made me feel less guilty about who I am, and things like that. So, yeah.

CLOSING REMARKS

- **GREEN:** Something I wanted to mention was a shout out to the allies in the room. Whether you have a disability or it is your mom or boyfriend or your roommate, whatever, whoever it might be, that's not an easy task. So, if you are close to someone like that, don't feel like your problems need to be minimized. Obviously don't tell them -- that they can't be upset because you are upset that they are upset. But you are also allowed to feel, because that is a hard task and that is very admirable.

However, it be very stressful to have a disability that allows you to not go out with your friends all of the time, or you feel you are burdening them. So okay I am always sad, or overly excited and I am too energetic, or I wanted to study and now I can't focus and now they are distracted. I don't have to give them a powerpoint about it. But the more open I am, the more open they can be and develop whatever relationship that might be.

- **CATHERINE SHARBAUGH (Health Services):** I would just like to say the Health Service is an ally to anyone. So we're a place that will listen and you can just come in, you never have to feel like you are judged, we will listen and it is a friendly place if you need some place to just lay your head for a little bit while you are adjusting, or just maintaining your life and what you need. So just remember that there are people on campus who listen, and will not judge and we are here! We are here because we want to help.
- **SHERRIE:** Well, I want to thank our students. And one thing that I, and I think these students and everyone feels is so important is education- informing, and understanding. And that is really what the purpose of this discussion, sharing information and helping us all learn and understand. If anyone has any question, Access and Disabilities Services is a resource for the whole campus- student, faculty, staff, parents. So -- just ask. Thank you so much.

FURTHER RESOURCES

- **Access and Disability Services Webpage**
<https://www.haverford.edu/access-and-disability-services>