

UNC Chapel Hill CEDI Lecture Series: Imani Barbarin

January 17, 2019

Getting a Word In: Prioritizing Disabled People's Narratives and Voices

>> Okay.

Thank you for coming.

This is our second lecture on our first day for the lecture series.

Today we have Imani.

I want to make sure I get it right.

She's director of communication for disability rights in Pennsylvania.

And famous internet person.

She has -- I posted her Twitter handle, Twitter name, which is her name.

She's a graduate of eastern university with a degree of creative writing and a minor in French.

And she writes from the perspective of a black woman with cerebral palsy.

Thank you.

I'm going to hand it off.

>> Hi, so my name is Imani, last year I graduated with my masters degree in communication from the global university of Paris as well.

And I do a lot of disability advocacy online.

And I write article les of disability for rewire and through my own blog.

I am currently the director of communication for disability rights Pennsylvania.

And I'm lucky for that to happen.

They recruited me from my Twitter feed, which is shock sog because that usually gets me in trouble.

And that's me.

And I wanted to talk to you about the importance of disabled people taking charge of their own narratives.

As you probably seen, there's a lot of backlash with disabled people in the new movie the upside.

Brian Cranston took a role playing a disabled man and a lot of disabled people disagree with that.

This is nothing new.

It happened with the Shape of Water.

It happened time and time again, abled body people taking roles and playing a disabled person without a disabled people involved.

I think I lost you quick.

Your video cut out.

But

.

>> It's just recording you.

>> Sorry.

Uh

.

>> What we find is disabled people are taken out of the narrative of disability.

And abled body voices are projected as the authority over disability because they have a proximal relationship or they love someone with a disability.

Doesn't make sense to me.

For any demographic because you know someone of that community doesn't mean you are a part of it or have the right to speak for it.

I wrote an article how ableism is a mask for white supremacy.

And getting into that a little bit, white supremacy as I'm sure you are

familiar with because Dr.

Gibson is your professor, it's an exercise of privilege based on your racial appearance.

And that can happen a lot for other march ma'am marginalized groups as well.

As we talk about marginalized groups within the community, when we see reputation of disabled people in the media, it's all white men or white women.

It's very rarely do you see disabled people of color.

And that's this idea of this crab in the barrel theory, which is a lot of minorities, especially racial minorities, have this party line of saying we are the same as everybody else, we look different.

And that can't be said when you think of the

LGBTQ community or disabled community, there's no more this equals this.

I'm disabled, I walk with crutches or appear different.

Beyond my racial implications.

When we see reputation of disability, black films, films of color, films featuring different races rarely feature disability either.

Race science has been used to correlate to pathologize, essentially race as disability.

When we talk about different experiments being performed on racial groups in the early s and s, they did so to find a reason why black people are the way they are.

We tried to wish away cultural aspects as diseasings.

As we talk through our presentation, there's a lot of nuance that goes on that we don't often talk about.

Now, (aspects as diseases).

One of my favorite things to talk about as a disabled person and a disabled black person is this idea what would happen if we get this opportunity to tell this story.

Right now, we're in a fight as a nation over health care.

Right?

Health care is so important to the way we live our lives.

What happens if we stop showing rich, white men as disabled people?

Think about it.

If you are your idea is to make sure everyone's health covered and everybody has a right to access health care, doesn't it fight against your argument to show somebody who is able to financially take care of themselves?

>> Are you talking about the movie especially?

>> Yeah, it's not just this movie.

The upside is there's a movie of a rich white man.

Before it was Me can have before You, which is the same.

And they show the same character trope, which isn't helpful.

And we know from statistics, black and indigenous people of color get disabled as they age because of racism.

Problems that start as nonserious of nonlife threatening start because people of color are not believed when they are

less serious.

And we see a lot of diseases doff over time in these communities.

And it doesn't matter what income level you are at.

This can happen to you, it happened to Serena Williams, she had to order her own CT scan and found a clot in her lung while giving birth to her daughter.

And we have to make sure when we talk about disability narratives, it's not just white people.

Melissa Tom son, I don't know if you talked about ?

>> Not yet.

>> She talks about this problem.

It's a lot more widespread than a lot of people think.

Especially with the opioid crisis going on, disability reputation representation effect our daily life.

If you only see a subset of people that are disabled, you'll run into problems on a day-to-day base.

Getting the care you need, a lot lot of time people of color don't get the medication they need because they are seen as drug pushers or people trying to get eve one over on the system.

They don't get the education they need because disability IEPs allow you to get more time on tests and they think we are cheaters.

And it's important to have diverse disabled voices at the helm to do away with these systems and talk about stories that actually matter.

So if you guys have any questions for me, I would love to do one more question and answer.

>> Okay.

>> All right.
Questions?

>> We're thinking.

>> That's okay.

>> I talk really fast, I apologize.

>> Thanks for being here, I'm wondering if you talk about images of disabled people in movies and the media have anybody looked at or do you know if anybody looked at images of disabled people of color in picture books?
Books for children?

>> I know there's some people that do that work.

I know I do believe maybe the Harriet Tubman collection can answer that question. I rarely hear about it at all.

It rarely comes across my feed.

>> I was thinking the earlier kids begin to see images of themselves and books that relay media are really important.

>> I agree with you, that makes total sense to me.

However, I really don't see a lot of discourse happening around children's books.

It's usually adult literature.

One thing we find is disabled people with infantilized.

When we talk about disability representation, it usually leans on the

side of adult representation because we are already seen as children.

>> I'm going to say, one thing that we talk about or one thing we're finding some work we're doing is that in our -- in libraryship, and that's either profession, a lot of times, things designed -- there are no things designed for disabled adults.

There are things designed for children and they extend them to adulthood.

And people who are responsible for services for people with disabilities in libraries, as it's phrased, are children's librarians.

When you talk about adults with disabilities being infantized, that's what that makes me think of.

>> Yeah.

A lot of weight is carried upon disabled children.

When I was a kid, my teacher used to make me get up in front of the class and explain my disability to everybody as a way of [overlapping speakers] people are hour horrified.

I heard the gasp.

And yeah, it was my responsibility to explain to people why I was different.

And why I wasn't in gym every day.

And we put a lot of pressure on kids, especially, because I think kids -- I think kids are more apt to adapt their thinking.

And also kids are kind of easier to get to do that stuff.

I mean, asking me to do that now, I would never do so unless it was under my prerogative.

But as a kid, I was like, oh, cool,
they are really excited to get to know me.
And that never works.
So...

>> I want to say, we are not going --
you don't have to spend the whole time.

And people are like, oh, disability
means children.

That's not what we're -- but some
people in the room are specifically do
work on children literature.

That was the question.

I have a question about -- okay, in the
last lecture, someone talked about how
often when people want to know about
disabled people's experiences, they ask
their parents.

And I think you had written something
about that.

That was in the first reading I
assigned you all.

Which one was that?

>> The one where she talks about --

>> [overlapping speakers]

>> Her they were in a store and her
mom's friends was introduced to her and
asked her mom's friend what her favorite
subject was.

>> Yes.

And the people in the room with kind
of distributed between library services
and information science and programming
service and system design.

And so I guess, I wanted to talk a
little bit about your experience being
able to or not being able to speak for
yourself in terms of what you need and

what you want.

Yeah.

>> Just a little background on my mom.

You don't mess with my mom.

[Laughter].

And as a result, she taught me to let nobody mess with me.

And so I still come across people when I'm with her or my father that will speak directly to my dad or directly to -- or yeah, directly to whoever is next to me.

And I'm like, you're talking to me.

And it happened the other day.

I was at the doctor's office.

And usually I advice disabled people if they are nervous to go to the doctor to bring someone who respects your voice to come with you.

And the doctor was crap wrapping up and giving orders.

And they handed papers to my mom, and you need to do this and take this medication.

And I said, I'm right here.

And she was taken a back that I said that at all.

I think I get the question a lot, how do you talk to disabled people?

And I kind of.

[Laughter].

>> [off microphone] a lot at least once a month.

But it's just like this story of the American melting pot, so to speak.

You walk up to any one person in the country and you have assurance they speak English and that's okay.

If you walk up to someone and they speak Spanish, you adjust the way you

Speak.

You look up things to make sure you are saying the right phrases.

You speak French to someone, you say [speaking French] you speak French.

With a disabled person, you come up to someone and you realize they can't hear you, you figure out a different way to communicate.

But you go in the interaction speaking to them like a person.

And that's basically the bottom line.

A disabled person may not appear they are listening.

But we hear everything.

A lot of times, we hear more than than abled bodied people because they are on the sidelines where people decided to leave us.

And adjust as you are going through and figure out different ways to communicate.

But there's going to be someone who wants to exercise their voice.

>> Other questions?

We have thoughtful looks, people need a second.

>> I don't mind.

Thoughtful questions beat any other questions any day.

>> You were talking about the movie earlier.

Are there disabled actor's guild or disabled actors trying to make a name for themselves?

I guess YouTube is maybe an avenue.

>> There are several.

[inaudible] she did a very popular Ted Talk.

She's the most watched Ted Talk in the country.

She's a Palestinian-American woman with cerebral palsy and she signed a deal with NBC to start her own show.

There's Dominic who is an actor in LA.

They are working on several films and trying to fundraise to finish their last one.

There's Ajani Murray, he's an African-American actor on speech lists.

He was on drunk history about how the disability rights movement and how it was aided by the black panthers, which is really cool.

There's it's Lolo, I don't know her last name out of LA.

>> [overlapping speakers]

>> There's a blind efilm maker.

There's several.

And there's an agent in LA and she's really the only agent that handles disabled actors.

And I was supposed to sign with an agent a week ago.

But negotiations fell through.

It's there's a lot of people out there willing to put in the work.

And there's a lot of YouTubers that are trying to do the same thing.

But when you talk about disability, again, there's a lot of institutions that don't want you to talk about disability realistically, and we do monetize disabled people's platform, meaning they can't accept money from

advertisements that YouTube puts on there because it's considered offensive to talk about bodily functions and things that goes on in a disabled person's life.

Even if it's not offensive, they are talking about their experience, that's seen as offensive to YouTube and their viewers and that platform is iffy for disabled people.

>> I have a question about I guess this is about disability, but more about social media.

And like how you choose how much of your identity and your life you want to share.

I guess it's following from your comment about people not -- certain platforms not wanting people to talk about certain things.

And I guess this is a question everyone has to answer.

But in terms of disability, how do you chose what you want to share or how to identify?

The previous lecture, Jessica talked about people who choose not to disclose or focus on disability.

And how do you make decisions on how much to share?

And what your online per
persona will be?

>> I studied branding during my master's class and they talked about a visual dictionary.

That's we see a certain symbol and we know they mean a certain thing.

And that's ground into our psyche over years.

And it's so prevalent we don't know what is happening.

If I say golden arches, what is that?

>>

McDonalds.

>> Yeah, certain things are ground into who we are based on advertisement and the information that comes across our eyeballs every day.

When you think of disabled people, you think of a very specific connotation.

We always think about inspiring.

Orbit

Or bitter or quiet.

And my goal is to break those and turn them on their head.

Who I am online is not -- isn't really quite -- it's more of a amped up version of who I am in person.

I'm not very loud.

I'm talkative but I'm not usually making a point.

And so when I'm online, I know people have expectations for who I'm going to be.

And I want to break them because I want those expectations to be broken for the next person.

And I want people to make an impression without the idea of what a disabled person is in their mind.

That's how I approach my online persona.

>> I have a question.

Dr.

Gibson said you write science fiction s that corr?

>> Yeah.

>> I think fantasy and science fiction are ways -- let's see if I can express this well -- to get at difficult topics.

Do you find that's true?

Do you write about this in your works?

Or does that fobbing factor into your works?

>> I write science fiction transitioning between teen and adulthood because we rarely see that talked about.

And everybody faces their own independence when they turn .

But nothing quites prepares for you being disabled and being an adult.

No one tells you what it's like to be an adulthood with a disability.

And everything online or TV never really talks about it.

I write a lot of characters in science fiction that goes with the same thing about finding who they are in complex situations and finding this is the first time they have to advocate for themselves.

And it's like therapy for me because I'm working through a lot of things that scare me.

About being dissed disabled and an adult.

I'm lucky enough to have a job where I have health care, but am I stuck in a job because of the health care debate?

Am I chained in a job with no ability to move up and progress in my career because I know I need health care at the end of the day.

Or the idea of disabled motherhood scares me.

One day I want kids, far in the future.
Far.

But you hear horror stories about disabled mothers who are met in the hospital room by child protective services because they are a disabled mother who gave birth.

One of my main characters is a young teen who has special powers.

Of course.

She gives birth to a child while she's in her teens.

And the child is taken from her and it's about her trying to get the child back and prove she can take care of this child in a world that doesn't want them together.

>> Questions?

?

>> As future librarians and educators and fields of information, do you have thoughts on how we can do a better job to make our services more inclusive and accessible?

>> Yeah.

Definitely.

I know putting announcements at lower heights helps.

I use crutches but people at a wheelchair are at a different height level than people.

And putting stuff at different levels helps.

And having resources ready is always really helpful.

There's libraries with an online portal and they'll be at the desk.

Having those so was services well-known is helpful.

And partnering with transportation organizations is hard for people with disabilities is they are not seen as capable with navigating their own transported.

So partnering with this organization so you can have library days or times you can come in and roam the library freely.

The internet is helpful.

I find you find the best community of disabled people online rather than in person because we are all trying to keep our heads down and not be seen as a group or like a school trip or something of disabled people in the same room.

And hopefully that will change.

We'll be more comfortable.

And resources that are readily available and resources that are either eye level for wheelchair users and people with a smaller stature.

Introducing yourselves.

I know it's a small thing but introducing yourself to a disabled person and making yourself available and saying I'll help you get resources if you need them is such a small thing but it makes a difference.

If I'm nervous about going to a library or being in a public space, knowing somebody can help me makes the difference.

And not only someone that can help me but also take what I need seriously is also helpful as well.

>> Thank you.

>> In terms of an infantilization and
infantilization and disabled people [off
microphone]

as a child, did this ever include other
children?

Like siblings and friends?

If so, were they being asked about you
by other children?

Or adults as well?

>> Huh.

I have a younger brother.

Um...

as a kid, I was always very loud myself
so people usually came up to me.

But I do remember a couple occasions
where people were other kids would be
like, is that your sister?

She can't play with us.

And my brother would say, I don't care
about her, what are you talking about?

Or like yeah, so in adulthood, you see
it a lot.

You see relatives and brothers and
sisters caregivers for their disabled
relatives be seen as a authority on
disability.

When I was living in Paris, there was
a huge uproar because a guy was -- just
a little background.

Institutionalization of disabled
people, when you come across that topic
is a no no.

We don't want to be institutionized,
we don't want to be locked away.

This man who was the father of a older
disabled man was advocating for the

institutionalization of disabled people because it gave him somewhere to go.

And you would not believe how many times that reasoning comes up, it gives disabled people a place to go.

And he's meeting with the French congress.

He's meeting with Senators and big politicians.

And that has a very negative effect over disabled people's lives but he's seen as the authority.

Not in my personal life.

My brother and I are big big personalities and there are never people trying to talk over me to him [off microphone].

>> Any other questions?

>> What have been your most popular and least popular blog posts?

>> I feel like I should measure them on which ones get me in trouble more or less.

[Laughter].

So the Brian Cranston one was huge.

And I didn't expect anyone to read it.

And all of a sudden, people are talking about it and angry with me I defamed Walter White.

He had a big fan base of abled white men.

They were excited about his career prospects.

[Laughter].

So that one got people really angry.

Any time I talk about hope for the future, I think I did a presentation

around that get people to survive
the next year.

And that was really well-received.

Any time I talk about representation in
media, it goes really well.

And job hunting.

Job hunting is really hard for
disabled people.

People are re
receptive to my story of finding a job
while disabled because they were going
through the same thing.

>> I knew the Brian Cranston thing
would not go well.

[overlapping speakers].

[Laughter].

>> [off microphone] this is my week now.

I had no idea anyone would care.

We talk about every single time a
movie comes out with a disabled character.

Whether Shape of Water.

Where was the home where she left the
bubble.

>> She would rather die.

>> Stop doing that.

so it literally happens every time.

But I had no idea it would get that
reaction.

I guess it was both Kevin Hart and
Brian Cranston during the R.

Kelly series.

The conversation was a whirlwind of
men upset we're talking about men again.

[Laughter].

So yeah.

>> You talked about the job surface search and challenges.

Can you talk about that?

>> I have so many stories.

I graduated in May and started looking for a job state side and Europe in January.

I sent out applications for a job every single day.

And I kept disclosing I was disabled on the equal opportunity forms.

That's what you are supposed to do, tell the truth.

Silly me.

I sent thousands of applications out and never got a inquiry.

As soon as I stopped disclosing my disability, I got - a week.

Some from the same companies I applied to before.

And that's disheartening because you see pleas from disabled people saying disabled people are out of the box thinkers, hire us.

Or disabled people make treasure troughs of information for abled companies, hire them.

And yet, the unemployment rate of disabled people is double that of abled body people.

And those statistics are taken from people who are still actively looking.

So I constantly go into job interviews and people, you are not legally allowed to ask me about my disability at all.

You can ask me about my ability to perform the job duties and my ability to get there.

They work around those legal requirements.

And ask me things like, how did you get here?

Like in New York City, where public transportation is everywhere.

Like how did you get here?

I don't understand.

How long did it take you?

Did you have trouble with the flights of steps because we don't have an elevator.

And I'm covered in sweat like...

[Laughter].

People I know people would call me and hear me over the phone and be excited about my resume and I would show up and you could see their face fall immediately as they saw me.

I had people get like I had people say I was really close to getting hired.

And they would -- I would go in with a mini strategic plan with what I do with communications.

And they would take my ideas and run with them.

And then not hire me.

The most annoying one, which I was really pissed about, thches one man who found me.

And he was a working for a chiropractor firm of an soaks of them association of them.

And I told him what I can do.

And I said if you don't hire me, I can do this work as an consultant.

And I sent the invoice and the projections of what I wanted to do.

And he never contacted me back after that.

But he friended me on Facebook.

Like for months on end, I kept getting page followers requests for all his new businesses he cycles through.

So as he's not hiring me, he's asking me to like his page.

That took a level of gall I had never seen before.

>> You can't see them.

But they are laughing.

[Laughter].

>> It's much appreciated.

I laugh now.

But I was very upset.

[Laughter].

So yeah.

And then a couple jobs were like, do you run?

And I'm like this is a marketing job, where am I running to?

[Laughter].

>> This is a fairly common thing going with librarianship.

A complaint I hear a lot is the job adds almost uniformly ask you to lift pounds, even though there's no lifting involved.

Can you lift.

And there's other things.

Like being able to walk a certain amount of time during the day.

Even though these jobs don't require anything.

It's something to think about in terms of workplace requirements.

>> We had students with disabilities graduate [off microphone] they disclosed because legally they are supposed to. And they haven't been called back for jobs.

>> Legally -- well, one thing is you are not legally required to. You can say you do not wish to answer. So a lot of disabled people don't want to do that because they get scared they'll show up and be called liars or whatever. But for all the forms people called me back on, I put, do not wish to disclose.

>> Good tip.

>> I'm not sure how to word this exactly. But how from your time in France, are how the systems there? How are they better or worse? Just the differences.

>> So our systems leads to our culture. So the system is night and day to what we have in the United States. I lived in Paris. I lived about blocks from the Eiffel Tower in the heart of the city. And it's it is most inaccessible part of the country. There were sidewalks lit to the side for drainage. And I was walking sideways all the time and trying to keep my balance. But the system itself.

Health care was taken care of. As a foreign student, I had health

insurance but it was pretty minimal.

I paid about \$ for the whole year.

And everything was taken care of for my health needs.

I didn't use them only because one of the things a lot of socialized -- one thing a lot of countries with socialized health care does is prohibit disabled people from immigrating to their country.

Canada just repealed that regulation just last year.

So I didn't want it on paper I had a disability and was taking up all these medical costs because I had plans to immigrate there.

But one thing that was different from a culture because of the health care is no one cares if you are disabled.

I think the entire time I was there, I saw disabled people in the city of Paris the entire time I was there.

And there's this sense that abled body people in France don't want to deal with it because they have health care.

Why are we talking about social issues with disability if we have health care?

What more could you want?

And so there was a lot of push back because there's a lot of disability advocates in France rightfully saying we don't have a voice in government.

We don't have a voice in local issues.

And yet, you are making rules for us that exclude us.

Case in point, there was a regulation saying that all new housing in Paris had to be handicapped accessible, at least % accessible.

That means accommodations and hotels and things like that.

And disability rights advocates or

disability approximate advocates
actually got that regulation repealed
saying it wasn't necessary.

And disabled people are saying, are
you kidding?

I can't barely get my wheelchair in a
restaurant or leave my home.

And they are like, well, you have
health care.

It makes no sense.

Because I'm living doesn't mean I
don't have a right to a life.

So that was their issue.

And here, because health care is on
everybody's minds.

And everybody's tongues at this time,
a lot of people in the United States,
people that are passing by, they feel
entitled to know what is going on with
my body, even if I never met them before.

Where French people would ignore you and
let you do your thing because they don't
want to be bothered with it.

Americans are deeply entrenched with
what is wrong with you.

I had literal strangers come up and say,
what is wrong with you?

Like I don't know you.

I had people, I remember I was at --
the largest buffet in the United States
is minutes from my house.

And I was leaving and walking across
the street with my friends.

And my friends were ahead of me
because I walk a little bit slower.

And they look like, and I'm in full
embrace of this random person and he's
praying over me and there's people
surround us crossing the street.

And I wasn't doing anything particularly inspirational.
[off microphone].

[Laughter].

people surrounded me and prayed with me.
And the funny part is there's a car trying to get across just like stopped in front of us like bumper about a foot away from us waiting for us to finish praying.

But yeah, there's a sense in America, you are entitled to know what is wrong with somebody.
Or what their diagnosis is.
And that's just not the case in France.

>> That's quite the story.

>> There's so many.

I had one mom come up to me in Barnes and Noble with her small child and goes, my child needs a life lesson, can you tell him what is wrong with you so he knows not to stare.

And I'm with my book like what happened?
And this child wanted nothing to do with me.

The child is like, mow mom, please, let's go.

And I'm like, can you end this now.
All I want is a Starbucks [off microphone] and now I'm in the middle of a Touched by an Angel story.

[Laughter].

It happens all the time though.

>> Any other questions or comments?

Okay, I'll give it -- as I slowly say
thank you -- I'll give it people maybe
another few seconds to come up with
questions.

>> That's fair.

>> I have one.

So I started following you the last
couple weeks and love you posts.

I was wondering -- [off microphone]
what other people should we be following
to [overlapping speakers]

>> We are taking out their films now.

>> Who should we follow on Twitter?

>> Of course.

So let me take out my phone.

[Laughter].

So I really like posts from
Melissa Thompson, she's like the mother
of the disability black rights movement.

She's the mom.

She's awesome.

There's also if you like
entertainment, there's Big Tambugi, her
handle is at mae underscore day j.

So she sells cannabis in LA.

And she basically tokes up and watches
TV.

And you can follow her on Twitch.

I love it because I'm like this is the
coolest niche activity you could be
doing.

I don't know how to pronounce it
[inaudible] tu madre.

She's a Hispanic and indigenous
artist.

Very cool.

She does a lot of -- people of color
in disability art work.

She is a [off microphone] I believe.

Annie Sigara as well.

They do YouTube content on disability
and chronic illness that is very popular.

Let me think of some more.

I like [inaudible] sometimes,
sometimes she likes to sub tweet me.

But I'm not ready.

I'm not going to lie.

Yeah.

I like a lot of disabled women.

Because we rarely see those voices
uplifted, especially women of color.

I don't want to trigger anybody, but
% of disabled women are sexually
assaulted in their lifetime.

And it's important we hear from
disabled women and nonbinary people
because we are in a very precarious
situation.

If you meet disabled women in their
lifetime, it's chances of them have
been sexually assaulted.

And I try to listen to those voices.

And also, little lobbyists are really cute.

They are little kids with disabilities.

And they go and the House and Senate
to lobby about disability rights.

And their moms handle their accounts.

It's really cute.

Jill yan is a disabled model.

She was in teen voig issue on

vogue disability issue.

>> I'll put these in one message.

>> I try to follow a lot of diverse disabled voices because we are not all white men and have the wealth like them. Like TV and media would have you know.

>> Thank you so much for joining us. Let me come out here. Here I am. Thank you so much for joining us and talking to us. We are going to close down for now. And do some housekeeping. And I will be messaging. So thank you very much. Let's -- thank you.

[APPLAUSE].

>> I will next be at south by southwest. I'm on a pool about disability in the media. I will be recording it so it will be on my website once that's done.

>> When is that?

>> March . And we're on the innovation track. I don't know what that means. But the social impact tract.

>> Okay. This is being recorded so I'll post it