Everyone here and on zoom. For those of you who do not know me, my name is Pam Koons. I’m the GI Oncologist, Director of the Center for GI Cancers and I also serve as the Vice Chief for Diversity, Equity and Inclusion. And in this capacity, we have a series of DEI talks for Yale Cancer Center grand rounds and it is my real honor to introduce my friend, a doctor,
Peter Pulos who is a clinical Associate professor of radiology, gastroenterology and hepatology at Stanford. He’s also the founder and cochair of the Stanford Medicine Alliance for Disability Inclusion and Equity. He received his MD at the University of Texas Medical School at Houston and did an internal medicine residency at University of California, San Francisco. He stayed at UCSF. As a gastroenterology fellow, however, after a spinal cord injury, he decided to retrain in radiology and did his residency at Stanford University, where he has stayed on.
He did fellowship and then stayed on as faculty. His clinical practice at Stanford is in CTMRI and ultrasound, primarily abdomen and pelvis. We overlapped while we were well while I was there in the realm of GI oncology. His interests include radiology of the acute abdomen, the potability imaging and colorectal cancer screening. So Smatty, which is the Alliance for Disability Inclusion and Equity at Stanford IN, is a group composed of people.
He’s also a member of the Radiology Department Diversity Committee, the School of Medicine Faculty Senate Subcommittee on Diversity, and the School of Medicine at Diversity Cabinet.

I have no doubt that this will be a really memorable presentation and I think we’ll really hope, hopefully open all of our eyes to thinking about disability as diversity and defining diversity broadly in medicine. So,
00:02:00.045 --> 00:02:00.635 doctor pulos,

00:02:00.635 --> 00:02:03.035 we are thrilled to have you here today

00:02:03.035 --> 00:02:05.187 and we have a fancy plaque for you.

00:02:18.430 --> 00:02:20.122 Photo op, Photo op. Yes.

00:02:20.122 --> 00:02:21.548 All right. I turn it over to you.

00:02:21.790 --> 00:02:23.402 All right. Thank you.

00:02:23.402 --> 00:02:25.417 Been looking forward to giving

00:02:25.417 --> 00:02:27.308 this talk for months now.

00:02:27.310 --> 00:02:30.028 And it’s such a pleasure to finally be here.

00:02:30.030 --> 00:02:32.228 And thanks to everybody for having me.

00:02:32.230 --> 00:02:34.624 So, yeah, that’s this is the title of my

00:02:34.624 --> 00:02:38.350 talk Disability as diversity in medicine.

00:02:38.350 --> 00:02:40.270 I have a few disclosures.

00:02:40.270 --> 00:02:42.406 I run a disability rights advocacy

00:02:42.406 --> 00:02:46.420 organization and I have a disability and so.
I must disclose that my worldview and my opinions about disability and about diversity in general, are heavily shaped by my experience.

I'm going to show you my learning objectives, communicate the importance of disability inclusion and its value in medical education to foster a culture of disability awareness and acceptance in your institution.

And understand the importance of allyship for those who have disabilities in the workplace.

And I promise I won’t be reading all of my slides like this.

So and here's the outline of my talk,
00:03:24.860 --> 00:03:26.045 my personal story,

00:03:26.045 --> 00:03:28.415 just a casual run through them.

00:03:28.420 --> 00:03:31.605 Some photos that I feel like are

00:03:31.605 --> 00:03:33.720 important to share to communicate with

00:03:33.720 --> 00:03:36.142 my experience has been like a little

00:03:36.142 --> 00:03:38.809 bit about Disability 101 going to talk

00:03:38.809 --> 00:03:41.420 about ableism and intersectionality.

00:03:41.420 --> 00:03:43.404 Have different systems of

00:03:43.404 --> 00:03:45.228 oppression are intertwined.

00:03:45.228 --> 00:03:47.220 Talk about disability,

00:03:47.220 --> 00:03:49.276 HealthEquity for our patients,

00:03:49.276 --> 00:03:52.455 and then the equity and treatment

00:03:52.455 --> 00:03:55.180 of disabled trainees and providers.

00:03:55.180 --> 00:03:58.246 And lastly a little bit about organizing

00:03:58.246 --> 00:04:00.619 and advocating if we have time.
So this is me.
In 2002 I was a medicine resident at UCSF.
In 2003 I was on a ski trip.
About a year before this picture was taken and I was sitting there in the lodge or in my room and trying to fasten up my ski pants, but they wouldn’t button.
And it was my year of internship had finally caught up with me, and Doctor Phil came on and he said something revolutionary, he said he asked me if my life
revolved around food.

Or if I ever did other types of activities with friends such as hiking or biking or and I thought to myself, no, this is all I do is eat and drink and work and so I decided to take up a hobby and that hobby was cycling and it was fantastic. I fell in love with it. It was a great time in the outdoors and I dropped my weight. I was feeling great and then. So that was like my third year of residency at UC and then I
00:05:11.314 --> 00:05:13.360 stayed on to be a GI fellow there.
NOTE Confidence: 0.912193175

00:05:13.360 --> 00:05:15.800 This is a photo of me and my mentor, Dr.
NOTE Confidence: 0.912193175

00:05:15.800 --> 00:05:18.920 John Sello from San Francisco General.
NOTE Confidence: 0.912193175

00:05:18.920 --> 00:05:23.091 And the date of this photo is January 4th,
NOTE Confidence: 0.912193175

00:05:23.091 --> 00:05:24.837 2003 was a New Year’s party.
NOTE Confidence: 0.912193175

00:05:24.840 --> 00:05:27.297 I remember the date because this is
NOTE Confidence: 0.912193175

00:05:27.297 --> 00:05:29.853 the last picture taken of me while
NOTE Confidence: 0.912193175

00:05:29.853 --> 00:05:33.318 I was still neurologically intact.
NOTE Confidence: 0.912193175

00:05:33.320 --> 00:05:36.064 I got. He’s drinking a glass of.
NOTE Confidence: 0.912193175

00:05:36.070 --> 00:05:37.510 California Chardonnay, most likely.
NOTE Confidence: 0.912193175

00:05:37.510 --> 00:05:40.110 And I’ve got a a Diet Coke there.
NOTE Confidence: 0.912193175

00:05:40.110 --> 00:05:42.670 I was on call and so I got pulled
NOTE Confidence: 0.912193175

00:05:42.670 --> 00:05:44.919 away from the party for a veraseal
NOTE Confidence: 0.912193175

00:05:44.919 --> 00:05:48.985 bleeder and I I drove into the the
NOTE Confidence: 0.912193175

00:05:48.990 --> 00:05:51.750 UCSF main hospital there they went
NOTE Confidence: 0.912193175

00:05:51.750 --> 00:05:55.194 to the ICU and my attending and I
did a banding on this on a guy who was bleeding and you know this is 6 months into my fellowship and I was starting to get the hang of procedures. And I'd tried Vera Seal banding before, but I'd always needed to be bailed out at some point by the attending who would like, grab the scope, say, all right, you know, that's enough of you trying to do this. I'm going to take over now. And this time I did it all by myself and so I was really proud of that. It was quite a milestone. The next day I rounded on service.
It was super light.

I got out at like 10:00 AM and I went for what I thought was going to be a one hour bike ride. Just. Just to get in a quick workout, but ended up unfortunately being a 2 1/2 month stay in the hospital and a total alteration of my life path. I’ve worked in this ICU as a doctor taking care of patients and now I was the patient being taken care of. I’ve been totally paralyzed from the neck down. And didn’t know at that moment
what was going to, you know,
what was going to happen with me.
It was very well, you know, you can imagine.
So after about a week in San Francisco General,
I got transferred to a spinal cord injury rehab center and this is me there.
I got a chin control around my neck on this power wheelchair and my hands are just dropped down to my side.
But I still have a smile on my face because of the cookie bouquet that I was looking forward to eating.
I could wiggle my left ankle at that point,
which was like, somewhat hopeful, didn’t really want to get out of bed if I couldn’t walk. I was at first opposed to this wheelchair, but they told me that. You know, we’re going to hope for the best, but prepare for the worst. And they met me each step exactly where I was in terms of my injury, trying to maximize my independence. And as my cord swelling went down, my legs started coming back first. I have a central cord syndrome, so my upper extremities are actually much worse than my legs, and so I started crab walking.
around the unit like this.

Also, this is me with a police system rigged up to my left hand and the motivation is hospital French toast. So wasn’t so bad actually.

Then eventually I graduated to these parallel bars with full leg braces and like things just kept coming back and I was just so fortunate that.

The biology of my injury was such that eventually I sort of ended up like this, walking around with one crutch and this is probably six months after my injury that I was able to walk like this.
So I was 2 1/2 months in the hospital
between the hospital and sorry,
after my discharge I continued
to rehab and but it wasn’t very. Long after I was discharged
that I went back to work, I was really excited to get back to my fellowship.
I was feeling very hopeful, somewhat victorious,
that I regained this function and I was like hoping that I would get back to my baseline.
I was also confused and angry,
but one thing was very different and that was seeing patients.
It was just completely different
than it was before my injury.

I found myself with much more empathy and understanding.

And I don’t know, a new sense of vulnerability.

My questions were different.

I wasn’t just asking them about, you know, how many stools they were having a day or, how many medications they were taking, but also about their daily life and their frustrations.

And so that was great, but it was also frustrating because I couldn’t do a good physical exam. I needed somebody to be with me to help me,
like with my stethoscope and opening doors, it was just very inaccessible and then maybe more importantly, it was also impossible to do procedures. And so I felt like I was going to be trapped in academics, maybe even just in the same place forever. And I wanted my independence and I wanted to practice without barriers. And so I decided to switch into radiology. And this is me as a first year radiology resident rocking the CRT monitors. They’re learning how to read chest X-rays. And eventually I got this wheelchair van from the state of California. And so I was able to drive to
work again in my motorized chair. And then in 2007, I got this Segway, and this is how I cruise around today. Unfortunately, I wasn’t able to bring it on this trip, but this is how I get around. And so, yeah, I started on the faculty on 2009. I did my fellowship and body imaging. So kind of full circle back to gastroenterology, but from the imaging side. And so at that point, I got heavily involved in education. I was an associate residency
program director.

I started doing quality and safety work on the performance improvement committee. And I would do scattered bits of disability advocacy or mentorship more sort of like one off things. People would come to me and ask for advice, etcetera.

But when I stopped doing the APD thing, I decided that I wanted to get involved in diversity work. I mean, diversity initiatives were sprouting up all over campus. I’d always been interested in diversity for different reasons and.
And radiology announced that they were forming a diversity committee and they came out with this cool infographic, which I was really excited about. It has two people with visible disabilities. But then I looked at the members of the committee and I saw that there really wasn’t anybody with a visible disability and I couldn’t really be sure that disability was being represented. And the mantra for disability advocacy is nothing about us without us. And so I felt a sense of obligation and desire to get involved and I volunteered for that and this sort
of becomes like a theme of my career. Since then is recurrent volunteerism to make sure that disability issues are raised in diversity settings. And so you know, but the more I learned about diversity at Stanford and other places, the more it looked like. This where there was a lot of representation of ethnic and racial diversity, of religious and sexual and gender diversity and all of those things are extremely important. But I felt like, for example, we had a diversity cabinet started at Stanford. We started in 2013 and 2010 and so it’s been operating for around a decade.
This is around. 2017, when I started doing this stuff, by the time I became a member of the diversity cabinet in 20/20, it had been 10 years without any disability representation. The hospital was starting up employee resource groups, and they had formed like eight or seven or eight out of nine of them. And the only one that hadn’t been formed yet was the disability employee resource group.
These are two examples, but I can give you many more examples of either disability being either an afterthought or last to the table and so I would argue and I'll try to make the case later on that disability has to be part of DEI efforts and why it makes total sense that that’s so but.

So in 2018, I joined this faculty subcommittee committee on Diversity and I sort of sheepishly suggested that we work on disability issues, and I was really surprised by that wasn’t really having any idea what that was going to look like. And I was really surprised by
the enthusiasm and sort of and yeah, the the like. The excitement around starting something related to disability, the people I talked to actually expressed a sense of relief that somebody was doing something because they had been wanting to do something for some time but didn’t exactly know how that they were going to do it. They were kind of almost afraid to say the wrong thing or do the wrong thing or ask the wrong question and so. I started branching out and trying to learn the A/B C’s of disability at Stanford,
and luckily there was a medical student group, Med Students with Disability and Chronic Illness there, MSDCI. They’re a national organization now, but they were really instrumental in helping me form this group, which I named the Stanford and Medicine Abilities Coalition because it makes. It’s pronounced smack and I really liked that about it. I didn’t really understand at the time. That is saying abilities instead of disabilities was a bit of a faux pas with the disability community. So we later changed our name to the
Alliance for Disability Inclusion and Equity to sort of lean into the word disability and show disability pride and solidarity. So it’s definitely been a learning journey for me and continues to be 1. Some of you in the audience might be wondering to yourself, you know the Americans with Disabilities Act was passed in 1990. You know, is there really a problem in 2023 and coming from a California and of course the only answer is dude, there is definitely a problem in 2023. They range from just minor annoyances.
to major structural inequities,

everything from just automatic
doors not working.

I was giving a talk on Access
one day and I got stuck in an
inaccessible bathroom stall.

And which was great.

I was really happy that that happened
because it made a great anecdote and
story that I keep telling at all my talks
and people seem to get kicked out of it,
but at the same time was pretty
nerve wracking because, you know,
I was a little bit late to give him my talk,
but the stalls weren’t built
with accessible handles.
And then more serious things, like people who are disabled, asking for accommodations, and those accommodations being inconsistently given or delayed, untrained staff, and even harassment and hazing.

So a little bit to back up about disability 101. I mean how many people are we really talking about here? This is an infographic from the CDC with 26 percent, one in four of adults in the US having some sort of disability. This percentage is highest in the South.
This is 61 million adults.

This is not a small population.

You know, we actually did a survey at Stanford.

As part of one of the first things we did and we and our responses, we had 26.7% of people at Stanford either having a condition that qualified as a disability under the law or identifying is disabled. The group that identified was only 8%.

And so a lot of people we a lot of responses in the survey were like I didn’t even know that.
may not understand that they have a disability and this gets into so this causes some problems when people are discussing accommodations because you know you may go to your boss and say you know I'm having problems with fatigue I need some breaks from night shifts and but not understanding that you know, what you're actually talking about is a disabling medical condition and that person that you're disclosing to might just think you're asking for a favor. And so the, you know things don’t
often get started on the right foot.

So who is a person with a disability so under the law. Two things are required.

One is an impairment. So this can be any physical or mental impairment. It’s very broadly defined. It’s documented by a doctor.

The second thing is a limitation. It’s it’s documented by a doctor. The second thing is a limitation. It can’t be trivial. It has to be something that has a real effect on your life. This is also broadly defined.

It’s also important to note
that under the ADA, disability is a legal definition, not a medical definition. There's over 50 definitions under federal law, you know, especially as it comes to like healthcare and disability insurance, and the ADA makes it unlawful to discriminate. It's important to know also that disability is diverse. So people, when they think of disability, they think of somebody who uses a wheelchair or as deaf or blind.
00:20:29.000 --> 00:20:31.424 But I mean there’s a lot of things
NOTE Confidence: 0.94780115
00:20:31.424 --> 00:20:33.319 that qualify as as disabilities,
NOTE Confidence: 0.94780115
00:20:33.320 --> 00:20:35.488 including chronic health conditions.
NOTE Confidence: 0.94780115
00:20:35.488 --> 00:20:39.520 So Crohn’s are all sort of colitis,
NOTE Confidence: 0.94780115
00:20:39.520 --> 00:20:42.800 ADHD or other learning disabilities,
NOTE Confidence: 0.94780115
00:20:42.800 --> 00:20:45.924 psychological disabilities or mental
NOTE Confidence: 0.94780115
00:20:45.924 --> 00:20:49.829 illness and then autism spectrum.
NOTE Confidence: 0.94780115
00:20:49.830 --> 00:20:52.990 And so some of these are visible,
NOTE Confidence: 0.94780115
00:20:52.990 --> 00:20:54.178 others are not.
NOTE Confidence: 0.94780115
00:20:54.178 --> 00:20:56.554 I think that the people with
NOTE Confidence: 0.94780115
00:20:56.554 --> 00:20:58.926 invisible disabilities face a
NOTE Confidence: 0.94780115
00:20:58.926 --> 00:21:01.466 lot more pushback and skepticism
NOTE Confidence: 0.94780115
00:21:01.466 --> 00:21:04.470 when asking for accommodations.
NOTE Confidence: 0.94780115
00:21:04.470 --> 00:21:05.975 Each group of these is a world
NOTE Confidence: 0.94780115
00:21:05.975 --> 00:21:07.492 unto its own and something there’s
NOTE Confidence: 0.94780115
00:21:07.492 --> 00:21:09.389 a lot of issues that are shared,
but others that are unique.

And my organization is open to anybody with the disability, with any kind of disability or an ally.

So what is ableism?

It’s just it’s more than overt discrimination against people and prejudice.

It’s also stereotypes, misconceptions, generalizations, the idea that people with without disabilities are superior to those with disabilities, that.

The disability is somehow defining.
character flaw and it’s also a system of oppression that interacts with multiple other systems of oppression.

So pop trivia, pop culture trivia, These are four movies here from the 70s up till the present we have. Whose Life Is It anyway? The C inside $1,000,000 Baby and Me before you. Does anybody know what these films have in common? Yeah, yeah. Yeah, exactly. Yeah, they’re they’re all about people with disabilities who want to die. And so these movies are about assisted
suicide. And this might as well be its own movie genre where disabled people are portrayed as a burden or suffering. Suicide seems like a reasonable and rational outcome. So in whose Life is it anyway? And the sea inside. These quadriplegics are fighting the medical establishment for the right to die. It's a mercy killing. And me before you. This guy has money and love and still wants to die because life is intolerable and you know people.
have commented that you know when. When non disabled people talk about suicide it’s discouraged and people are offered. Prevention and even though it’s legal, it’s not desirable. But when a disabled person talks about it, it’s peppered in. There’s peppered in words like autonomy and choice and people rushing to uphold these and you know, talk about prevention and mental health is sort of rare and what kind of message is this that we’re giving disabled people and a non disabled? Audience, and I mean,
don’t get me wrong, it’s not like these incidents have never occurred, but they’re the minority, and they’re definitely not counterbalanced by films about everyday disabled people just out there living their lives. And so the healthcare providers are less than immune to this. And so there’s this classic 1994 study from the Annals of Emergency Medicine, they asked 153 emergency care providers. Beliefs about quality of life after...
spinal cord injury and they compared those with quality of life studies of a group of 128 high quadriplegics and only 18% of providers imagine being glad to be alive after a severe spinal cord injury, compared with 92% of true patients with spinal cord injury. And the amount imagine quality of life and the outcomes of such an injury were much more negative.

And I mean, granted, I don’t think I could have imagined being happy after a spinal cord injury either.
brief period of adjustment, my happiness kind of went back to baseline, which was like, so, even before I had a spinal cord injury, frankly, as are a lot of doctors. And so you know, I think the part of the problem is that we see disabled people. In crisis, when they’re in the hospital, when they’re having like the worst day of their life, we don’t see them thriving and succeeding in the community.
And so it’s a skewed perception.

So how does this affect people who are non-disabled? So if you’re a woman or a sexual orientation or gender identity, Group or member of any minoritized group, ableism is relevant and it intersects with other systems of oppression. And it’s not just these other three, it’s many of them. And so intersectionality is a term used to describe what happens when these different isms intersect, and so, for example, a disabled women may experience.
their disability or to their gender or some combination of both. And so poverty and and under resourced issues can make people, you know less able to access supports, which further exacerbates disability and ableism and other. Societal systems of oppression can also contribute to ableism. So if you’re under resourced, you’re also more likely to be disabled due to a lack of healthcare or education or other resources. And then when those people are disabled, they’re even further pushed to the
side and face additional barriers.

So I would say it’s important in order to address ableism, we must. Address these other systems of oppression.

And in order to address these other systems, we also have to address ableism. And it was a it was an eye opener for me, and I’m going to break the rule again of reading something off the slide, but I can’t say it any better than in the book. And when disability is considered to be synonymous with deficiency and dependency, it contrasts sharply with American
00:27:37.600 --> 00:27:40.380 ideals of independence and autonomy.

00:27:40.380 --> 00:27:42.494 This idea of pulling yourself up by

00:27:42.494 --> 00:27:44.740 your bootstraps and be, you know,

00:27:44.740 --> 00:27:46.980 the rugged mountain person.

00:27:46.980 --> 00:27:47.984 Disability. Therefore,

00:27:47.984 --> 00:27:52.000 I served as an effective weapon in powers

00:27:52.083 --> 00:27:54.825 in contest over power and ideology.

00:27:54.830 --> 00:27:55.715 So, for example,

00:27:55.715 --> 00:27:57.190 at varying times African Americans,

00:27:57.190 --> 00:27:58.870 immigrants, gays and lesbians,

00:27:58.870 --> 00:28:02.021 poor people and women have been defined

00:28:02.021 --> 00:28:04.245 categorically as defective citizens

00:28:04.245 --> 00:28:07.025 incapable of full civic participation.

00:28:07.030 --> 00:28:09.816 And so the idea that these ablest

00:28:09.816 --> 00:28:12.312 arguments are used to justify
00:28:12.312 --> 00:28:15.322 discrimination and oppression was was
NOTE Confidence: 0.948080688888889
00:28:15.322 --> 00:28:19.424 really like a major epiphany to me.
NOTE Confidence: 0.948080688888889
00:28:19.430 --> 00:28:21.668 And this sort of this manifest
NOTE Confidence: 0.948080688888889
00:28:21.668 --> 00:28:22.787 As for example,
NOTE Confidence: 0.948080688888889
00:28:22.790 --> 00:28:24.980 disabled people being categorized as
NOTE Confidence: 0.948080688888889
00:28:24.980 --> 00:28:28.064 unfit for certain jobs and and that’s
NOTE Confidence: 0.948080688888889
00:28:28.064 --> 00:28:30.524 used to justify their exclusion in
NOTE Confidence: 0.948080688888889
00:28:30.524 --> 00:28:32.754 the workplace and ideas about what
NOTE Confidence: 0.948080688888889
00:28:32.754 --> 00:28:34.860 is normal or desirable in terms
NOTE Confidence: 0.948080688888889
00:28:34.937 --> 00:28:37.237 of physical or mental attributes
NOTE Confidence: 0.948080688888889
00:28:37.237 --> 00:28:39.537 were used to justify discrimination
NOTE Confidence: 0.948080688888889
00:28:39.606 --> 00:28:41.226 based on race or gender.
NOTE Confidence: 0.948080688888889
00:28:41.230 --> 00:28:43.198 Then of course there’s the genetics
NOTE Confidence: 0.948080688888889
00:28:43.198 --> 00:28:45.207 movement which is very popular at
NOTE Confidence: 0.948080688888889
00:28:45.207 --> 00:28:47.115 the beginning of the 20th century.
NOTE Confidence: 0.948080688888889
00:28:47.120 --> 00:28:50.198 That was used to justify sterilization,
segregation and euthanasia,

but not just disabled people,

but also people of color,

ethnic minorities and others.

And you could even take it one step further.

Into like colonialism and imperial

exploitation and the idea that certain

people were in need of civilizing

and that our culture is superior.

And so I just think it’s really

critical to be aware of these

intersections to actively work to,

to challenge and dismantle them.

So now we’re going to talk about

disability and healthcare and our patients,
how well are we serving our patients with disabilities.

So this graph is from the CDC.

It’s divided into social determinants of health, health and health risk, behaviors and access.

And people without disabilities are in the light blue and people with disabilities are in dark blue.

And you can see that people with disabilities are more likely to be unemployed, to be victims of violent crime, to have premature cardiovascular disease, to be obese, to smoke cigarettes.

To engage in no leisure time activity.
They’re less likely to be current with a mammogram and they’re more likely to be needing medical care due to cost. But in other cancer sort of categories, they’re also less likely to be screened for cervical cancer because they’re falsely assumed to be asexual or nonsectional. A nonsexual by their providers. We did a study recently of the accessibility of US comprehensive cancer websites recently. This is unpublished submitted data. You know, cancer is one of the most frequently searched terms on...
the Internet and we probably all agree that patient facing sides should be accessible to those with disabilities and there are like readily available accessibility standards that you can use to check websites for accessibility and so. This is what smart IT people at Stanford did and we went through the 50 NCICCM websites and we checked for conformance using these automatic accessibility testers that I really don’t understand to be frank because our IT did this, we did code validation blah blah blah. So anyways. We went through these fifty
websites and the results were pretty abysmal. Using this a checker only one website at the standard of 0 errors. Using this other tool, 3 sites completely failed checking and no websites met the standard. And then under the third accessibility checker there was a mean of 68 errors per site. But nobody’s been able to tell me so far as like how many errors do you need before a website becomes inaccessible. And I think that one would argue that the more the more errors you have, the worse it probably is.
But you know these there are standards and we’re not doing well. And I know you can’t read this micro writing here that we rank them according to errors, so. The tiny bars at the top are good and the big bar at the bottom with 400 and something errors is bad. I thought I would just give you guys props because you’re pretty close to the top there at Yale. University Cancer Center. So I Stanford is somewhere. I didn’t make an arrow for Stanford. So one of the problems and
there are many problems that the ADA requires equitable care. But the things are required are just very basic. So parking spots, external doors, and restrooms have to be accessible, but the furnishings and equipment inside don’t have to be. The weight scales, exam tables and chairs, none of that has to be accessible. Diagnostic imaging equipment also doesn’t need to be accessible. And so it’s just a problem. And let me tell you, even the stuff that is required is not often.
00:33:11.370 --> 00:33:13.970 Provided that the enforcement of

NOTE Confidence: 0.929814439166667

00:33:13.970 --> 00:33:17.465 the ADA is pretty weak and the only

NOTE Confidence: 0.929814439166667

00:33:17.465 --> 00:33:19.587 mechanism disabled people have is

NOTE Confidence: 0.929814439166667

00:33:19.587 --> 00:33:22.570 really to file lawsuits to get people

NOTE Confidence: 0.929814439166667

00:33:22.570 --> 00:33:26.698 to change other than asking nicely.

NOTE Confidence: 0.929814439166667

00:33:26.698 --> 00:33:28.225 But so you know,

NOTE Confidence: 0.929814439166667

00:33:28.225 --> 00:33:30.899 this is is just one of many problems

NOTE Confidence: 0.929814439166667

00:33:30.899 --> 00:33:33.134 that keep people with disabilities

NOTE Confidence: 0.929814439166667

00:33:33.134 --> 00:33:34.850 from getting appropriate care.

NOTE Confidence: 0.949059075

00:33:37.300 --> 00:33:38.820 So what about ourselves?

NOTE Confidence: 0.949059075

00:33:38.820 --> 00:33:40.340 What about the medical?

NOTE Confidence: 0.949059075

00:33:40.340 --> 00:33:41.766 Medical students,

NOTE Confidence: 0.949059075

00:33:41.766 --> 00:33:43.192 trainees, Practitioners.

NOTE Confidence: 0.949059075

00:33:43.192 --> 00:33:46.036 So again, people with disabilities

NOTE Confidence: 0.949059075

00:33:46.036 --> 00:33:48.868 of the largest minority in America

NOTE Confidence: 0.949059075

00:33:48.868 --> 00:33:51.044 without disabilities is here in
blue and with disabilities in red.

So it’s an 80:20 split, let’s say in medical school. According to the most recent data, about 8% of medical students disclose a disability. In residency programs it’s pretty similar, 8% and then you get down to practicing physicians and it’s only 3% disclose a disability according to the latest study in 2021. So it’s like highly underrepresented amongst physicians and I think that part of this is underestimated because of the stigma.
And reluctance to disclose that a lot of people have, even responding to anonymous surveys. But I think that we are underrepresented. So why is this? And I think that a big part of it is the culture of strength in medicine. We are expected to tolerate a lot of suffering, especially in Med school and residency and fellowship the likes. We’re expected to work long shifts, don’t complain, don’t ask for help, just be super fast and efficient. We’re not given any time for self-care.
and then we brag about how busy we are.
And I only slept 5 hours last night and I’m on.
I’m doing the job of three people and my administrative roles etcetera and things are changing.
I think that you know, people are starting to focus more on Wellness issues, but even then.
I see, people are need to be talking about fixing a system that’s broken.
resilience and you know, developing personal strength when people are need to be talking about fixing a system that’s broken.
And so and this idea of a superhuman physician rushing in the room to save the day is a damaging stereotype. And I would say that the real superhero is a Doctor Who can connect with a patient who has empathy and has the creativity to solve the problems that our patients expect us to solve. And certainly one can do that without having a disability. But I'll make some additional arguments later. So this is one of my proteges. Her name is Suchi Rastogi. She's a third year medical
NOTE Confidence: 0.949059075
00:36:14.910 --> 00:36:16.434 student at Stanford.
NOTE Confidence: 0.949059075
00:36:16.440 --> 00:36:19.576 She I met her after a miserable experience
NOTE Confidence: 0.949059075
00:36:19.576 --> 00:36:22.558 she had during her first rotations.
NOTE Confidence: 0.949059075
00:36:22.560 --> 00:36:26.158 She had been diagnosed with an uncertain
NOTE Confidence: 0.949059075
00:36:26.160 --> 00:36:29.358 neurologic condition around as the AS.
NOTE Confidence: 0.949059075
00:36:29.360 --> 00:36:31.796 She was exiting the PhD phase of
NOTE Confidence: 0.949059075
00:36:31.796 --> 00:36:34.089 her training and going into the
NOTE Confidence: 0.949059075
00:36:34.089 --> 00:36:36.760 clinics and she the she didn’t
NOTE Confidence: 0.949059075
00:36:36.760 --> 00:36:40.559 know who to turn to for help the.
NOTE Confidence: 0.949059075
00:36:40.560 --> 00:36:43.752 Advertising, or the assistance directing her to
NOTE Confidence: 0.949059075
00:36:43.752 --> 00:36:47.022 like a point of contact where she
NOTE Confidence: 0.949059075
00:36:47.022 --> 00:36:49.758 could ask for help with accommodations,
NOTE Confidence: 0.949059075
00:36:49.760 --> 00:36:50.666 was completely lacking.
NOTE Confidence: 0.949059075
00:36:50.666 --> 00:36:53.151 And so she bounced around for a long
NOTE Confidence: 0.949059075
time before finally figuring out the right person to talk to you at the Office of Accessible Education. She, you know, got brought in her disability documentation. She got a letter. Stating what her accommodation should be and she was handed that letter to then go deliver to her attendings and you know, deliver she did. Sometimes delivering up to twice a day to different attendings who were rotating on her service, often in public places. Some of the supervisors openly
challenged her accommodations. She was. Granted an accommodation to sit down on rounds occasionally but and asking the team to take the elevators but they would still take the stairs and when she went home early in keeping with her preapproved disability related working hours restrictions she was shamed for leaving and and made to feel bad about it and and so you know this is a was a complete failure of the system and kudos to her for. This act of political disclosure
where she disclosed for the benefit of others and actually goes through stepwise that ways the system can be improved to help students with disabilities. There are a lot of myths about learners with disabilities that admitting them lowers program standards and we sent unqualified graduates out into the world but they can’t fulfill the requirements of the programs that. If we provide accommodations to them that compromises patient safety and that accommodations in the clinical saying don’t prepare, prepare them for the real world.
And so you know there have been studies and there are plenty of anecdotes out there that these are not true and that if people are given the support that they need that they are able to succeed. And so for example, taking this real world myth. People often say like, if we accommodate them in medical school, we’re not doing them any favors because their residency will never accommodate this. But then they don’t understand that there are residencies currently.
00:39:16.680 -- 00:39:18.468 accommodating people with disabilities
00:39:18.468 -- 00:39:20.703 or with the same disability,
00:39:20.710 -- 00:39:22.750 and then the argument can
00:39:22.750 -- 00:39:24.382 get propagated in residency.
00:39:24.390 -- 00:39:26.460 Also that they’ll never get a
00:39:26.460 -- 00:39:29.283 real job where there are plenty of
00:39:29.283 -- 00:39:31.107 people with similar disabilities
00:39:31.107 -- 00:39:32.960 practicing in other areas.
00:39:32.960 -- 00:39:33.560 And so,
00:39:35.720 -- 00:39:38.400 you know, there’s a lot of of misconceptions.
00:39:38.400 -- 00:39:42.016 And so this is part of the reason why I give
00:39:42.016 -- 00:39:46.560 these talks to to present myself and other
00:39:46.560 -- 00:39:49.840 physicians as as an example that people
00:39:49.840 -- 00:39:52.712 with disabilities can succeed in medicine.
00:39:52.712 -- 00:39:56.840 And So what can we do about this?
00:39:56.840 -- 00:39:59.678 I think it’s very important that.
That we consider our approach to disability inclusion. So this is a pyramid and the first level is compliance. This is where most places are at. So we will do the minimum necessary to accommodate, but no farther. We will follow the law to avoid lawsuits. Then the next level up is the spirit of the law. This has a more liberal interpretation and this is law as the floor. Some institutions are at this level where they take a more nuanced view and look.
at disabled people as an opportunity for practice or environmental improvement, and they speak of going above and beyond the law. And then the pinnacle of the pyramid is a transformative approach. And I would argue that this approach doesn’t really exist anywhere. You get glimpses of it. The transformative approach focuses more on social justice, looks at disability as just another difference, that it’s normal that disabled people are assumed to be present and that their experiences are honored.
This is an anti ableist system. It's flexible, it's focused on universal design to benefit everyone. And the idea that we should reflect the same diversity as our patients, and this is what we're striving to achieve. My own experience with Stanford Radiology was overwhelmingly positive. And my program director here, Doctor Desser, she's very openminded. She understood her flexibility as a program director, what was required, what wasn’t required. And we we focused on putting together win wins.
So for example, pairing me up on call with people so that you know I would be an extra person to help relieve the load on my colleagues on IR for example, I would carry the consult phone. And so everybody else wanted to be doing procedures and seeing patients and I was more than happy to just talk on the phone and like get the patient history and review the imaging and talk to the attendings and fellows about the treatment plan. And so I think these win wins are also important to cultivate if they can be, although it shouldn’t be a requirement.
On one thing that’s really enabled me to succeed at Stanford is a volunteer program I have for Premed. And foreign medical graduates where they come in and they give me assistance throughout the day in return they get mentorship, they get exposure to medicine and letters of recommendation, etcetera. And all the other benefits of having a mentor who’s a physician and this doesn’t cost the hospital anything and is an example of another winwin and I think I’d be remiss to. Not mentioned my residency classmates.
who are also like very giving and supportive, and I’d like to think that my influence on them was also extremely positive. And Lisa Meeks writes about this upward spiral of positive or informed information about people with disabilities. So the idea is that. If we have interactions with a student or a professional with a disability like an equal status relationship, then that leads to increased awareness on disability of the part of the non disabled person. That leads to reduced assumptions or stereotyping about disability.
and that has the ability to inform patient care and reduce the stigma and stereotypes that we bring to our clinical encounters and hopefully reduces healthcare disparities caused by stereotype.

So again this is the idea that equal status relationships improve attitudes towards disability and can have a profound effect throughout healthcare system. And then so going back to the benefit of including people like me in medicine socalled provider patients and we’ve lived on both sides of the stethoscope.
We have a unique perspective on life and health that comes from being a patient and a physician. We’re often working for access and for inclusive care for all patients, not just those with disabilities. We are role models and we represent what’s possible. We have grit having had to work twice as hard to accomplish the same things. And I think that our presence has the ability to improve. Conditions for everyone. Just lastly, I’d offer you some strategies to combat ableism. So that disabled mantra,
nothing about us without us.

So if you're doing projects related to disability, bring patients and providers with disability in at the beginning, so.

To enter projects at the beginning and so that they can help build programs with you.

So many times I get asked to rubber stamp like educational courses or projects that people are doing right before they're ready to launch and say you know it would have been nice for you to bring us in at the beginning so we would.
have some sort of influence over this and frankly could make it better and more representative. So take a look around your unit, your educational program and ask like how inclusive are your policies and procedures around disability. Look at your messaging. Are you including inclusive language and representation? Are you encouraging people with disabilities to apply to your programs if you have a disabled person? Who needs accommodations?

Do they have an expert that
they can turn to to get advice in a confidential fashion?
Somebody with specialty with specialized experience who understands clinical accommodations?
Are you promoting education and awareness around disabilities events like this?
Talk today and then looking at your diversity programs.
Do they include disability?
And I would say that’s extremely important and it’s just crucial to form alliances between groups that are underrepresented or minoritized to work together.
to address these common issues of discrimination and to dismantle these systems of oppression, so. I realize this could be a bit overwhelming, especially for people who haven’t heard talk about this before, but there are plenty of resources out there. You don’t have to reinvent the wheel. There’s a AA FC report, there’s NIH tools that can give you basically a checklist of things to work on, from some very low hanging fruit to more complex systems issues. There are books, there are websites, and I challenge you like you know. Did you put something like this on
Yale’s website that you support and encourage applicants with a wide range of abilities and disabilities, including disabilities that are not immediately apparent?

Could you invite disabled people to come to Yale and to be a part of your culture and to contribute?

And with that, I’m going to close. I have a thank you slide here. Thanks for inviting me. It’s been a pleasure talking to you. Thanks.

Doctor police, thank you. That was powerful and truly inspiring
and I think really helps us think about diversity in very broadly. And I learned a lot even though I've heard you give talks before, I learned a ton. So thank you so much. We thank you for leaving. We have about 10 minutes. Any questions from the room and then I'll take a look at our our chat also. Questions maybe I'll ask, I'll ask a question to start. You raised this issue of disabilities that are not apparent.
Can you kind of speak to that in terms of us thinking more broadly about being inclusive of really invisible disabilities?

So, yeah, as I mentioned, people with invisible disabilities have a more difficult time accessing accommodations. And I think that there’s that we have this inherent sort of skepticism in medicine that sometimes patients are either not telling us the truth or the full truth or maybe exaggerating their symptoms. There’s a stereotype about people with disabilities trying to game the system and get something for nothing,
00:49:55.720 --> 00:49:57.199 that, you know,
NOTE Confidence: 0.93622824
00:49:57.199 --> 00:50:00.157 that accommodations are more like favors
NOTE Confidence: 0.93622824
00:50:00.157 --> 00:50:03.838 or special treatment rather than rights.
NOTE Confidence: 0.93622824
00:50:03.840 --> 00:50:06.816 And so, and I think it’s just difficult
NOTE Confidence: 0.93622824
00:50:06.816 --> 00:50:09.878 for people and human nature to sometimes,
NOTE Confidence: 0.93622824
00:50:09.880 --> 00:50:13.048 you know, look at somebody who looks well.
NOTE Confidence: 0.93622824
00:50:13.050 --> 00:50:15.114 And he was complaining of something
NOTE Confidence: 0.93622824
00:50:15.114 --> 00:50:17.208 that that can’t be seen and
NOTE Confidence: 0.93622824
00:50:17.208 --> 00:50:19.164 really asking like is this true,
NOTE Confidence: 0.908460702666667
00:50:22.250 --> 00:50:24.586 you know? And and a lot of people
NOTE Confidence: 0.908460702666667
00:50:24.586 --> 00:50:26.770 I talked to say the same thing.
NOTE Confidence: 0.908460702666667
00:50:26.770 --> 00:50:29.170 You know, the comments are but you look
NOTE Confidence: 0.908460702666667
00:50:29.170 --> 00:50:34.014 so good or you know, you know, are you.
NOTE Confidence: 0.908460702666667
00:50:34.014 --> 00:50:38.708 Is it really that bad people
NOTE Confidence: 0.908460702666667
00:50:38.708 --> 00:50:41.998 especially with like chronic pain.
NOTE Confidence: 0.908460702666667
00:50:42.000 --> 00:50:45.000 Have like a special,
special sort of experience. Pain is something that I think is incredibly difficult for us to gauge. I mean impossible to gauge how much suffering somebody is undergoing. And so I think that sometimes we underestimate, underestimate what that feels like. Or maybe we don’t understand that we’ve never had. Like excruciating pain before we haven’t dealt with a situation that felt the same. And so I think that part of it is just is human nature and part of it
is also like a lot a lack of education

or understanding on the topic and

and so I don’t I don’t really know

how to change the default from

like skepticism to acceptance but.

I think we have a long way

to go in this regard.

Culture change is is slow I think

for a lot of a lot of different

things and and you know we’ve

we’ve moved the needle quite a

bit in society about implicit bias

towards racial and ethnic groups

towards racial and ethnic groups

that are underrepresented or

even like sexual orientation and.

Maybe not so much gender identity,
considering, you know, the political wars that are going on right now around transgender rights. But, you know, research has shown that bias towards disability hasn’t really budged in the same way that other groups have benefited from. And so that’s what I’m working on on changing.

Thank you. We do have a question in the chat. So amazing talk, actually two comments. There was another one of amazing talk, 2 questions. One, did accessibility play a role
ultimately choosing radiology as your specialty versus others? And what if your university doesn’t even have a compliance, what do you do? Yeah, So radiology, the accessibility of radiology was definitely attractive. You know, this, like prepare or hope thing also applied to my situation. And like, you know, the fact that I might age faster than other people that I could become. You know that, you know, if I’m 30 years old and can barely walk, that what’s going to happen.
when I’m 60 years old?

And what happens if my condition worsens?

Well, I can do radiology from my bed if I have to.

And so I have the ability to like make money and contribute even if my condition like worsened to some extent.

And and also I wanted to do like the same amount of work as my colleagues think that experience is incredibly important for physicians. 

like the number of reps you get, 

the number of patients you see and I.

I didn’t want to really compromise on that.

I mean, I do have some accommodations
around my work hours,

but for the most part,

I do the same amount of work

And so the second question was,

what if you’re not even at the compliance level?

And that’s tough,

you know,

Yeah, I would say that we are not.

In all places at the compliance level either at Stanford.

The problem is in a big system like this where you have a university

where you have a health system

where you have like multiple silos,
00:54:38.590 --> 00:54:41.790 the disability competency or

00:54:41.790 --> 00:54:45.616 expertise can vary widely and

00:54:45.616 --> 00:54:48.746 one person may receive excellent.

00:54:48.750 --> 00:54:52.030 Treatment or around their accommodations.

00:54:52.030 --> 00:54:55.066 And a person in, you know,

00:54:55.070 --> 00:55:00.147 the cubicle down the hall may have

00:55:00.147 --> 00:55:02.667 a totally different experience

00:55:02.670 --> 00:55:05.196 Our students at Stanford are relatively

00:55:05.196 --> 00:55:07.881 well supported and they have like

00:55:07.881 --> 00:55:12.870 education office who deal with their cases.

00:55:09.970 --> 00:55:15.710 But like the residents don’t,

00:55:15.710 --> 00:55:18.360 post dogs don’t and so.

00:55:18.360 --> 00:55:21.680 They often get left behind.
And so right now we’re trying to get all of these people talking to each other. You know, the Children’s Hospital, talking to the adult hospital, talking to the School of Medicine, talking to the university and like trying to develop some common policies and procedures, trying to push education out to the masses because you’re not always going to be disclosing to somebody who’s like at a high level and who may have like a better understanding or appreciation. You may be just like disclosing show if you’re a nurse like the charge
00:55:59.520 --> 00:56:02.376 nurse and she may not have any
00:56:02.376 --> 00:56:04.464 inkling about that you’re even
00:56:04.464 --> 00:56:07.254 disclosing a disability or what the
00:56:07.254 --> 00:56:09.321 resources are that are available
00:56:09.321 --> 00:56:11.960 or what her obligations are or his
00:56:12.041 --> 00:56:14.176 And so I think a top down approach can
00:56:14.180 --> 00:56:18.498 also be really helpful in this regard.
00:56:18.498 --> 00:56:21.338 you need the education at all levels,
00:56:21.338 --> 00:56:24.758 but we’re trying to get a high level
00:56:24.758 --> 00:56:27.862 leader like at the vice Provost level
00:56:27.862 --> 00:56:31.054 around there to really somebody who
00:56:31.054 --> 00:56:33.482 can be in a position to affect change
00:56:33.482 --> 00:56:36.290 throughout the entire enterprise
00:56:36.365 --> 00:56:38.373 and bring things.
00:56:39.880 --> 00:56:42.958 Into a into an alignment because
NOTE Confidence: 0.909611934
00:56:42.960 --> 00:56:44.157 and right now we don’t have that.
NOTE Confidence: 0.948487290909091
00:56:45.560 --> 00:56:47.340 Thank you. Any other questions
NOTE Confidence: 0.948487290909091
00:56:47.340 --> 00:56:49.560 from the audience before we close?
NOTE Confidence: 0.943608066666667
00:56:51.800 --> 00:56:55.400 Yes, Kevin, thank you. I’m just wondering
NOTE Confidence: 0.915145514285714
00:56:55.760 --> 00:56:58.936 if you could give an example of in the
NOTE Confidence: 0.915145514285714
00:56:58.936 --> 00:57:01.560 web data that we helped it pretty well.
NOTE Confidence: 0.915145514285714
00:57:01.560 --> 00:57:03.120 I would imagine some other areas,
NOTE Confidence: 0.915145514285714
00:57:03.120 --> 00:57:06.000 we probably have a lot of areas to
NOTE Confidence: 0.915145514285714
00:57:06.000 --> 00:57:07.980 improve on a lot of opportunity.
NOTE Confidence: 0.915145514285714
00:57:07.980 --> 00:57:10.500 Are there particular examples of other,
NOTE Confidence: 0.915145514285714
00:57:10.500 --> 00:57:12.300 you know, around other institutions
NOTE Confidence: 0.915145514285714
00:57:12.300 --> 00:57:14.260 that you work with or you visited
NOTE Confidence: 0.915145514285714
00:57:14.260 --> 00:57:16.580 and so forth where you do the day
NOTE Confidence: 0.915145514285714
00:57:16.580 --> 00:57:18.338 Like there’s some real examples
NOTE Confidence: 0.915145514285714
00:57:18.340 --> 00:57:20.260 of something to action to avoid
real states that organizations sort of stepped into as a sort of trying to go down this path
you would suggest to us, you know here at like one or two or three things you really want to not do
For the Zoom audience, yeah, like what are the landmines to avoid essentially around disability inclusion?
You know, I guess I would just say that the landmines end up happening when you’re not including disabled people in the conversation. And but I don’t think it’s so
much around landmines or talking

It’s more just the omission of any sort of information that I see as the real problem that there’s no welcoming language on a website. I mean, we’ve done a study of disability inclusion amongst diversity statements at radiology residency programs, for example. It was like 14% of residents of radiology residencies, mentioned disability as part of their diversity statement.
00:58:46.380 --> 00:58:49.260 is the information on a website easy to find?

00:58:49.260 --> 00:58:50.940 Is there a point person that

00:58:50.940 --> 00:58:52.060 people can go to?

00:58:52.060 --> 00:58:55.096 Is there a clear process for

00:58:55.096 --> 00:58:57.120 requesting accommodations and it’s

00:58:57.207 --> 00:58:59.699 really just frequently missing.

00:58:59.700 --> 00:59:02.400 And so I I think that this these are

00:59:02.400 --> 00:59:05.695 more sins of omission rather than Commission.

00:59:05.700 --> 00:59:10.145 I haven’t seen too many examples of

00:59:10.145 --> 00:59:14.818 just like egregiously discriminatory.

00:59:14.820 --> 00:59:15.217 Well,

00:59:15.217 --> 00:59:17.599 I would say actually that these

00:59:17.599 --> 00:59:20.154 legalistic sorts of things that that

00:59:20.154 --> 00:59:22.740 that people put into like technical

00:59:22.740 --> 00:59:27.492 standards and and the way that.

NOTE Confidence: 0.899770627857143

93
Accommodations are described in materials can be very discouraging. You know, like people with a bona fide disability may be entitled to reasonable accommodations that don't interfere with the essential functions of their job according to applicable federal and state laws. Like this sorts of things could be like very intimidating and discouraging for somebody. So and there are examples like in those resources and I can share those with everybody of like the things that you can say and do very
low hanging fruit to make your institution more inviting. You can’t be just about the messaging. You also have to change some of the processes behind the scene. But language is important.