



Stanford
MEDICINE | Radiology

Diversity Newsletter

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“

Awareness is like the sun. When it shines on things, they are transformed.

— Thích Nhất Hạnh

”

National Disability Employment Awareness Month



Celebrate With Us!

National Disability Employment Awareness Month 2021

Stanford Medicine Abilities Coalition



Forward

The Stanford Medicine Abilities Coalition (SMAC) is proud to co-produce the October 2021 Radiology newsletter with the Radiology Diversity Initiative to celebrate [National Disability Employment Awareness Month](#). This issue will feature both original essays from SMAC team members, as well as recent publications from our community. We hope you enjoy what we've put together for you! And please, check out our [October events website](#) for details of all of our fantastic events.

Sincerely,

Peter D. Poulos, MD
Clinical Associate Professor of Radiology
Founder and Co-Chair, SMAC
Stanford Medicine | Radiology

Ken Sutha, MD, PhD
Clinical Instructor of Pediatric Nephrology
Co-Chair, SMAC
Stanford Medicine | Radiology

on behalf of the Stanford Medicine Abilities Coalition (SMAC) Board of Directors

Our Vision

SMAC is dedicated to advancing disability equity, accessibility, and inclusion at Stanford School of Medicine, Stanford Healthcare, and Stanford Children's Health/Lucile Packard Children's Hospital, and beyond. SMAC endeavors to transform the culture of Stanford Medicine from compliance to anti-ableism where patients, employees, and trainees with all abilities can thrive. The long-term goal is to promote disability as an integral part of human diversity, inclusivity, and equity.

Our Purpose

SMAC advocates for accessibility, resources, policies, and services at Stanford Medicine, not guided solely by law and an accommodations-based approach, but by dismantling systemic discrimination through universal design. SMAC encourages collaboration within and beyond the Stanford community to eliminate ableism and provide equitable access and opportunity.

Stanford Medicine Abilities Coalition



SMAC Update

Peter D. Poulos, MD

*Clinical Associate Professor of Radiology
Founder and Co-Chair, Stanford Medicine Abilities Coalition (SMAC)*

This year has been busy for SMAC, filled with milestones and achievements beyond our expectations. We are actively involved in disability research, education, advocacy, community, and health equity. I'm excited to share our work with you.

DISABILITY RESEARCH

In December, in conjunction with the Commission on Justice and Equity, led by Terrance Mayes, Associate Dean of Equity and Strategic Initiatives, we distributed the first-ever enterprise-wide Justice, Equity, and Abilities Survey. We received over 3300 responses from the Stanford School of Medicine (SOM), Stanford Health-care (SHC), and Stanford Children's Health (SCH). We found that approximately 25% of people employed at Stanford Medicine identified as having a disability or had a qualifying medical condition as defined by the Americans With Disabilities Act (ADA). Most, over 80%, of people with disabilities are not accessing accommodations of any kind because of real and perceived administrative and cultural factors. The administrative factors include broken processes, perceived budget restrictions, and lack of information on available accommodations or how to access them. Cultural aspects include stigma, lack of organizational commitment to disabled employees, and fear of discrimination or losing one's career. Information from this survey will inform upcoming initiatives as we attempt to dive in and fix the system.

The SOM is a site collaborator on the Pathways Project, studying the performance and trajectory of medical students with disabilities, led by Dr. Lisa Meeks from the University of Colorado and Dr. Michael Kim from the University of Minnesota. We examined the primary outcome measures of scores on USMLE step one and step two, time to graduation, residency matching, leaves of absence, and match specialty. The results have not yet been published but will contribute to our understanding of disabilities in medical education and areas needing further support.

We also participated in a study led by Dr. Kristina Petersen, New York Medical College, entitled Disability Inclusion Amid COVID 19. The study examined attitudes about physicians with disabilities and their ability to

provide effective patient care during the pandemic. We also looked at feelings around the provision of reasonable accommodations, such as reassignment to telehealth duties, for physicians with high-risk conditions. The data from the eight participating institutions will advance our understanding of bias towards physicians with disabilities during the pandemic.

SMAC is participating in a project called [The COVID Journey](#), which also explores the interplay between disability, race, ethnicity, and illness. We received a \$50,000 Respond, Innovate, Scale, Empower (RISE) grant from the School of Chemistry, Engineering & Medicine for Human Health (ChEM-H) to fund part of the project. My co-PI is Malathi Srinivasan, MD from the Department of Medicine. She received a Stanford Ethics, Society, and Technology seed grant for the project. Our core research team includes research assistants Lilly Bar, Kalpana Balaraman, and Sofia Schlozman. Contracted journalists from Memory Well are interviewing participants from different racial and ethnic groups and with five different types of disabilities, including blind/low vision, deaf/hard of hearing, mobility, dementia, and autism. We are hoping the stories and data collected will improve our ability to serve our diverse patients and those with disabilities.



ADVOCACY

SMAC has been acting as an unofficial clearinghouse for disability knowledge and assistance at Stanford Medicine. We are frequently contacted by students, trainees, and faculty for advice on navigating the healthcare system with a disability. Some people who approach us have tried to negotiate accommodations with little assistance on whom to turn to or denied accommodations. These instances allow us to identify pain points in the system that we can address. And these individuals, inspired to make changes in the system for the betterment of future employees, often get involved in SMAC. For example, we have been approached by a second-year resident who had the sudden onset of severe neurologic dysfunction to the point of needing a wheelchair. Despite reaching out for assistance, she had difficulty accessing accommodations, which severely limited her ability to work. Now she is working with us to improve access to Graduate Medical Education (GME). A medical student, Suchita Rastogi, reached out to us in a similar fashion. Her involvement led to a publication about her experience in the *New England Journal of Medicine*, also included later in this newsletter. One by one, as people come to us for help, they become part of our team and dedicate their time to serving others.

COMMUNITY

SMAC, together with the Society of Physicians with Disabilities (SPD) and the Stanford Medical Students with Disability and Chronic Illness (MSDCI), has established a national peer mentoring program for students and healthcare providers with disabilities. We meet once per month to discuss issues important to our community, such as disclosure, self-advocacy, disability legal rights, and accommodations. We recently received a \$20,000 grant from the Stanford Teaching and Mentoring Academy to expand the mentorship program and study its effect on our members. Anecdotally, we have heard from two medical students who credit the group with motivating them to not drop out of their programs. Disabled physicians and students scattered throughout the country are lacking community in many institutions. Our members are thirsty for fellowship, and this program makes that possible. For example, our formal meetings usually last one and ½ hours, but we leave the Zoom open afterward, and people talk and informally share their experiences for hours.

There are two meetings a month for SMAC, the second Wednesday of each month at 5:30 PM, and the third Wednesday at noon. Information about these meetings is posted on the SMAC website. These meetings provide a valuable forum for community building as we work together to plan events and build the organization. We had our first retreat earlier this year, which took place spread out over several days. We were able to revise our bylaws, including our mission and vision. The retreat was led by Dr. Jennifer Stollman of J.A.Stollman Consulting and Dr. Rania Sanford, director of faculty professional development and internal faculty coach. Our strategic planning is ongoing, thanks to generous support from the Office of Faculty Development and Diversity (OFDD), SHC Office of Inclusion Diversity and Health Equity (IDHE), and the Lucille Packard Children's Hospital Office of Diversity, Equity, and Inclusion (DE&I). Thank you to Drs. Bonnie Maldonado and Magali Fasiotto from the OFDD, Barbara Hardy and Anna Dapelo-Garcia from IDHE, and Leslie Truong from LPCH DE&I.

Lastly, we reorganized our Board of Directors and created new leadership positions. I am now the Co-chair of Strategy and Development. Dr. Ken Sutha from Pediatric Nephrology, himself a two-time kidney transplant recipient, is the Co-chair for Operations. And Doug Neu, Senior Informatics Educator from SHC, who is hard of hearing, is the Vice-Chair.



ABOUT MISSION: ASTROACCESS

On October 17, 2021, Zero-Gravity Corporation will fly its first parabolic flight mission with twelve AstroAccess Ambassadors on board. These Ambassadors have different disabilities and were carefully selected to model the goals of AstroAccess in space. The ultimately goal of this mission is to expand the world of STEM for people with disabilities by demonstrating their abilities to work in the micro-gravity environment. This flight will highlight changes to be implemented across communication, physical accessibility, and safety procedures to make space travel more attainable for those with disabilities.

EDUCATION

In April 2021, SMAC, together with MSDCI, posted the Second Annual Stanford Conference on Disability in Healthcare and Medicine. We had over 1000 attendees from more than 30 countries. This year's conference featured a disability lawyer, a panel of disabled physicians, a session on disability healthcare research, and a presentation of do-it-yourself advocacy. There were also two breakout sessions, where attendees could choose from three options; providers with disabilities, patients with disabilities, and disability law. A special thanks goes out to our entire team, especially my Co-lead Zainub Dhanani, MS, and Katie Pontius and Ashley Williams from Stanford Radiology Event Planning. Videos from the conference can be accessed on the website.



2nd Annual

Conference on Disability in Healthcare and Medicine

Medical Students with Disabilities and Chronic Illness (MSDCI)
Stanford Medicine Abilities Coalition (SMAC)

Saturday, April 10, 2021

Starting in January, I started co-hosting the DocsWithDisabilities Podcast with Dr. Lisa Meeks from the University of Colorado. She developed the concept and began hosting the podcast in 2019 and has turned it into a force in disability inclusion in healthcare. In March 2021, Dr. Meeks, Gillian Kumagai from the Stanford Health Library, Vongai Mlambo from MSDCI, and myself were awarded a \$20,000 JEDI Grant from the Stanford Radiology Department to do a special BIPOC series of interviewees. We are focusing on the unique aspects of being BIPOC and disabled in medicine. This is an incredible opportunity to expand the reach of SMAC and advance the anti-racist mandate by the SOM and our Radiology Department.

HEALTH EQUITY

In January, SMAC, in conjunction with the [Patient Family Partner Program](#), led by Sarah Foad, Interim Manager of Patient Relations, established the first Disabilities Patient Family Advisory Council (PFAC). The group is composed of six staff members and 11 patients with disabilities. The Chair of the group is a patient named Brittany Postle. She wrote an article for this newsletter detailing some of her struggles in the medical system and the meaning of community and partnership, which you can find on subsequent pages. I am the Co-Staff Advisor with Revenue Cycle Optimization Manager Kelly Andersen. Our Executive Sponsor is Alpa Vyas, Chief Patient Experience Officer. Together, patients and staff set goals, including improving navigation, transportation and parking, and storytelling. Storytelling is especially important to help people understand who our patients are beyond their diagnoses.

I participated in the Ambulatory Transformation Task Force (ATT) health equity workstream, led by Dr. Lisa Chamberlain from Pediatrics. Our group focused on creating a health equity dashboard prototype to understand better the patient population we are serving to improve our care to underresourced communities. This first iteration focused on race and ethnicity and zip codes ranked by COVID impact rates, but future iterations will include data about patients with disabilities and those who identify as sexual/gender minorities. The ATT also ties in with the We Ask Because We Care Project focusing on enhancing patient data collection to better care. Representatives of SMAC have been active in creating a mechanism within EPIC to identify patients with disabilities and accommodations that must be made to facilitate their visits. By being proactive instead of reactive, we can make the process smoother for our patients.

I have also participated in the Stanford Healthcare Ethics Committee, Led by SMAC Member Holly Tabor, PhD and Stephanie Harman, MD. We meet monthly to discuss policies where ethical principles must be followed, such as the SHC visitor policy during COVID 19. Many patients with disabilities rely on a caregiver to assist them with personal care or communication, among other reasons. For this reason, patients with disabilities have been allowed one companion. However, because most visitors have been prohibited during the pan-

demic, there was much confusion around this policy, including what constituted a disability and who qualified for a visitor. The committee successfully worked on refining this policy to be as inclusive as possible. In our ongoing work, many ethics consults we discuss involve patients with disabilities and help us identify holes in the system that can impact patient care.

The projects are too numerous to describe in detail in this section. Unfortunately, there are also too many people to thank within this short update. However, I would like to make a special acknowledgment of our administrative assistant, Denise Pincombe, on whom we rely for just about everything. She has done an amazing job. Also, our intern Louis Tan, who works mostly on our social media, but also on a multitude of other projects. Thanks to him for his hard work and dedication. For additional acknowledgments, please see the dedicated section at the end.



Dr. Poulos is Clinical Associate Professor of Radiology and Gastroenterology at the Stanford University School of Medicine. In 2003, as a G.I. fellow at UC San Francisco, he suffered a spinal cord injury and subsequently re-trained in radiology. His specialty is body imaging, focusing on CT, MRI, and ultrasound of gastrointestinal diseases. He is the Founder and Co-chair of the Stanford Medicine Abilities Coalition. He is a member of the School of Medicine Faculty Senate and the Stanford Medicine Diversity Cabinet. His work focuses on advocacy, education, and health equity for those with disabilities. He is the cohost of the Docs With Disabilities Podcast.

<https://profiles.stanford.edu/peter-poulos>

Society for **PHYSICIANS** with **DISABILITIES**

Disability Mentorship

Joe Kim, MD, MPH, MBA

*Founder and Managing Director of the Society of Physicians with Disabilities (SPD)
President, Q Synthesis LLC*

I founded the Society for Physicians with Disabilities (SPD) in 2010. After meeting many physicians with disabilities, I recognized both a need and an opportunity to bring them together to share stories, answer questions, and provide support. At first, I searched for an organization called the American Society for Handicapped Physicians (ASHP), founded around 1981. I could not reach any members or find any information about the group (beyond an inactive Yahoo Group). So, I formed an online membership organization and made it freely available to anyone who would want to join. I felt that this online social community would be a social enterprise that would voluntarily provide resources and support for physicians, medical students, other health care professionals with disabilities, family members, and friends.

As of Oct 2021, the SPD membership has grown to over 1,800 people across the world. Members are free to ask questions, hear from others who have experienced similar situations, and suggest practical resources. Over the years, SPD has been approached by journalists seeking to interview physicians with disabilities. SPD has also had the opportunity to promote events such as the Stanford Conference on Disability in Healthcare and Medicine. SPD has collaborated with groups like the International Council for Disability Inclusion in Medical Education and the Coalition for Disability Access in Health Science Education.



**MEDICAL STUDENTS WITH
DISABILITY AND CHRONIC ILLNESS**
Community. Advocacy. Education. Accessibility.

In June 2020, Dr. Pete Poullos contacted me to collaborate on a mentorship program that would be coordinated across the Stanford Medicine Abilities Coalition (SMAC), the Medical Students with Disabilities and Chronic Illness (MSDCI) Students, and SPD. We promoted this event and held our first virtual mentorship meeting in December 2020 with over 40 people. We continued holding monthly meetings to support students, trainees, and physicians with disabilities. Each month, we discuss topics such as disclosure, advocacy, accommodations, legal considerations, and more. Meeting attendees spend time in a large group for the first 15 minutes, then go into breakout rooms for 30-45 min to share their experiences and ask questions. For the last 20 minutes of the meeting, attendees come back together as a large group to debrief. On average, 30-40 people attend each monthly meeting. In 2021, SMAC was awarded a Stanford Medicine Teaching and Mentoring Academy (TMA) grant to enable SMAC, MSDCI, and SPD to provide additional mentorship programs and services.

Looking to the future, I hope that SPD will expand our mentorship services and find ways to develop more practical resources for medical students, trainees, and physicians who have disabilities. SPD will continue to collaborate with organizations actively engaged in efforts to advance disability research, advocacy, and policy. I also see future opportunities to engage in interprofessional efforts that will include nurses, pharmacists, advanced practice providers, and other members of the health care team who may have disabilities.



As President of Q Synthesis LLC, Dr. Joseph Kim develops practice-based Quality Improvement (QI) and Continuing Medical Education (CME) programs by applying principles of implementation science. Dr. Kim is also a speaker, workshop facilitator, and consultant in digital health, clinician engagement, and social media strategies. He is the founder of several websites including NonClinicalJobs.com, an online community that provides resources for physicians interested in non-clinical careers.

<http://www.DrJosephKim.com>

*Just because a man lacks the use of his eyes
doesn't mean he lacks vision.*

— Stevie Wonder



The DocsWithDisabilities Podcast

Sofia Schlozman

*Stanford University Undergraduate Senior
Co-Producer, DocsWithDisabilities Podcast*

In the summer of 2020, I was eating dinner with my family and listening to my mom, Dr. Ruta Nonacs, talk about a virtual medical conference that she had just attended. The Stanford Medical Abilities Coalition hosted this conference, and it focused specifically on Disability in Healthcare and Medicine.

My mom told my dad, my sister, and me how incredible it was to hear people talk openly about the existence of disability among healthcare providers, how much she related to the physicians who shared their stories, and how excited she was to have found a community of healthcare providers who understood what it was

like to navigate the healthcare system as a person with a disability. Across the table, my younger sister looked confused. “Why would you relate to those people so much,” she asked my mom, “when you don’t have a disability?”

My sister was both right and wrong. My mom has a form of macular degeneration called Stargardt’s disease, which means that she’s legally blind. But for most of my life, I never heard my mom use the word “disability” to describe her eyesight. It wasn’t until she attended that conference and began listening to the Docs with Disabilities podcast that she began to talk openly and thoughtfully about her disability. My mom’s transformation showed me firsthand how impactful and important this podcast can be, and I knew immediately that I wanted to be a part of this project.



Sofia Schlozman, Co-Producer, DocsWithDisabilities Podcast

A few months later, I had the extraordinary opportunity of helping to produce [an episode with my mom as the guest](#). In the introduction, I share how proud I am of my mom for telling her story and how honored I am to be a part of her journey and watch her embrace this part of her identity. Recording the narration in that episode was the first time that I realized that my work on the podcast wasn’t just about creating and sharing stories that would be impactful to others; it was also an experience that would have a profound effect on me, helping to shape how I view medicine, my future career, and my role and responsibilities as a student who hopes to one day enter the medical profession.

Now, with 15 Docs with Disabilities episodes under my belt, I am immensely grateful for the knowledge, insight, and advice that each guest has shared. As a producer, I spend a lot of time with each episode, working on structuring each interview in a way that is engaging and interesting and that honors the insights and experiences shared by each interviewee. This role allows me to develop an intimate relationship with the content of each episode, and this work has taught me lasting lessons about everything from how to be a good ally for future classmates with disabilities, to strategies to encourage help-seeking among physicians, to an increased awareness of moments of inaccessibility in my day-to-day life.

In [Dr. Meeks’ interview with Dr. Lisa Iezzoni](#), for example, Dr. Iezzoni shares her insights on the hidden curriculum of medical education and the process by which the openness of young physicians is dampened by the ableist and paternalists attitudes of their mentors. This episode exposed me to a side of medical education that I hadn’t previously acknowledged and forced me to start thinking about how I can avoid following the path that Dr. Iezzoni describes in my future studies.

In another episode, [Dr. Justin Bullock, Dr. Jessi Gold, and Dr. Erene Stergiopolous discuss the challenges of help-seeking for medical students and physicians](#), touching on topics like the need to normalize vulnerability, the punitive nature of fitness-for-duty examinations, and the perceived consequences of sharing mental health struggles as a healthcare professional. I was so taken by the episode and the sheer amount of work needed to combat these barriers that I began conducting my own research on mental health among medical students as part of my senior thesis project at Stanford University.

These examples represent just a tiny fraction of all of the knowledge I’ve been exposed to as a member of the Docs with Disabilities team. It’s rare to find an opportunity to learn so much about medicine and medical education as an undergraduate, and I’m so appreciative of this podcast’s ability to help me reflect on what I think is vital in medicine and to think critically and thoughtfully about the type of healthcare provider that I aspire to be. After editing each episode, I find myself sharing particularly impactful quotes and ideas with my friends, professors, and family members the next day. The wealth of knowledge I’ve acquired by listening to the stories that people have shared through this platform is invaluable. What’s more, I know that I have so much more to learn about disability and medicine, and I look forward to all of the future stories that I will learn from and that I can help share with others as I continue to work with this team.

Disabilities Patient Family Advisory Council (PFAC)

PATIENT PERSPECTIVE

Brittany Postle

*Student at Foothill Community College
Chair, Disabilities Patient Family Advisory Council*

I came to discover Stanford PFACs by serendipity and happenstance. As a patient with multiple chronic and complex issues, I had been shuffled through a multitude of departments, never quite finding my right fit--- until I did. Once I knew what it felt like to be truly heard by a physician and be a part of planning my own care, no longer just a passenger along for the ride, I felt safe. It was a new feeling for me in the healthcare system.

I had been seeking treatment for over a decade. I'm now in my mid-thirties and finally able to return to finishing my education. I will be transferring to a university this Fall to complete my Bachelor's degree and go on to get my Master's, something I had long ago given up. This would still be a dream and impossible without access to the clinics that keep me going. I am being treated for a cerebrospinal fluid leak; this means that I can go from walking around upright and fine to bed-bound and unable to functionally live my life within a day, having to remain flat until I can receive another patch. My rheumatologist keeps adjusting my meds to keep me stable and out of a flare, and autonomic specialists are there for me when my postural orthostatic tachycardia syndrome (POTS) goes haywire. Going through this process and seeing my quality of life improve has made me realize how fortunate I am to have access to world-class, compassionate physicians. When I say Stanford saved my life, I genuinely mean it. They saved who I am as a person and allowed me to continue with my life, albeit on an unplanned pathway. But with this gratitude comes the realization that other patients with disabilities are still struggling in the system, suffering as I once did. That is why I am grateful for the existence of the Disabilities PFAC.



I had no idea what it meant to be on a Patient Family Advisory Council. It sounded like a chance to give back to the healthcare system, so I jumped at it. More than that, it sounded like I might have a chance to partake in a system that didn't always see me. At the first meeting we held, I looked around me and saw people who had taken very different journeys than myself to end up with their seat at this table. Our PFAC was composed of persons who encompassed such a vast swath of the disability world. When we began to look at issues that affected us, it truly opened my eyes to how diverse the world of disability is.

Attending our meetings made me realize how I had been looking at disability all wrong. I had been focused on how limiting disability is instead of how limiting the idea of able-bodiedness is. Dr. Pete Poulos describes how disability is just a natural part of the life process that will happen to us all unless we stumble into a premature grave. By partaking in the human experience but denying disability, we are trying to force people to fit into the cookie-cutter shape of able-bodiedness. In doing so, we end up denying ourselves chances at joy in the experience of the fullness of life and what it could be if we expanded our ideas around disability culture in mainstream society.

I learned this lesson here at Stanford from physicians and medical teams that listened to me. Not all of them. I had to sift through to get to the right clinics and physicians. But Stanford helped me gain my health back to the point where I have quality of life again. I have an identity outside of being a patient. I want that for more people. I want more people to experience what I experienced at Stanford: being heard, being accepted, and getting to be a part of my medical team.

Part of sitting on this PFAC was hearing other people's challenges in the medical system: from not being allowed access with caregivers during COVID to having a hard time navigating the system as patients with complex needs and myriad providers. I've also gotten to hear and share incredible stories about patients' lives being saved by compassionate medical care teams who saw them as a person and listened to them for the first time. It is the reason many of these people sit on our PFAC today.

Our PFAC has taught me how complex the human condition is and how varied we all are in our needs. Also, how one institute cannot possibly hope to cater to every single one of these needs. At the same time, it has made me aware of areas where I truly believe we can influence the culture of medicine to raise awareness of where we can do better. Areas where we can utilize technology to offer services that allow people to have access and maintain dignity. This PFAC gives me hope that Stanford Healthcare could be a leader and innovator in the area of disability. It has already created a shareholder community of patients and healthcare providers to create opportunities for collaboration. I am excited and hopeful to see what comes next in this area.

Thanks to this PFAC, I have learned how complex it is to live with disabilities because we can't just make one universal adjustment, such as a ramp, and say we have accomplished equity for all. It is an ongoing conversation that will evolve. As a healthcare community, we must stay engaged and keep learning to keep up with it. The critical takeaway for me has been to learn how worthwhile it is to make room for these accommodations and learning experiences outside of the disability community so that people know that they are seen and recognized as humans--- never burdens.

Disabilities Patient Family Advisory Council (PFAC)

STAFF PERSPECTIVE

Kelly Andersen

*Revenue Cycle Optimization Manager, Stanford Health Care
Co-Staff Advisor, Disability Patient Family Advisory Council*

Prior to my current role as a Revenue Cycle Optimization Manager, I was an Emergency Department Registration Manager, working hands-on with employees, patients, and family members. So often, I would see the challenges that individuals with disabilities would face when coming to the Emergency Department and Hospital campus. Days were fast-moving and chaotic and gave me visibility into the challenges and obstacles that individuals with disabilities (and their loved ones) face on a daily basis. I would see mobility challenges in finding available wheelchairs, concerns with the distance from the parking lot to the care area, navigation around the hospital campus, and design flaws making accessibility around campus very challenging.

As a staff member, I could voice my concern; however, with daily competing priorities, it would be challenging to push for change. About a year ago, I heard about the creation of a Disabilities Patient and Family Advisory Council (PFAC) being formed for Stanford Health Care. In the ED, I had worked with numerous members of the PFAC community. I was curious to learn more about how I could actively help improve the patient experience at Stanford, potentially making a difference for countless individuals. Upon attending a preliminary session, I became excited about how I could help. When the opportunity to volunteer as a Co-Staff Advisor presented itself, I put my name in the hat to see if I could push myself and step out of my comfort zone to positively impact the lives of individuals with disabilities and learn from them.

Working with PFAC has been incredibly rewarding. In the six meetings that we have had, individuals with various disabilities and caregivers have come together to set goals, tell their stories, and work to improve the SHC experience for all. One current project is identifying where additional benches could be added to help with the distance between parking and buildings and provide frequent rest stops for those who may need them. Once a month, I get to work with outstanding individuals who are willing and open to share some of the challenges they face to continue to improve their experience with Stanford Health Care. As a Staff Advisor, my role is genuinely to listen to what group members have to say, guide the conversations in a productive manner, and help them achieve their goals.

My current role does not include patient interaction- a huge change from the seven years in the Emergency Department. Being a Staff Advisor brings the patient experience back to the forefront for me and allows me to continue to work to make a difference in health care and attack the challenges of our current system. I am learning more than I am advising with the PFAC, and hearing their stories has only made me more focused on how we can make a difference. I have been provided the chance to work hands-on with a group of incredible individuals, and I look forward to seeing the changes that we can make as a team.



A Piece of My Mind

GROWING PAINS

Maité Van Hentenryck, MD, MS

Co-founder of Stanford Medical Students with Disability and Chronic Illness (MSDCI)

Intern, Stanford University Pediatrics Residency Program

JAMA. 2020;324(8):745-746. doi:10.1001/jama.2020.13442

It started as a blue spot in the crease of my arm. My grandma pointed it out. She's a hypochondriac, so no one was inclined to believe it was serious. I was a fussy 20-month-old baby at baseline, but fussier than normal that day, so my parents brought me to the pediatrician. Not long after, I was in an ambulance headed for the hospital.

I had meningococcal meningitis, complicated by septic shock, disseminated intravascular coagulation, and purpura fulminans. My organs were failing: I was intubated, was placed on hemodialysis, and had 2 episodes of cardiac arrest, becoming unresponsive for almost a month. The purpura turned to necrosis, erupting in bursts onto my skin, burrowing into my bones, and forcing a below-knee amputation of my right leg. Debridement and dressing changes were too painful to be performed awake, so I was taken to surgery every day for weeks.

The doctors said they wouldn't know the extent of the brain damage until my mental status improved. The growth plates in my long bones were so affected that my doctors believed I would only grow to be 4 feet tall and require braces, at a minimum, to walk.

But I was lucky. I survived. I completely recovered from the infection. Within a few weeks of being discharged, I was walking unfazed on a new prosthetic. I grew up healthy, with all the advantages that come with a leg I could whip off anytime I needed. I would stick it out of the car window to scare passing drivers. I once planted it in a graveyard for friends to find one night. When I played soccer, sometimes I could swing 2 goals in 1 if I got my leg to pop off at just the right moment for it to fly into the net along with the ball. I managed to distract my high school English class for an entire period with a debate over what pattern to make my leg (we settled on tie-dye).

But I wasn't completely in the clear. By kindergarten, my legs and left arm had stopped growing. My wrist and my ankle started turning inwards. I had to wear a clunky brace around my foot.

In first grade, I went to Baltimore, Maryland, to see a limb lengthening specialist. Essentially, he surgically broke my bones, inserted pins through the skin and into the bone on either side of the break, and attached them to an external fixator. Every day, I would turn screws on the fixator to mechanically pull the pins apart from one another, increasing the gap between the 2 sections of the bone to force new growth to fill the space. I did these procedures for 6 summers spanning elementary through high school.

If it sounds barbaric, it was. The pins would drag through 1 mm of skin and muscle daily for months. The pin sites were infected constantly, and more often than not, I remember chasing bitter liquid oxycodone with delicious pink antibiotics. I lived in an extended stay home for patients and families called the Hackerman-Patz House near the hospital for 3 months with my mom. When the school year started, we returned home to Rhode Island, continuing twice daily physical therapy and returning to Baltimore every 10 days. After 6 months, the fixator would be dismantled, the pins would come out, and I would be sent home to rehabilitate in time for the next summer, the next lengthening.



But I almost looked forward to those summers. There was always a diverse and supportive community at the House, and people shared all kinds of foods, customs, and stories. We had wheelchair races outside, sang the same Nickelback songs on repeat for karaoke, and shared pictures of our dogs to distract one another when we were in pain. We even tie-dyed our orthopedic surgeon's white coat to match my prosthetic.

Then we'd go home. After months of living with other patients going through exactly the same procedures, I went back to elementary school, to middle school, then to high school with peers who had no knowledge of this. My classmates asked me if I took off the fixators at night, or accidentally whack them with their backpacks. One time at school, my fixator broke, contorting and twisting the 2 halves of my broken radius and ulna in opposite directions. My mom rushed me home, fashioned a makeshift structure using spare screws to keep the bones in place, and booked the next flight to Baltimore. I went back to school a day later, my peers completely unaware of the incident.

After college, I lived in France for a year. There, I was forced to confront my limitations in ways I had easily ignored in the US. I was never so conscious of my limp until I started receiving condescending comments from Parisians on the street. If I took the stairs, people stared and pointed toward the elevator. My ultimate Frisbee coach told me not to return for the next practice because it would be unpleasant for everyone if I continued. I cried the entire walk home.

In fairness, my Belgian family wasn't much better. A well-meaning older relative said they hadn't thought I'd be able to keep up with them after a day of walking through the streets of Paris. Another relative brought me a book of exercises to improve my gait. Yet another told me I should wear pants to hide my leg. When my brother and his fiancée came to visit, I was reassured someday I'd find someone too, once a couple years pass and boys are mature enough to see past my leg.

I thought medical school would be different: people would understand my history, yet not define me by it. But in modern medicine, people with disabilities are our patients, not our colleagues. While an estimated 19% of US residents have disabilities, only 4.6% of medical students from US allopathic schools identified as having a disability in 2019.^{1,2} The barriers to entry are extensive: applicants to medical school must meet often-rigid technical standards, such as the ability to hear effectively, suture wounds, and perform cardiopulmonary resuscitation, and those with disabilities rarely have representative mentors to guide them.^{3,4} Once matriculated, students must fight for needed accommodations, from visual stethoscopes to dictation and magnification software to alternative learning experiences.¹ And yet, physicians with disabilities can have an inherent connection to patients and understanding of their experiences.

In medical school, 2 course assessments have asked what I would do if I saw a person with a disability. Peers have complained about how slow I walk. My teams consistently walk 4 paces ahead of me. When I tell classmates how the pain in my foot wakes me from sleep if rounds run long or how I'll have pain in my wrist if I tie surgical knots for an hour, they fall silent. Few residents have offered me accommodations. I didn't have the courage to tell one of the surgical fellows the reason I wasn't considering his field was not for lack of interest, but because I wouldn't let myself consider a career so dependent on my body.

Some of my peers who have learned my medical history tend to change the subject quickly. "Oh yeah, distraction osteogenesis. I know what that is."

Do you? Have you ever really thought about it?

Have you ever thought about what it must be like to have your bones physically pulled into the right alignment and length? Have you ever thought about what it must be like, in a cold New England winter, to feel icy metal pins tunneling through your bones? If you've never had surgery, have you ever thought about how vulnerable it feels to be pulled onto a hard operating room table while 6 hands stick cold electrodes on your chest, lock your arms into restrainers, and shove a mask onto your face? Have you ever thought about what it would be like, for each year, to have to relearn how to walk, to shower, to sleep?

Every week during my first year of medical school, I visited a little girl at the hospital through a program called Pals. My 10-year-old pal drove 4 hours to the hospital for 3 hours of dialysis, 4 days a week. When she wasn't

drawing in Sharpie all over my hands, she would effortlessly rattle off her entire medication list and tell the nurses exactly which buttons to press when the dialysis machine alarmed. I watched her struggle to read simple sentences because she has never been able to regularly attend school. I observed the closeness between her and her mother, born from spending their weeks so dependent on one another.

My pal received a kidney transplant during the summer, and I never had the chance to see her before she went home. I wish I had told her the following before she left:

Kiddo, you will live through more pain than most people will ever know. It will feel normal to you; it will seem impossible to everyone else. You will be forced to mature more rapidly, yet so differently, than your peers. Be patient with them. Tell them your story.

Keep making them ever so gently uncomfortable with kidney-related humor.

Teach your care team.

Remind them that some of their most exciting moments are your most terrifying.

Remind them that you will understand medicine in ways they may never know.

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Establishing Equity in Medical Education

SUPPORTING CLINICAL TRAINEES WITH DISABILITIES

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The first time I broke bad news in a health care setting, it wasn't to a patient; it was to my medical school classmate.

My classmate, who has a chronic illness, sought my advice about training on the medical wards. As a more senior chronically ill student, I had experience with the issue she confronted now: Would her preceptors support her physical and educational needs?

Having no graceful answer, I sidestepped the question and taught her how to bargain with attendings who might hold her disability against her. In reality, medical schools lack infrastructure to support disabled students on the wards. Students' access to accommodations depends on their preceptors' knowledge of — and buy-in to — disability-inclusion practices.

My own disability, a rare autoimmune disorder that destroys my small-fiber nerves, triggers unpredictable symptoms. Some days, a short walk can incapacitate me for 48 hours. Other days, my hands burn too badly to hold a pen. I always run too hot or too cold, since I can't sweat in the sun or warm up in the air-conditioned hospital. Some nights, attacks of nausea, diarrhea, heart palpitations, and adrenaline surges keep me up for hours.

To control my symptoms, I use a wheelchair, adjust my on-site hours, and take brief breaks. These measures don't impede my ability to perform physical exams or medical procedures or to communicate with patients, families, and clinical teams. If anything, my day-to-day experiences enrich my understanding of the physical, emotional, financial, and professional hardships that patients face.

But no road map exists to help medical students with disabilities navigate the wards. For any given clerkship, the schedule, required competencies, number of overnight shifts, and description of on-call duties are often disclosed at the last minute. Unable to address expectations in advance, many students must negotiate their needs in real time, which can necessitate disclosing personal health information to evaluators.

To avoid this situation, I solicited information from the disability service providers (DSPs) at my institution's accessibility office. But at our first meeting, my assigned DSP confessed, "I am unfamiliar with the medical wards. Can you tell me more about them?"

I stared back at her helplessly. I had intended to ask her the same question.

My DSP later confided that she regretted her lack of knowledge regarding clinical expectations but had little ability to remedy it, since her time was divided among multiple departments. Although many top medical schools have a dedicated DSP who specializes in medical education, other DSPs lack the resources and expertise to provide appropriate assistance.

Without adequate support from DSPs, students must investigate requirements, identify disability-related barriers, and anticipate needs for accommodation. Consequently, I spent weeks before each clinical rotation researching appropriate faculty members to consult about accommodations and passing information between them and my DSP. Scores of emails are needed to confirm arrangements. These tasks are additions to the time commitments that many disabled students require for health and well-being needs. Communicating



with preceptors about accommodations can bring additional challenges. In my first week on the wards, I met my preceptor in a crowded physicians' workroom. "I'd like to touch base regarding a letter you received about me yesterday," I said. The letter contained information about my approved accommodations.

"I must have missed it," my preceptor answered apologetically.

"I have a chronic illness," I explained. While the room's other occupants avoided my eye, I blundered through a mumbled description of my needs.

At many institutions, students who require accommodations must similarly disclose their disability status in person to new preceptors, often in communal settings. Wards are ill equipped to implement recommendations that a third party discreetly communicate with preceptors about accommodations, and preceptors often hand off students to colleagues without briefing them on the students' needs. When preceptors are too busy to discuss accommodations, students must either abandon their accommodations or risk being reprimanded for invoking them without permission. Disabled students also regularly confront ableist notions about who is qualified to become a physician. Before I disclosed my chronic illness, a trusted advisor served as my cheerleader throughout training-related struggles. After learning about my disease, she adopted a new refrain: "Maybe you should leave the program." Such hostility permeates the wards. Many training sites don't adhere to modern accessibility standards, such as those regarding wheelchair access and height-adjustable exam tables.¹ Clerkship directors often don't provide adequate time for appointments and self-care.¹ Offensive remarks about psychiatric patients are regularly made by trainees who are unaware that at least one in four of their colleagues has a mental illness.²

Many supervisors challenge students' approved accommodations. Despite an accommodation to limit time spent on my feet, I was expected to climb stairs instead of taking elevators. When I went home early, in keeping with my preapproved, disability-related working hours, authority figures shamed me for leaving. DSPs often lack the time and authority to protect students from such pushback.

These attitudes and expectations stem from an ingrained culture of medicine as an endurance sport. The long hours and denial of self-care expected of clinicians generally aren't necessary, except in subspecialties that involve lengthy procedures. Such expectations deter chronically ill and disabled people from entering the profession and may explain why less than 5% of allopathic medical school students identify as disabled,³ as compared with 26% of Americans in general. These expectations may also contribute to high rates of burnout among physicians without disabilities.

Other industries are adopting policies that foster a culture of accessibility, reasonable accommodations, and

equity for people with disabilities. Although people with disabilities are poorly represented in the general workforce, assistive technologies and accommodations are available to enhance functioning, and metrics such as the Disability Equality Index and public resources such as the Job Accommodation Network increase the visibility of disability-inclusion efforts. The Americans with Disabilities Act and Section 504 of the Rehabilitation Act of 1973 prohibit discrimination based on disability in employment, public venues, and government services and also prohibit discrimination by many private entities. In addition, the Affordable Care Act mandates data collection to assess disability related health disparities and requires facilities to have accessible screening equipment, among other protections.

Initial Measures to Support Clinical Trainees with Disabilities.*	
Recommendation	Rationale
Hire a medical school-specific DSP	A dedicated DSP with clinical knowledge and clout to enforce accommodations empowers students to focus on training, rather than on addressing disability-related barriers.
Establish disclosure mechanisms driven by preceptors	Students shouldn't need to divulge their accommodation requirements in public spaces; preceptors should be required to read communications about accommodations and discreetly brief other supervisors before handoffs.
Publish clinical expectations in advance of each clerkship	Releasing syllabi, generic schedules, and other requirements provides students and DSPs adequate time to establish and implement accommodations.
Inform all educators and administrators about best practices for disability inclusion	Education should include antistigma training; normalization of disability, accommodations, and use of assistive technology; and guidance on recognizing students who could benefit from accessibility services.
Restructure institutional policy and infrastructure to treat people with disabilities as vital to the medical education system	People with chronic illnesses and disabilities are integral to the diverse health care provider community, and schools must account for their needs; this concept is especially relevant during the era of Covid-19, which poses particular risks to immunocompromised students.

* DSP denotes disability service provider. Data are from Meeks and Jain.¹

Systemic change is needed to dismantle structural barriers in medical training for students with disabilities. Schools should establish streamlined, coordinated policies to support students; analogous policies in other industries have been most effective when employers spearhead policy development and implementation.⁴ Such measures have generally succeeded only when their social effects — for example, their effects on attitudes toward people with disabilities — have been anticipated.⁵ For this reason, faculty, staff, and trainees must be educated to consider assistive technologies and accommodations not as forms of special treatment, but as tools that enable equal access to medical education. Students with disabilities don't require lower standards than nondisabled students; "accessible" doesn't mean "less rigorous."

Several steps suggested by the Association of American Medical Colleges¹ to improve accessibility are attainable for most schools (see table). These measures represent only the beginning of medicine's journey toward inclusion. The rich diversity of students with disabilities demands a shift away from a one-size-fits-all model of training. Equity for all trainees can be achieved only by means of an approach based on flexibility, compassion, and cultural humility.

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Acknowledgments & Resources

[Disabled Doctors Were Called Too 'Weak' To Be In Medicine. It's Hurting The Entire System. - Huffington Post, July 22, 2021.](#)

Disability Survey - Dr. Sarah Kate Selling, Dr. Arghavan Salles, Dr. Magali Fassiotto, Dr. Richie Sapp, Dr. Steven Dominic Losorelli

Pathways Project - Dr. Mijiza Sanchez Guzman

Disability Inclusion Amid COVID 19 project - Dr. Sarah Kate Selling, Dr. Mijiza Sanchez-Guzman

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– Barack Obama