00:00:00.000 --> 00:00:01.465 Everyone here and on zoom.
00:00:01.465 --> 00:00:04.238 For those of you who do not know me name,
00:00:04.240 --> 00:00:05.560 my name is Pam Koons.
00:00:05.560 --> 00:00:08.436 I'm the GI Oncologist,
00:00:08.436 --> 00:00:10.344 Director of the Center for GI Cancers and I also serve as
00:00:10.344 --> 00:00:12.177 the Vice Chief for Diversity,
00:00:12.177 --> 00:00:13.597 And in this capacity,
00:00:13.600 --> 00:00:15.022 Equity and Inclusion.
00:00:15.022 --> 00:00:16.918 we have a series of DEI talks
00:00:16.920 --> 00:00:20.960 for Yale Cancer Center grand rounds and it is my real honor to
00:00:20.960 --> 00:00:24.696 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. 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.
with disabilities and their allies at Stanford Medicine. 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. It is. 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,
doctor pulos, we are thrilled to have you here today and we have a fancy plaque for you.

Photo op, Photo op. Yes.

All right. I turn it over to you.

All right. Thank you.

Been looking forward to giving this talk for months now. And it’s such a pleasure to finally be here.

And thanks to everybody for having me.

So, yeah, that’s this the title of my talk Disability as diversity in medicine.

I have a few disclosures.

I run a disability rights advocacy 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. This is just getting through the paperwork. So and here’s the outline of my talk,
my personal story,
just a casual run through them.
Some photos that I feel like are
important to share to communicate with
my experience has been like a little
bit about Disability 101 going to talk
bit about ableism and intersectionality.
Have different systems of
oppression are intertwined.
Talk about disability,
HealthEquity for our patients,
and the equity and treatment
of disabled trainees and providers.
And lastly a little bit about organizing
and advocating if we have time.
So this is me.

In 2002 I was a medicine resident at UCSFI,

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,

And it was my year of internship had finally caught up with me,

I think with all of the bagels and Donuts at 3:00 in the morning and you know,

the clothes weren’t fitting anymore.

And 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 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
stayed on to be a GI fellow there.

This is a photo of me and my mentor, Dr. John Sello from San Francisco General.

And the date of this photo is January 4th, 2003 was a New Year’s party.

I remember the date because this is the last picture taken of me while I was still neurologically intact.

I got. He’s drinking a glass of California Chardonnay, most likely.

And I’ve got a Diet Coke there.

I was on call and so I got pulled away from the party for a veraseal bleeder and I drove into the UCSF main hospital there they went to the ICU and my attending and I
00:05:55.194 --> 00:05:58.927 did a banding on this on a guy who
00:05:58.927 --> 00:06:01.532 was bleeding and you know this is 6
00:06:01.532 --> 00:06:03.694 months into my fellowship and I was
00:06:03.694 --> 00:06:05.815 starting to get the hang of procedures.
00:06:05.820 --> 00:06:07.619 And I’d tried Vera Seal banding before,
00:06:07.620 --> 00:06:09.041 but I’d always needed to be bailed
00:06:09.041 --> 00:06:10.659 out at some point by the attending
00:06:10.659 --> 00:06:12.499 who would like, grab the scope,
00:06:12.499 --> 00:06:14.012 say, all right, you know,
00:06:14.012 --> 00:06:15.580 that’s enough of you trying to do this.
00:06:15.580 --> 00:06:18.177 I’m going to take over now. And.
00:06:18.177 --> 00:06:20.310 But this time I did it all by myself
00:06:20.372 --> 00:06:22.340 and so I was really proud of that.
00:06:22.340 --> 00:06:24.180 It was quite a milestone.
00:06:24.180 --> 00:06:26.539 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.

And so this is me in the ICU at San Francisco General.

I’ve worked in this ICU as a doctor taking care of patients and now I was the patient being taken care of. 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,
00:07:41.440 --> 00:07:45.680 which was like, somewhat hopeful,
NOTE Confidence: 0.9402536
00:07:45.680 --> 00:07:47.294 didn’t really want to get out
NOTE Confidence: 0.9402536
00:07:47.294 --> 00:07:49.360 of bed if I couldn’t walk.
NOTE Confidence: 0.9402536
00:07:49.360 --> 00:07:52.240 I was at first opposed to this wheelchair,
NOTE Confidence: 0.9402536
00:07:52.240 --> 00:07:54.320 but they told me that.
NOTE Confidence: 0.9402536
00:07:54.320 --> 00:07:56.039 You know, we’re going to hope for the best,
NOTE Confidence: 0.9402536
00:07:56.040 --> 00:07:57.520 but prepare for the worst.
NOTE Confidence: 0.9402536
00:07:57.520 --> 00:08:01.600 And they met me each step exactly
NOTE Confidence: 0.9402536
00:08:01.600 --> 00:08:04.880 where I was in terms of my injury,
NOTE Confidence: 0.9402536
00:08:04.880 --> 00:08:08.597 trying to maximize my independence.
NOTE Confidence: 0.9402536
00:08:08.600 --> 00:08:11.078 And as my cord swelling went down,
NOTE Confidence: 0.9402536
00:08:11.080 --> 00:08:12.880 I have a central cord syndrome,
NOTE Confidence: 0.9402536
00:08:12.880 --> 00:08:14.915 so my upper extremities are
NOTE Confidence: 0.9402536
00:08:14.915 --> 00:08:17.400 actually much worse than my legs,
NOTE Confidence: 0.9402536
00:08:17.400 --> 00:08:19.824 and so I started crab walking.
00:08:19.824 --> 00:08:21.800 around the unit like this.

00:08:25.230 --> 00:08:27.790 I had to learn how to use my arms again.

00:08:27.790 --> 00:08:31.018 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.

00:08:31.018 --> 00:08:34.283 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.

00:08:34.283 --> 00:08:37.430 The biology of my injury was such that eventually I sort of ended up like this, walking around with one crutch and

00:08:39.830 --> 00:08:41.714 eventually I sort of ended up like this, walking around with one crutch and

00:08:41.714 --> 00:08:44.540 and I was just so fortunate that.

00:08:44.627 --> 00:08:47.189 The biology of my injury was such that eventually I sort of ended up like this, walking around with one crutch and

00:08:47.189 --> 00:08:50.262 and I was just so fortunate that.

00:08:50.262 --> 00:08:53.610 The biology of my injury was such that eventually I sort of ended up like this, walking around with one crutch and

00:08:53.610 --> 00:08:56.250 eventually I sort of ended up like this, walking around with one crutch and

00:08:56.250 --> 00:08:58.726 eventually I sort of ended up like this, walking around with one crutch and

00:08:58.730 --> 00:09:01.810 eventually I sort of ended up like this, walking around with one crutch and

00:09:03.890 --> 00:09:06.585 this is probably six months after my injury that I was able to walk like this.

00:09:06.585 --> 00:09:09.970 this is probably six months after my injury that I was able to walk like this.

00:09:09.970 --> 00:10:10.000 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.

00:09:09.970 --> 00:09:13.849 So I was 2 1/2 months in the hospital
NOTE Confidence: 0.90556938375
00:09:13.849 --> 00:09:17.801 between the hospital and sorry,
NOTE Confidence: 0.90556938375
00:09:17.801 --> 00:09:19.956 after my discharge I continued
NOTE Confidence: 0.90556938375
00:09:19.956 --> 00:09:22.646 to rehab and but it wasn’t very.
NOTE Confidence: 0.90556938375
00:09:22.646 --> 00:09:24.391 Long after I was discharged
NOTE Confidence: 0.90556938375
00:09:24.391 --> 00:09:26.148 that I went back to work,
NOTE Confidence: 0.90556938375
00:09:26.150 --> 00:09:27.974 I was really excited to get
NOTE Confidence: 0.90556938375
00:09:27.974 --> 00:09:29.190 back to my fellowship.
NOTE Confidence: 0.90556938375
00:09:29.190 --> 00:09:31.550 I was feeling very hopeful,
NOTE Confidence: 0.90556938375
00:09:31.550 --> 00:09:32.334 somewhat victorious,
NOTE Confidence: 0.90556938375
00:09:32.334 --> 00:09:35.863 that I regained this function and I was like
NOTE Confidence: 0.90556938375
00:09:35.863 --> 00:09:38.743 hoping that I would get back to my baseline.
NOTE Confidence: 0.90556938375
00:09:38.750 --> 00:09:41.426 I was also confused and angry,
NOTE Confidence: 0.90556938375
00:09:41.430 --> 00:09:42.858 but one thing was very different
NOTE Confidence: 0.90556938375
00:09:42.858 --> 00:09:44.270 and that was seeing patients.
NOTE Confidence: 0.90556938375
00:09:44.270 --> 00:09:45.540 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 stools they were having a day or, their medication dose, 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 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 Xrays. 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.

I wasn’t able to bring it on this trip, unfortunately.

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. And 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 also just a desire to get involved and so 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 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, 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 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. And so it was just kind of, and this is not.
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.
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 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. 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. You know, is there really a problem in 2023 and coming from a California. They range from just minor annoyances.
to major structural inequities, everything from just automatic door openers 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.

28
And then more serious things, like people who are disabled, asking for accommodations, 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.

I had a disability and so you know there’s people with disabilities
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, 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.

The second thing is a limitation and the law reads an impairment. It’s documented by a doctor.

The second thing is a limitation. It’s also important to note and the law reads an impairment that substantially limits one or more major life activities. In other words, 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, they think of somebody who uses a wheelchair or as deaf or blind.
But I mean there's a lot of things that qualify as disabilities, including chronic health conditions. So Crohn's are all sort of colitis, ADHD or other learning disabilities, psychological disabilities or mental illness and then autism spectrum. And so some of these are visible, others are not. I think that the people with invisible disabilities face a lot more pushback and skepticism when asking for accommodations. Each group of these is a world unto its own and something there's 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? And this is something that I didn’t understand before starting Smatty. 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? 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, talking 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 compared, they asked 153 emergency care providers. Beliefs about quality of life after
00:24:25.789 --> 00:24:28.393 spinal cord injury and they compared
NOTE Confidence: 0.951754628571429
00:24:28.393 --> 00:24:30.852 those with quality of life Studies
NOTE Confidence: 0.951754628571429
00:24:30.852 --> 00:24:34.028 of a group of 128 high quadriplegics
NOTE Confidence: 0.951754628571429
00:24:34.028 --> 00:24:36.858 and only 18% of providers imagine
NOTE Confidence: 0.951754628571429
00:24:36.858 --> 00:24:38.754 being glad to be alive after
NOTE Confidence: 0.951754628571429
00:24:38.754 --> 00:24:40.749 a severe spinal cord injury,
NOTE Confidence: 0.951754628571429
00:24:40.750 --> 00:24:43.790 compared with 92% of true
NOTE Confidence: 0.951754628571429
00:24:43.790 --> 00:24:45.870 patients with spinal cord injury.
NOTE Confidence: 0.951754628571429
00:24:45.870 --> 00:24:48.126 And the amount imagine quality of
NOTE Confidence: 0.951754628571429
00:24:48.126 --> 00:24:50.773 life and the outcomes of such an
NOTE Confidence: 0.951754628571429
00:24:50.773 --> 00:24:52.563 injury were much more negative.
NOTE Confidence: 0.951754628571429
00:24:52.570 --> 00:24:54.106 And I mean, granted,
NOTE Confidence: 0.951754628571429
00:24:54.106 --> 00:24:54.490 I,
NOTE Confidence: 0.951754628571429
00:24:54.490 --> 00:24:57.442 I don’t think I could have imagined being
NOTE Confidence: 0.951754628571429
00:24:57.442 --> 00:25:00.004 happy after a spinal cord injury either.
NOTE Confidence: 0.951754628571429
00:25:00.004 --> 00:25:02.128 I was surprised that after a
brief period of adjustment,
my happiness kind of went back to baseline,
which was like, so,
so to begin with,
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
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, I’d say 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 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 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,
ideals of independence and autonomy.

This idea of pulling yourself up by your bootstraps and be, you know, the rugged mountain person.

Disability. Therefore, I served as an effective weapon in powers in contest over power and ideology.

So, for example, at varying times African Americans, immigrants, gays and lesbians, poor people and women have been defined categorically as defective citizens incapable of full civic participation. And so the idea that these ablest arguments are used to justify
discrimination and oppression was really like a major epiphany to me.
And this sort of manifest As for example, disabled people being categorized as unfit for certain jobs and that’s used to justify their exclusion in the workplace and ideas about what is normal or desirable in terms of physical or mental attributes were used to justify discrimination based on race or gender. Then of course there’s the genetics movement which is very popular at the beginning of the 20th century. 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

people 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,
00:29:27.920 --> 00:29:30.224 how well are we serving our
NOTE Confidence: 0.923618903846154
00:29:30.224 --> 00:29:31.376 patients with disabilities.
NOTE Confidence: 0.923618903846154
00:29:31.380 --> 00:29:34.082 So this graph is from the CDC.
NOTE Confidence: 0.923618903846154
00:29:34.082 --> 00:29:36.286 It’s divided into social
NOTE Confidence: 0.923618903846154
00:29:36.286 --> 00:29:37.939 determinants of health,
NOTE Confidence: 0.923618903846154
00:29:37.940 --> 00:29:39.700 health and health risk,
NOTE Confidence: 0.923618903846154
00:29:39.700 --> 00:29:41.460 behaviors and and access.
NOTE Confidence: 0.923618903846154
00:29:41.460 --> 00:29:42.764 And people without disabilities
NOTE Confidence: 0.923618903846154
00:29:42.764 --> 00:29:45.121 are in the light blue and people
NOTE Confidence: 0.923618903846154
00:29:45.121 --> 00:29:47.179 with disabilities are in dark blue.
NOTE Confidence: 0.923618903846154
00:29:47.180 --> 00:29:49.820 And you can see that people with disabilities
NOTE Confidence: 0.923618903846154
00:29:49.820 --> 00:29:52.018 are more likely to be unemployed,
NOTE Confidence: 0.923618903846154
00:29:52.020 --> 00:29:54.456 to be victims of violent crime,
NOTE Confidence: 0.923618903846154
00:29:54.460 --> 00:29:56.820 to have premature cardiovascular disease,
NOTE Confidence: 0.923618903846154
00:29:56.820 --> 00:30:00.216 to be obese, to smoke cigarettes.
NOTE Confidence: 0.923618903846154
00:30:00.220 --> 00:30:03.139 To engage in no leisure time activity.

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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 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 cancer websites recently.
00:30:42.301 --> 00:30:44.047 the Internet and we probably all
NOTE Confidence: 0.938740938461539
00:30:44.047 --> 00:30:45.832 agree that patient facing sides
NOTE Confidence: 0.938740938461539
00:30:45.832 --> 00:30:48.118 should be accessible to those with
NOTE Confidence: 0.938740938461539
00:30:48.118 --> 00:30:50.980 disabilities and there are like
NOTE Confidence: 0.938740938461539
00:30:50.980 --> 00:30:52.840 readily available accessibility
NOTE Confidence: 0.938740938461539
00:30:52.840 --> 00:30:56.364 standards that you can use to check
NOTE Confidence: 0.938740938461539
00:30:56.364 --> 00:30:58.470 websites for accessibility and so.
NOTE Confidence: 0.938740938461539
00:31:00.745 --> 00:31:01.245 This is what smart IT people at
NOTE Confidence: 0.938740938461539
00:31:01.245 --> 00:31:03.377 Stanford did and we went through the
NOTE Confidence: 0.90771276
00:31:03.377 --> 00:31:05.620 50 NCICCM websites and we checked
NOTE Confidence: 0.90771276
00:31:05.620 --> 00:31:07.630 for conformance using these
NOTE Confidence: 0.90771276
00:31:07.630 --> 00:31:09.740 automatic accessibility testers
NOTE Confidence: 0.90771276
00:31:09.740 --> 00:31:11.187 that I really don’t understand to
NOTE Confidence: 0.90771276
00:31:11.187 --> 00:31:13.941 be frank because our IT did this,
NOTE Confidence: 0.90771276
00:31:13.941 --> 00:31:16.495 we did code validation blah blah blah.
NOTE Confidence: 0.90771276
00:31:16.495 --> 00:31:18.978 So anyways. We went through these fifty
NOTE Confidence: 0.90771276
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 like 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.
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.
Provided that the enforcement of the ADA is pretty weak and the only mechanism disabled people have is really to file lawsuits to get people to change other than asking nicely. But so you know, this is just one of many problems that keep people with disabilities from getting appropriate care. So what about ourselves? What about the medical? Medical students, trainees, Practitioners. So again, people with disabilities of the largest minority in America 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.
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.

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.
student at Stanford. She met her after a miserable experience she had during her first rotations. She had been diagnosed with an uncertain neurologic condition around as the AS. She was exiting the PhD phase of her training and going into the clinics and she didn’t know who to turn to for help the. Advertising, or the assistance directing her to a point of contact where she could ask for help with accommodations. was completely lacking. And so she bounced around for a long time.
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.

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 to 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 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
NOTE Confidence: 0.925986301578948
00:39:18.468 --> 00:39:20.703 or with the same disability,
NOTE Confidence: 0.925986301578948
00:39:20.710 --> 00:39:22.750 and then the argument can
NOTE Confidence: 0.925986301578948
00:39:22.750 --> 00:39:24.382 get propagated in residency.
NOTE Confidence: 0.925986301578948
00:39:24.390 --> 00:39:26.460 Also that they’ll never get a
NOTE Confidence: 0.925986301578948
00:39:26.460 --> 00:39:29.283 real job where there are plenty of
NOTE Confidence: 0.925986301578948
00:39:29.283 --> 00:39:31.107 people with similar disabilities
NOTE Confidence: 0.925986301578948
00:39:31.107 --> 00:39:32.960 practicing in other areas.
NOTE Confidence: 0.925986301578948
00:39:32.960 --> 00:39:33.560 And so,
NOTE Confidence: 0.92708284375
00:39:35.720 --> 00:39:38.400 you know, there’s a lot of of misconceptions.
NOTE Confidence: 0.92708284375
00:39:38.400 --> 00:39:42.016 And so this is part of the reason why I give
NOTE Confidence: 0.92708284375
00:39:42.016 --> 00:39:46.560 these talks to to present myself and other
NOTE Confidence: 0.92708284375
00:39:46.560 --> 00:39:49.840 physicians as as an example that people
NOTE Confidence: 0.92708284375
00:39:49.840 --> 00:39:52.712 with disabilities can succeed in medicine.
NOTE Confidence: 0.92708284375
00:39:52.712 --> 00:39:56.840 And So what can we do about this?
NOTE Confidence: 0.92708284375
00:39:56.840 --> 00:39:59.678 I think it’s very important that.
That we consider our approach to disability inclusion. This is a pyramid and the first level is compliance. This is where most places are at. 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. 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. 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 like 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.

Self-assessment.

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 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 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,
that, you know, accommodations are more like favors or special treatment rather than rights.
And so, and I think it’s just difficult for people and human nature to sometimes, you know, look at somebody who looks well. And he was complaining of something that can’t be seen and really asking like is this true, you know? And a lot of people I talked to say the same thing. You know, the comments are but you look so good or you know, you know, are you. Is it really that bad people especially with like chronic pain.
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. Sometimes we don’t understand that we’ve never had. Like excruciating pain before or we haven’t dealt with a situation that felt the same.
is also like a lot a lack of education or understanding on the topic and so 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 slow for a lot of different things and you know we’ve moved the needle quite a bit in society about implicit bias 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,
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
00:52:41.658 --> 00:52:43.490 in ultimately choosing radiology
NOTE Confidence: 0.934215498
00:52:43.490 --> 00:52:45.490 as your specialty versus others?
NOTE Confidence: 0.934215498
00:52:45.490 --> 00:52:47.326 And 2:00, what if your university
NOTE Confidence: 0.934215498
00:52:47.326 --> 00:52:49.250 doesn’t even have a compliance,
NOTE Confidence: 0.934215498
00:52:49.250 --> 00:52:50.010 what do you do?
NOTE Confidence: 0.955907726666667
00:52:51.850 --> 00:52:54.870 Yeah, So radiology, the accessibility
NOTE Confidence: 0.955907726666667
00:52:54.870 --> 00:52:59.570 of radiology was definitely attractive.
NOTE Confidence: 0.955907726666667
00:52:59.570 --> 00:53:02.048 You know, this, like prepare or hope
NOTE Confidence: 0.955907726666667
00:53:02.048 --> 00:53:05.002 for the best and prepare for the worst
NOTE Confidence: 0.955907726666667
00:53:05.002 --> 00:53:07.610 thing also applied to my situation.
NOTE Confidence: 0.955907726666667
00:53:07.610 --> 00:53:09.198 And like, you know,
NOTE Confidence: 0.955907726666667
00:53:09.198 --> 00:53:12.649 the fact that I might age faster than
NOTE Confidence: 0.955907726666667
00:53:12.650 --> 00:53:16.808 than other people that I could become.
NOTE Confidence: 0.955907726666667
00:53:16.810 --> 00:53:18.690 You know that, you know,
NOTE Confidence: 0.955907726666667
00:53:18.690 --> 00:53:20.922 if I’m 30 years old and can barely walk,
NOTE Confidence: 0.955907726666667
00:53:20.930 --> 00:53:22.440 that what’s going to happen
00:53:22.440 --> 00:53:23.950 when I’m 60 years old?

00:53:23.950 --> 00:53:26.190 And what happens if my condition worsens?

00:53:26.190 --> 00:53:27.745 Well, I can do radiology

00:53:27.745 --> 00:53:29.990 from my bed if I have to.

00:53:29.990 --> 00:53:32.606 And so I have the ability to like

00:53:32.606 --> 00:53:35.513 make money and contribute even if my

00:53:35.513 --> 00:53:39.374 condition like worsened to some extent.

00:53:39.374 --> 00:53:41.835 And and also I wanted to do like

00:53:41.835 --> 00:53:44.226 the same amount of work as my

00:53:44.226 --> 00:53:46.101 colleagues think that experience is

00:53:46.101 --> 00:53:47.611 incredibly important for physicians

00:53:47.611 --> 00:53:50.103 like the number of reps you get,

00:53:50.110 --> 00:53:52.334 the number of patients you see and I.

00:53:52.340 --> 00:53:54.820 I didn’t want to really compromise on that.

00:53:54.820 --> 00:53:57.137 I mean, I do have some accommodations


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around my work hours, but for the most part, I do the same amount of work as my colleagues. 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 in all places at the compliance level either at Stanford. The problem is in a big system like where you have a university or a health system where you have like multiple silos.
the disability competency or expertise can vary widely and one person may receive excellent. Treatment or around their accommodations. And a person in, you know, the cubicle down the hall may have a totally different experience with a different supervisor. Our students at Stanford are relatively well supported and they have like specialized people in the accessible education office who deal with their cases. But like the residents don’t, post dogs don’t and so. 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
nurse and she may not have any inkling about that you’re even disclosing a disability or what the resources are that are available or what her obligations are or his obligations are under the law. And so I think a top down approach can also be really helpful in this regard. So you need the education at all levels, but we’re trying to get a high level leader like at the vice Provost level around there to really somebody who can be in a position to affect change throughout the entire enterprise and bring things.
Into an alignment because and right now we don’t have that. Thank you. Any other questions from the audience before we close? Yes, Kevin, thank you. I’m just wondering if you could give an example of in the web data that we helped it pretty well. I would imagine some other areas, we probably have a lot of areas to improve on a lot of opportunity. Are there particular examples of other, you know, around other institutions that you work with or you visited and so forth where you do the day. Like there’s some real examples of something to action to avoid.
NOTE Confidence: 0.915145514285714
00:57:20.260 --> 00:57:22.460 real states that organizations
NOTE Confidence: 0.94276945
00:57:22.940 --> 00:57:25.218 sort of stepped into as a sort
NOTE Confidence: 0.94276945
00:57:25.220 --> 00:57:27.980 of trying to go down this path
NOTE Confidence: 0.94276945
00:57:27.980 --> 00:57:29.284 that you would suggest to us,
NOTE Confidence: 0.94276945
00:57:29.284 --> 00:57:31.090 you know here at like one or two or
NOTE Confidence: 0.94276945
00:57:31.090 --> 00:57:33.380 three things you really want to not do
NOTE Confidence: 0.823929486
00:57:33.540 --> 00:57:34.820 as you sort of approach.
NOTE Confidence: 0.920932492
00:57:37.200 --> 00:57:39.920 For the Zoom audience, yeah,
NOTE Confidence: 0.817522878571429
00:57:40.360 --> 00:57:43.034 like what are the landmines to avoid
NOTE Confidence: 0.817522878571429
00:57:43.040 --> 00:57:47.920 essentially around disability inclusion?
NOTE Confidence: 0.817522878571429
00:57:47.920 --> 00:57:52.078 You know, I guess I would just say that
NOTE Confidence: 0.899770627857143
00:57:54.480 --> 00:57:56.740 the landmines end up happening
NOTE Confidence: 0.899770627857143
00:57:56.740 --> 00:57:59.000 when you’re not including disabled
NOTE Confidence: 0.899770627857143
00:57:59.079 --> 00:58:00.959 people in the conversation.
NOTE Confidence: 0.899770627857143
00:58:00.960 --> 00:58:03.781 And but I don’t think it’s so
NOTE Confidence: 0.899770627857143
much around landmines or talking
It's more just the omission of any
It was like 14% of residents of
the of residencies,
mentioned disability as part
of their diversity statement.
And then you go and and people
have looked at like,
is the information on a website easy to find?
Is there a point person that people can go to?
Is there a clear process for requesting accommodations and it’s really just frequently missing.
And so I think that this are more sins of omission rather than Commission.
I haven’t seen too many examples of just like egregiously discriminatory.
Well, I would say actually that these legalistic sorts of things that that people put into like technical standards and the way that.
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 in a very easy short order of course. You can't be just about the messaging. You also have to change some of the processes behind the scene. But language is important. Great. Thank you. I think we are at time.

So thank you again, Dr. Pulis. This was just an incredible talk today. Thanks so much.