2022 Eleanor Clarke Slagle Lecture

Finding Our Strengths: Recognizing Professional Bias and Interrogating Systems

Kristie K. Patten

Kristie K. Patten, PhD, OT/L, FAOTA, is Vice Chair of Academic Affairs, NYU Steinhardt School of Culture, Education and Human Development, and Professor, Department of Occupational Therapy, New York, NY; kristie.patten@nyu.edu.

No one builds their lives on remediated weaknesses. No one. Who does a deficits-based approach benefit? Those we serve, or the professional community? Do our current models of practice support flourishing? Our professional biases make it hard for us to see not only how our practice may be getting it wrong today but is also perpetuating systems that prevent us from getting it right tomorrow. A paradigm shift to a strengths-based model that interrogates the educational, research, and practice systems we work in is proposed. It is a shift that we must see, speak, and act on. Our vulnerability and willingness to rethink is our strength, which will meet the changing needs of society. This lecture will draw on literature from positive psychology, disability justice, well-being, and research that centers the voice of self-advocates.

I would like to begin my talk by grounding us in the words of a famous philosopher who once described a process to examine our own lives. But first, I will give you an advanced organizer of my Eleanor Clark Slagle lecture. I am going to ask you to question the models you use to practice, teach, and research. Our practices are often grounded in a deficit approach, where we are the experts who provide services to remediate weaknesses. No one builds their lives on remediated weaknesses (Patten, 2022). No one.

Who does a deficit-based approach benefit? Do our current models of practice support flourishing? Our professional biases make it hard for us to see how our practices are getting it wrong. Bias also perpetuates system-wide deficit-based models (FitzGerald & Hurst, 2017). I will propose a paradigm shift to a strengths-based model that interrogates our educational, research, and practice systems. So that is where we are going. So back to that famous philosopher. In the words of Ted Lasso, I am going to ask you to “Be curious, not judgmental.” Be curious, not judgmental. Curious about your own practices, curious about your research. Curious about how you are educating the next generation of occupational therapy practitioners. And for students, curious as to what type of practitioner, educator, or scholar you want to be.

Zora Neale Hurston, a noted scholar and author, defined research as “formalized curiosity . . . poking and prodding with a purpose” (Neale Hurston, 1942, p. 91). So I would like to invite you to poke and prod and be curious and challenge our assumptions as occupational therapy practitioners. What biases do we bring to our work? How can we truly embrace a strengths-based lens? I will argue that, to do this, we have to be curious. We also have to be wrong.

The Power of Being Wrong

As Sydney Harris, a journalist and essayist, identified, “The three hardest tasks in the world are neither physical feats nor intellectual achievements, but mortal acts: to return love for hate, to include the excluded, and to say, ‘I was wrong’” (Harris, 1968, p. 6). Being wrong requires us to reflect and rethink our views. Being wrong requires an inquiry mindset. It is hard to admit we are wrong. Think about the last time you admitted you were wrong. We need to lower the stakes of being wrong. With a curiosity or inquiry mindset, we might ask “What are the limitations of what I currently

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know? Who do I know it from? What voices inform our practice, education, and research? What have I gotten wrong and how do I know?"

With my bachelor's OT degree in hand from Elizabethtown College, I began to practice, addressing "deficits" that autistic individuals display. As a researcher, I studied these "deficits" and examined the efficacy of interventions designed to reduce these deficits (Kinnealey et al., 1999; Koenig et al., 2012; Pfeiffer et al., 2011; Smith et al., 2005). I worked hard to help autistic individuals be more like their peers—more neurotypical, if you will. I believed that if we could fix, or change, behavior, we could help autistic individuals overcome barriers that prevented inclusion. Then, while at Temple University, my colleague, Dr. Moya Kinnealy, and I interviewed individuals who typed independently to communicate but were nonspeaking. Each of these individuals demonstrated atypical behaviors associated with autism: flapping, repetitive movements, lack of eye contact, and sensory hypersensitivities. I knew these weaknesses; these were familiar deficits. I knew this narrative.

And I Could Not Have Been More Wrong

Our first interviewee typed that he wanted to write a book on how Foucault looked at normalcy and disability and how power and knowledge marginalize those who differ from the norm. This was his aspiration, while each and every semester he had to prove that he was more capable than his below-70 IQ test, which had labeled him as less than capable for a college degree. While at the same time, be impaired enough to need a full-time aide. His professors questioned his competence based on his presentation. Today, we still would focus on his outward behavior versus his inherent strengths and aspirations. We would want to reduce his self-stimulatory behaviors and would do as Foucault (1975) identified, marginalize him as being different from the norm. I realized that by focusing on deficits, autistic individuals could not identify their own strengths after a life of others underestimating their abilities and failing to see their competence. We thought we had done our job, and done it well. But we had not given autistic individuals a path to success. Service providers, myself included, had framed a language of deficit, and weaknesses, that was reinforced by society. This doesn't mean there are not challenges. The challenges are real. Sensory issues like auditory hypersensitivity were familiar to me. But by taking a deficit lens, my focus would be to treat the auditory hypersensitivity. What does that miss? As Paul Kotler, a nonspeaking friend and activist, described, it misses the rest of the story. He wrote:

> Rain means different sounds. Sounds out of the ordinary of daily and sounds that are utterly fascinating. I have heard people say that no two snowflakes are the same. Well, I can also say that no two rainstorms are the same. They each have distinctive sound. It is like a symphony and it is delightful. Rain falling on a flat roof sounds different than rain falling on an angled roof. Rain hitting windows of different thickness makes different tones. I can almost hear the glass ringing with sound. The way the wind blows absolutely changes the music of the rain. Overall, it is a wonderful sound that I wish I could share with others.
> (P. Kotler, personal communication, September 15, 2018)

Auditory hypersensitivity? Yes. Breathtaking auditory magic because, not in spite of, the sensitivity? Yes.

Others we interviewed said autism is who they are, not what they have. The autistic way of being was central to how they experienced the world. Yet most professionals held the cards as to how they should behave, com-municate, and maintain eye contact as a sign of success. A chorus of autistic adults told us flat out, "I can look at you, or I can listen, but you need to pick one." By forcing our neurotypical rules about what makes a successful student, worker, or friend, we missed who they were, their story. Service systems were complicit with a deficit-based approach, leading to poor outcomes, including the anxiety and depression often associated with autism.

Professionals have set a "Look More Like Everyone Else" standard for neurodivergent individuals. Sit still, don't flap, look at me. Imagine asking a wheelchair user to stand up, walk like me. We can't imagine that. But we have been judging neurodivergent performance by unattainable and unnecessary standards. Imagine a world where the object or activity that helped you make sense of the world was only given to you if you did exactly what you were told to do, and maybe only if you did it for three out of three trials. Imagine a world where everyone around you focused on improving your weaknesses, every single day. That is the community we created for many of our autistic students. By listening, I realized I was wrong. I learned a different perspective. A strengths-based model seeks to affirm, challenge, and evolve our beliefs (Patten, 2022). We can learn if we lower the stakes of being wrong. We have been well intentioned but wrong. We study lack of empathy in autistic individuals without examining our own lack of empathy toward the autistic way of being. We focus on deficits while giving lip service to a person's strengths. How was I perpetuating this? I had to be curious. Why was I studying all that was wrong without considering what was right? How is society complicit in perpetuating a deficit narrative, and what is my role in overturning that paradigm? How can we acknowledge the challenges while seeing a person's capacity and brilliance? This is the power of being wrong. I now frame all my work and my identity as a human being in strengths-based, authentic partnerships. What I consider relevant is now rooted in the wisdom of the lived experiences of autistic scholars and activists. That is the power of embracing being wrong. That is my story. But what does that mean for the profession?

Examining Occupational Therapy's Bias

The American Occupational Therapy Association's (AOTA's; 2017) Vision 2025 states we are "an inclusive profession" that "maximizes health, well-being, and quality of life for all peoples, population and communities, through effective solutions that facilitate participation in everyday living" (p. 1; AOTA, 2017). Let's break that down and be curious. Are we an inclusive profession? Do we view disability, gender, race, sexual identity, and class as multiplying factors that discriminate against historically marginalized groups? Do we acknowledge that these intersections create overlapping barriers to access and independence? Does our focus on deficits maximize health, well-being, and quality of life? Does our intense focus on individual independence turn our attention away from solutions that facilitate fuller participation? Whose voices do we include as we think about effective solutions? What have we gotten wrong?

The Power of Centering the Advocate Voice

Grant Blasko, an 18-year-old nonspeaking autistic young man from the Northwest, a consultant with our inclusion programs, stated, "To use whether or not someone is independent as the measure of success when professionals have no idea what it is like day in and day out to deal with systemic biases, seems cruel and insensitive" (G. Blasko, personal communication, February 8, 2022).

We may be taken aback at being called cruel and insensitive for having independence as a goal. If we are curious, we wonder why we use independence as a measure of success, and what could be wrong about that metric. Personal independence ignores systematic barriers that interfere with independence as well as the desire for self-defined interdependence. For example, if Grant is not independent by our standards, how quickly do we attribute his failures to a lack of motivation or, even worse, failure to comply, rather than considering how a lack of resources, opportunities, and environmental barriers contribute to his performance? Grant demands that we consider more than client factors. If we are curious, we would ask, "What is missing"?

Lauren Melissa Elezy, an Autistic Adult Woman, Speaks Directly to You, the Therapy Community, and Asks You

> To pause. Listen to what we need from you. Listen to what has hurt us. I have encountered practitioners who are overjoyed to see autistics behaving more like their neurotypical peers. Is that truly something to celebrate? Is our goals to teach autistics to mask? Because autistics will always be autistic. Each time I am praised for not being autistic, I learn that people like me . . . when I am not me. (L. M. Elezy, personal communication, February 22, 2022).

Lauren asks us to pause and reflect. By writing goals for "normal behavior," are we maximizing health and well-being? Or are we telling individuals that to be successful, you have to be more like others, to mask your true self? Kenji Yoshino (2006) wrote, "Outsiders are included, but only if we behave as insiders—that is only if we cover. . . . Groups should make a common cause against coerced covering, demanding an equality not staked on conformity" (p. 48).

Are we demanding conformity? When we remove demands for individuals to mask or cover their authentic selves, what choice and autonomy and life does that open up? Can we challenge intervention and research that support this type of "coerced covering"?

Lawrence Carter-Long, Born With Cerebral Palsy, Outlines an Impossible Demand

> In order for people with disabilities to be respected or even considered worthy or valuable they must "overcome" their conditions. They must strive to be normal—meaning not disabled, which is impossible. This is a recipe for guaranteed failure. . . . Success is determined not only by the person's achievements, skills, and talents but rather by disabled persons' desire to become like nondisabled people. A deficit-based approach is of little to no practical value at best and, at worst, sets everyone up for disappointment if not failure across the board—disabled or not. We can, we must, do better. (L. Carter-Long, personal communication, January 15, 2019)

Lawrence Highlights a Philosophy That Is Grounded in the Field of Disability Studies

We have strong roots arguing for occupational therapy to embrace a disability studies perspective over the years but have been slow to integrate these concepts into our practice, education, and research. We have made strides in thinking beyond the medical model to embrace the social model of disability, but how have we shifted our daily practice? We do so many things right, so why do we have to look critically? Why do we need to be curious? Why do we need to consider what we may have gotten wrong?

Because, I would argue, historically, health care professionals have had an oversized role in determining disability identity. Disability activists argue, and I agree, that this gatekeeper role perpetuates experts who fix the problem and may continue to ask research questions that are irrelevant to the people we serve. A focus on person factors misses opportunities to research, develop supports, and teach about systemic and environmental barriers as the true challenge. We center disability as residing in the individual, which leads to singular therapeutic solutions rather than creating collective public solutions. For some illnesses, wounds, injuries, and disease processes, the medical model is appropriate. We as OT practitioners are an integral part of the medical system as applied to medical problems, but we cannot apply the same mindset to fix disability. For people with disabilities, the medical model has not provided all the answers nor asked all the right questions. Disability studies scholars have offered alternative models that now dominate much of the discourse, but how does that translate into occupational therapy practice? I would like us to go back to move forward.

Occupational Therapy's Historical Call to Shift to a Disability Studies Paradigm

In his book The Politics of Disablement, Michael Oliver (1990), a disabled activist, first used the term social model to describe a shift toward the examination of disability that looks at how society's attitude and environments disable the individual. The field of occupational therapy, being at the forefront at that time, quickly took up this call to make the shift. Dr. Mary Law's Muriel Driver Memorial lecture for the Canadian Occupational Therapy Association in 1991 called for OT to eliminate disabling environments, dismantle classification of individuals based on norms, change the perception of disability as deviance, and examine the unequal power dynamic between clients and clinicians that contributes to these issues. Dr. Law also urged OT practitioners to use environmental interactions, look at how we produce space for access, and see questioning by clients as desirable to the occupational therapy practitioner.

In her 1994 Slagle lecture entitled "Building Inclusive Community: A Challenge for Occupational Therapy," Dr. Ann Grady (1995) highlighted that, in the past, "Disability was usually viewed as a medical problem with the expectation that, to be accepted, persons with disabilities needed to be as much like persons without disabilities as possible without regard for their own uniqueness" (p. 303). Dr. Grady felt that change lay in shifting to an interactional model where disability is derived from an interaction between the individual and the environment, and we needed to have opportunities and resources in communities to support inclusion.

In 2005, in a special issue on Disability Studies and Occupational Therapy, AJOT guest editor Dr. Gary Kielhofner (2005) called on our profession to examine the critiques of rehabilitation from a disability studies perspective and consider their implications for occupational therapy.

He suggested emphasizing public education and societal attitude change with the need to foster self-advocacy. He wanted us to play a role and stop practices that encourage negative attitudes and self-doubt in the populations we serve. And finally, he wondered if we were strong enough to let our consumers decide whether we are valuable. Since that special issue OT scholars have made significant contributions to disability studies, culminating in a recent issue of AJOT in Summer 2021, whose guest editors from the Occupational Therapy and Disability Studies Network renewed the call for change and hoped that occupational therapy would finally make the changes necessary to better align with the disability community and prioritize working for social change.

Sheth and colleagues (2021) interviewed 11 of the 13 original authors of the 2005 AJOT issue to revisit their thoughts as to how occupational therapy has aligned itself with disability studies in the past 15 years. We have come far in some areas. The authors specifically viewed progress in that we now recognize client-directed meaningful occupations as central to OT's purpose, we consider environment and community accessibility, and we have made promising shifts to focus on population health and primary care (Sheth et al., 2021). But what is missing? These pioneering authors felt that we still need to: (1) embrace nontraditional research methodologies that center voices; (2) collaborate with and center marginalized populations in our profession; (3) connect disability studies content with practice realities; and finally (4) partner authentically with the disability community in practice, education, and research. And I would add that it is also essential for occupational therapy to give priority to and center voices of historically marginalized communities at the intersection of disability, race, gender, sexuality, and class—who face ableism and discrimination from systems that create barriers to full participation.

Ableism and Occupational Therapy

The profession must ask itself, what do we need to do so that we are not writing the same thing in 15 years? Why have we not realized the vision set out in the 1990s by leaders in our profession (Grady, 1995; Law, 1991)? I believe we have not adopted an anti-ableism lens. Ableism refers to a societal preference for nondisabled ways of being that contributes to bias and discrimination against disabled people (Campbell, 2014). It is the belief that typical abilities are superior. Like racism and sexism, ableism defines entire groups as "less than."

Ableism is entangled in our assessments. We create assessments that measure deficits and confirm that individuals are "disabled" because they are different from the norm. Ableism in health care results in a person with a disability receiving lower quality care. The disparities grow exponentially when disability, race, and gender intersect. A study from 2020 found that nearly 84% of health care professionals implicitly preferred people without disabilities (Friedman & VanPuymbrouck, 2021). Educators have not embedded training on ableism and disability justice; we have not centered the voices of historically marginalized groups in our narratives. Researchers have not partnered with advocates to ask their questions or address their priorities.

Self advocates and stakeholders need to be designers of research.

We need to ask questions that are meaningful to the disability community.

We need to be the profession that shifts from a narrative of overcoming disability to one of overcoming ableism.

To accomplish these changes, we must commit to listening to disabled experts and center those voices in practice, research, and teaching.

A quick example. For years, neurodivergent individuals have told us that eye contact is distracting and even overwhelming. Why do we insist on eye contact? We have all been part of a natural experiment the last couple of years that illustrates how important it is to have the right voices asking the right questions and being listened to when they share their truth, their experiences. What is the experiment you have all unknowingly participated in? Over the last several years all of us have experienced Zoom fatigue. Professor Jeremy Bailenson, director of Stanford University's Virtual Human Interaction Lab, has postulated that "nonverbal overload is a potential cause for fatigue, specifically exceeding eye gaze" (Bailenson, 2021, p. 1).

A deficit approach that prioritizes normalization and compliance leads to writing goals to increase eye contact in spite of autistic advocates claiming it's an inappropriate goal and produces stress (Patten Koenig, 2019). Well, we now have had the lived experience of excessive eye contact demands and the impact on our levels of fatigue. If "appropriate eye contact" is the goal, then Zoom gave us many opportunities to practice. But what happened? We all wanted to turn our cameras off, were happy when our calendars showed a phone call or, better yet, a webinar, where we don't have to be on camera or speak! As Dr. Bailenson (2021) pointed out, "From a perceptual standpoint, Zoom effectively smothers everyone with eye gaze" (p. 1).

Zoom asks for eight times more eye gaze (Bailenson, 2021), and how do we respond? We say no. We turn off our camera. We respect differences, and no one demands more. When we long for less eye contact, we have options. If eye gaze is your goal for me in therapy and is the only way I get rewarded with movement, a break, or a favorite object, I have no options.

So, How Do We Shift Our Thinking?

We need to widen our lens and, as Maya Angelou once said, once we know better, we have to do better. So where do we start to be better? Dolly Chugh (2018), author of The Person You Mean to Be: How Good People Fight Bias, says it depends on where you enter this conversation. She calls it her "10% rule." Let's apply the rule to confront ableism and occupational therapy.

If this is the first time you have heard the word ableism, if you have have never had a conversation with a disabled individual regarding their views of the medicalization of their disability, or never considered your own professional bias, be 10% more mortified. Why 10%? That means it's a challenging but attainable goal. Why mortified? If this is your first time looking at your own practice, it is a little mortifying to realize your unwitting actions, your past practices, interactions with colleagues, and the ableist world around you. Chugh (2018) recommends staying with these uncomfortable feelings. We can't shut down and ignore this discomfort but rather need to use it to build our knowledge. Be willing to be wrong.

If you have done some work, you have posted on social media, and are learning about disability justice and ableism, be 10% more terrified. You have been on the bench, watching others take the lead. Get in the game and take a risk, bet on your new insights and values, ask the hard question, challenge someone. Chugh (2018) recommends that you seize moments where you would have stepped back, and step in! Act on your knowledge and stay curious. If you are committed to disability justice, because of an identity you hold, or because it's part of who you are, be 10% more satisfied, satisfied that hopefully the rest of us are stepping up and you don't have to respond to every request and every demand on your time; you can catch your breath knowing others are stepping in. Take a break, be better.

Be Willing to Be Wrong, Be Curious, Be Better—and You Get to Decide How and What Matters

I am hoping this talk will sensitize you to a different perspective and you come away with, as Adam Grant (2021) says, "The person most likely to persuade you to change your mind is you. You get to pick the reasons that are the most compelling, and you come away with a real sense of ownership" (p. 25). Once you begin to see ableism you will see it everywhere.

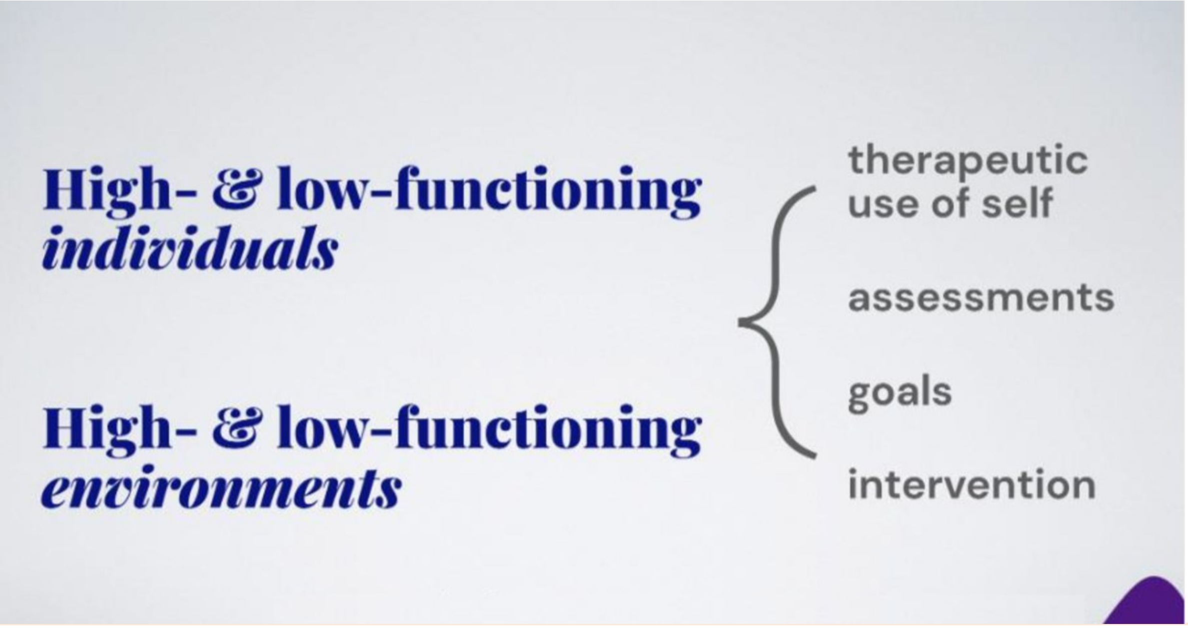
Roy Grinker (2008), an anthropologist who wrote Unstrange Minds, used a famous image of negative space to point out that there was not an unexplained epidemic of autism. In fact, autistic individuals were always there, but we never saw autistic representation and had a narrow definition. He asked people to see what was in this famous logo that they may not have noticed. What do you see besides FedEx? Looking between the E and the x of the famous logo, the white space is used and contains a shape of an arrow. If I know that specific instruction to look there, I can see it. It was there all the time. Once we knew, we could see it, clearly and every time. It has always been there!

So for those of you who are seeing the arrow for the first time, my apologies as you overfocus on FedEx trucks in the next couple of weeks. But a very small specific part of your world and the way you see it has been changed. Maybe just by a millimeter in terms of all you see. But a millimeter can be critical, as James Baldwin identified. He wrote: "The world changes according to the way people see it, and if you alter, even by a millimeter, the way a person looks or people look at reality, then you can change it" (as cited in Romano, 1979).

Shift From High- and Low-Functioning Individuals to High- and Low-Functioning Environments

My work is with autistic adults, children, and youth. I give a disclaimer in my lectures and writing when I use the term autistic adult or autistic student, which violates the person-first language that we are all taught. The majority of autistic individuals prefer this identity-first language. Why do I say "nonspeaking" versus "nonverbal"? Quite simply, the work I have done with disability advocates informs all I do, starting with language. It is the FedEx arrow I cannot unsee. "Nonspeaking" simply implies the individual does not speak verbally and may use alternative means to communicate. If I say "nonverbal," we already have an opinion on ability to speak, but we also may quickly make assumptions regarding cognitive ability. I have used the term nonverbal in my past writings, and I have been wrong (Shoener et al., 2008). I no longer say "high" or "low functioning" but rather discuss functioning by considering how much support someone

Figure 1. Shifting from an individual to an environmental perspective.



High- & low-functioning *individuals*

High- & low-functioning *environments*

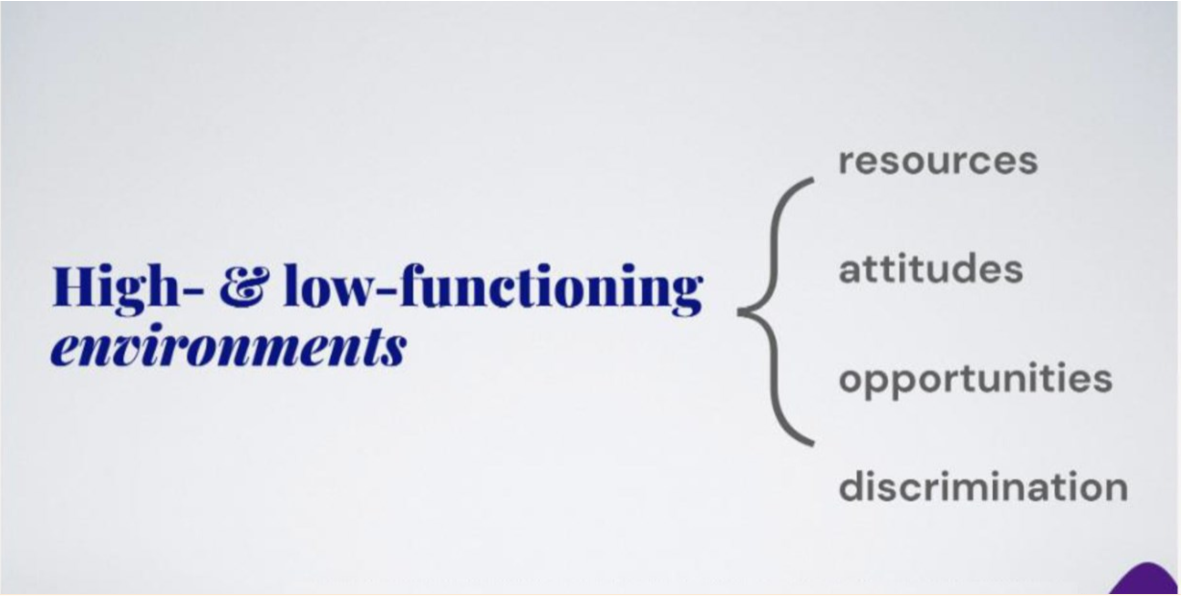
therapeutic use of self

assessments

goals

intervention

Figure 2. The scope and power of shifting to high- and low-functioning environments.



High- & low-functioning *environments*

- resources
- attitudes
- opportunities
- discrimination

needs and how many barriers they face daily. How about we stop labeling high- and low-functioning individuals and start labeling high- and low-functioning environments instead (see Figure 1 and Figure 2)?

The tools of the profession serve the needs of the individual. If we commit to a disability studies, rights, and justice perspective in practice, then we would also use our skills and turn these tools onto the environment, systemic bias, and ableism every chance we get.

A high-functioning environment might consist of a school with an OT and SLP who work closely and are experienced with a variety of augmentative and alternative communication options that are integrated seamlessly with a student's day with a fully trained staff. Schools without the same financial and personnel resources could be a low-functioning environment. Every environment where ableism, discrimination, and stigma are present is low functioning. We must advocate for high-functioning environments and stop giving the systems that enable an environment to be low functioning a pass! Wheelchair users gain independence, mobility, and freedom, so the term wheelchair bound is inappropriate. It is the low-functioning environments that bind them: inaccessible public transportation, homes, and workplaces. We, as a profession, will make a commitment to doing better when we choose descriptors that honor lived experiences. And what does it mean to say "special needs"? Housing, employment, transportation, friends, and meaningful hobbies are important to everyone. "Special" quickly becomes wrong or defective as we attempt to normalize others in what are often segregated low-functioning environments, ultimately excluding those at the margins. We also stigmatize and bully "special" at significantly higher rates as a society (Blake et al., 2012).

Occupational Therapy and Bias

Professionals foster this ableist language. We simulate disability experiences in educational programs by spending a day in a wheelchair, which merely shows how difficult it is for a non–wheelchair user to navigate. We learn what barriers exist in a day. What if we show how difficult it is for an expert wheelchair user to navigate an appointment or work due to unreliable transportation options? What if we listen as wheelchair users explain what they deal with and the bias they face? We understand physical inaccessibility, but do we see the systemic bias that makes an environment difficult to navigate due to stigma, discrimination, low expectations, and policies that deny inclusion and full participation?

Friedman and VanPuymbrouck (2021) examined OT students' explicit and implicit disability attitudes. From entry to graduation, conscious explicit attitudes about disability became more positive overall, while negative implicit bias grew or stayed the same. Does OT education actually reinforce ableist attitudes? What happens when new practitioners enter the profession with the preconceived notion that disability is negative, or something to be fixed, with their expertise? As you read, you may be saying, "Of course I am not biased toward disability as an OT practitioner." But I ask you again to be curious, not judgmental. Let us examine that bias in how we write up our evaluations, as can be seen in Figure 3.

This should ring true if you think about every evaluation report you have read or written. We focus on what we assess, and this is how we assess. We strengthen the bias toward disability as deficit with each evaluation we do, or goals we write where the balance is tilted so dramatically toward impairment. Our impairment-based models rely on assessments that place the problem solely within the person.

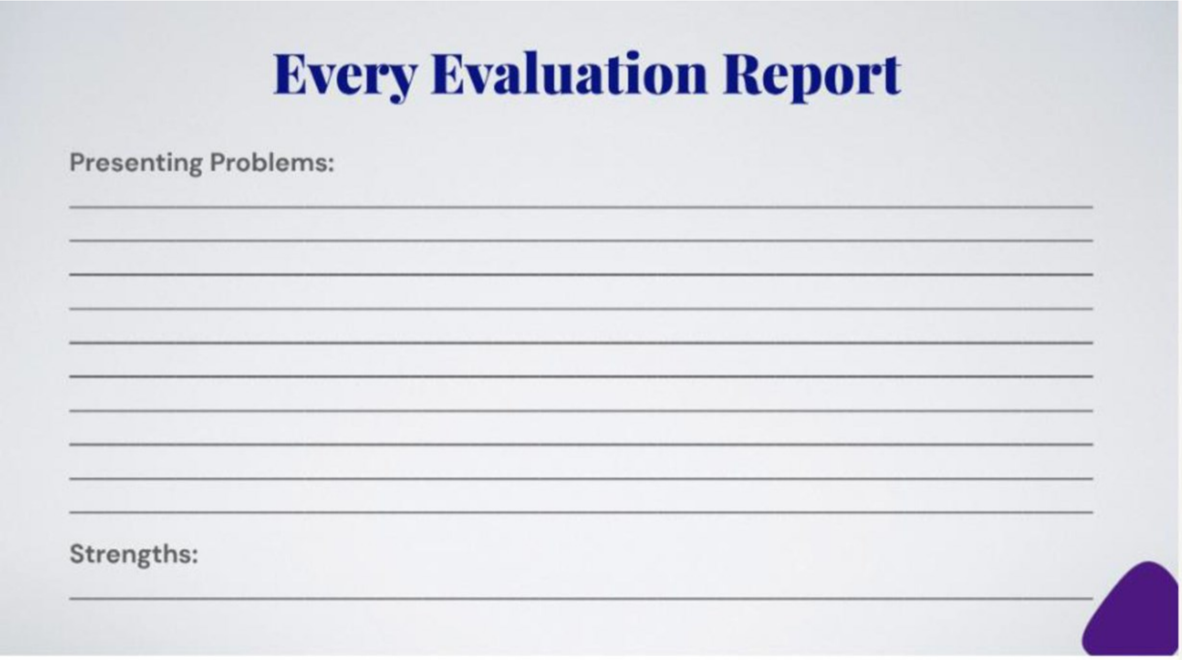
The social model situates the problem within the environment. Holler and colleagues (2021) found greater support among occupational therapy practitioners for the social model when they thought about involving clients; however, interventions still leaned toward the medical model. Once we choose the medical model, societal attitudes, stigma, bias, and ableism get a pass. The individual is now defined by weaknesses and impairments to overcome, and the therapist has to change the individual's behaviors.

So where does a strengths-based model land? It is an understanding of the challenges but with a recognition that we build our lives on our strengths. We first have to recognize our bias toward the medicalization of disability and have, as Steele (2011) described, a "constant back-and-forth between ideas and research results [that] hammers away at bias, and, just as important, often reveals aspects of reality that surpass our original ideas and insights" (p. 14).

What this back and forth with disability advocates has revealed is that we need new models that are more than individual impairments and environmental barriers. Liz Jackson at Critical Axis asks us to consider what the disability story is and who is telling it (Table 1).

We get a more nuanced model rooted in authentic relationships with disabled people. The cultural model presented here is grounded in the disabled individual's story. Not how the medical community frames the story. Shakespeare

Figure 3. Every evaluation report.



Every Evaluation Report

Presenting Problems:

Strengths:

Table 1. Disability Stories

Model of disability	How the Story Makes the Audience Feel	Why?	Where Can These Stories Be Found?	Outcomes	Recommended?
Medical	Good	Person overcomes their body/mind	Content-focused publications and advertising	Negative	Never
Social	Bad	Barrier remains unresolved	▪ Investigative reporting ▪ Local publications	Useful if followed up on	If committed to
Cultural	Complex and intrigued	Delves into the complexities of bodies and society	▪ Disability-led publications ▪ Niche disability opinion/editorial sections	▪ Expansive ▪ Positive	Always

Note. Table information from Liz Jackson, criticalaxis.org

and colleagues (2018) stated that the bifurcation of these models that reduce disability to either impairment or barriers or oppression misses the relational piece that situates disability as the outcome of the interactions between the person with the impairment and the wider context.

Shifting to a Strengths-Based Approach in Research, Education, and Practice

My research team, in partnership with autistic activists, has questioned the deficit-focused approach as we try to be better. For example, the world of research looks at interests that autistic individuals have from a deficit lens, labeling them as restricted with a negative connotation. They have a higher degree of interference with other activities, and the individual shows a higher degree of resistance when these interests are interrupted, with the autistic individual showing less interest in involving others, greatly interfering with activities with others (Klin et al., 2007; Turner-Brown et al., 2011). It is the researcher's story, not the autistic individual's story.

The research community clearly saw evidence that restricted interests were problematic and grew that evidence base in their designs and questions. But what happens when we conceptualize restricted interests with a more relational or cultural frame between the person and the environment? To do that, we have to talk to the person and see their view of these interests. It becomes their story, not the professionals' or researchers' story. And when it is their story, a very different picture emerges than deficit-based research puts on display. When it is their story, interests are viewed as central to learning, and could be incorporated into all aspects of learning, endorsed by nearly 88% of the respondents but only happening 13% of the time (Patten Koenig & Hough, 2017). That is their story. That is the real story (see Figure 4).

These interests were calming and positive. The opposite of anxiety producing. This was their story, and there was strong agreement. We know that we have gotten it wrong in controlling interests and utilizing these interests primarily as rewards. We as a profession have taken an evidence-based stance in AOTA's most recent "Choosing Wisely" campaign as we stated, "Don't provide interventions for autistic persons to reduce or eliminate 'restricted and repetitive patterns of behavior, activities, or interests' without evaluating and understanding the meaning of the behavior to the person, as well as personal and environmental factors" (American Board of Internal Medicine Foundation, 2021, para. 7).

Which is an excellent recognition and shift from viewing restricted interests as problematic.

My autistic colleagues would ask us to go even farther and be wiser and would edit it down to, "Don't provide interventions for autistic persons to reduce or eliminate 'restricted and repetitive patterns of behavior, activities, or interests.'"

Figure 4. Interests: A different story.

Note. From Koenig and Hough (2017).

In Other Words, Just Don't

So, this is a start, but how can we be better? What would be 10% more terrifying? It could be questioning interventions that try to reduce or eliminate interests, researching use of interests and the outcomes, changing the way we write about these interests, educating parents as to how these interests should be reframed, with occupational therapy practitioners taking the lead. This is knowing that we were wrong and doing better! In Dr. Ann Grady's Slagle lecture, she hints at the fallacy of readiness. She discusses how children and adults with disabilities have to demonstrate a sense of self-esteem before they can be included in a typical classroom or work or living environment (Grady, 1995). A low-functioning environment is one where disabled individuals have to prove themselves capable. We build vocational and social skills often as preparation and readiness for work and social connection. Others learn work and social skills through participation. What is the price of admission for inclusion? What systems demand normalization, compliance, covering, and masking versus authenticity? Instead of professionals determining readiness, what if we created opportunities and high-functioning environments that were related to interests, access, and abilities that didn't demand readiness first but rather presumed success (Chen & Patten, 2021)?

In our National Science Foundation project (NSF#1614436), entitled IDEAS: Inventing, Designing and Engineering With Autistic Students, interest-based maker clubs let students build and create with their interests and passions and be socially, authentically themselves. It is a high-functioning environment. In strengths-based focused research related to this grant, Chen et al. (2021) observed social behaviors and interactions between autistic and nonautistic middle school students. Damian Milton's (2012) "Double Empathy Problem" suggests that when people with very different experiences of the world interact with one another, they struggle to empathize with each other.

Milton (2012) posits that there is a breakdown in reciprocity and mutual understanding that can happen between people with very differing ways of experiencing the world. Chen et al. (2021) confirmed that mutual understanding and better interactions were seen among youth within rather than across neurotypes. In other words, autistic-to-autistic social interaction did not have "autistic social deficits." This suggests that autistic social difficulties may result from differences in the social expectations and profiles between autistic and nonautistic youth. Interventions, then, to support peer engagement among autistic youth should focus on facilitating mutual understanding across neurotypes and promoting a culture of openness to nonnormative social styles versus an overfocus on the autistic social deficits. Instead of linking social interactions with autism, negative social factors, such as a lack of mutual understanding, explain how the double-empathy problem may empirically play a much larger part in the well-being of and disparities in social interaction experienced by autistic individuals.

Minority Stress Models

These added social stressors can be simply due to membership in a marginalized and socially oppressed group. Meyer (2003) coined the term minority stress models to describe the added stress that is experienced by these groups above and beyond the day-to-day stressors that are typically experienced. They are additive, chronic, and driven by social forces.

Social disadvantage and marginalization create an increased burden that can result in mental and physical health disparities. Think of our well-being generally as having a strong foundation.

If you are a member of a marginalized group, you can experience proximal stressors, including internalized stigma and internalized ableism, often caused by living in a world not built for you or designed with you in mind, which is underscored by lack of representation. This can cause feelings of worthlessness, anxiety, and exhaustion and perceived burden. This is magnified in multiply marginalized groups. The distal stressors pile up and significantly decrease psychological well-being, including harassment, discrimination, bullying, and violence. This is magnified in multiply marginalized groups. For example, disabled LGBTQ1 youth have a higher suicide rate and a higher rate of peer victimization than either disabled youth in the sexual majority or nondisabled LGBTQ1 youth. (Duke, 2011). The proximal and distal stressors magnify.

These minority stress models have more recently been applied to disability communities. Minority stressors affect the severity of depression in those with physical disabilities (Brown, 2017). Monique Botha, an autistic academic and activist, and David Frost (Botha & Frost, 2020), showed that minority stress models predicted significantly worse well-being, higher psychological distress, and poor mental health in the autistic community. Community connection and peer support from affinity groups combat the impact of minority stress. Autistic researchers are reading what nonautistic researchers are writing and, as Monique Botha (2021) has stated, “To be involved in autism research when you are autistic is to constantly experience the aggression of a field which has yet to come to terms with its own ableism.”

She was speaking of psychology, and we have to be curious about what autistic researchers would say about OT research. Those with the most power in the systems of care ought to be doing 10% more terrifying work, so my self-advocate colleagues will know that OTs will be challenging their own professional systems that are ableist, and by listening to disabled individuals in research when they say, “This is not okay,” or “This is not important to me.”

Call to Action

A strengths-based model for occupational therapy has us leaning into our strengths. We are a profession that is already making these shifts in partnership with stakeholders. I would argue that we are a step ahead of other health care professionals. Now it is time to take a leap, in practice, education, and research. It is now time to act. So I offer this call to action. You decide where you are in the conversation. But as a field we need to confront our own ableism and commit to be better. There are many actions we can take. We just have to start by committing to one, as can be seen in Figure 5.

I committed to apologizing. Remember those autistic adults who taught me how wrong I was? I committed to apologizing for not knowing what I know now. Let me tell you a quick story. After those interviews I called up Bill’s mother. Bill was a 28-year-old nonspeaking autistic man who came to me for sensory-based therapy before I interviewed all of the nonspeaking adults. He enjoyed it and made progress, but I always knew there was so much more in there then I could get out. Once I had done these interviews that fundamentally changed the way I practiced, I called Bill’s mom and asked her to put him on the phone. I told him how sorry I was that I didn’t know how important it was to presume competence and work tirelessly for a communication system. I continued my one-way conversation for another couple of minutes before his mother took the phone back and asked me what I had said to Bill. I told her that I had apologized

Figure 5. Commitment to act.

I COMMIT TO...

Changing my language.

Documenting strengths intentionally and with substance.

Using different outcomes of success.

Understanding the impact of race, gender, sexuality, and class on services and outcomes.

Educate on ableism, disability studies, and disability justice.

Hiring disabled educators, therapists and researchers.

Teaching my students to be wrong and understand their biases.

Collaborating with disabled researchers.

Assessing if I am contributing to a high or low functioning environment.

Focusing my intervention on making high functioning environments

Supporting self-advocacy.

Stopping the normalcy narrative.

for being wrong. His reaction the whole time I was talking was a big smile coupled with tears running down his face. I had to do better.

We can and will be leaders in this shift. But a warning. This will be hard work. We truly have to listen. Be curious. Be wrong. Be better. The work will be counterintuitive to what you have learned to get to this moment. Mottron (2011) identifies that we not only have to learn a different language but that

> scientists should do more than simply study autistic deficits. By emphasizing the abilities and strengths of people with autism, deciphering how autistics learn and succeed in natural settings, and avoiding language that frames autism as a defect to be corrected, they can help shape the entire discussion. (p. 35)

As researchers we have to learn a new language. Can we design research that highlights the abilities and strengths of not only the individual but characteristics of high-functioning environments? Can we look at the findings through a strengths-based lens? Researchers, we can do better.

Paul Kotler asks us to be better in our expectations and creativity. He writes:

> I think expectations should change. People like me are asked to act like neurotypical people to be included in things. We have not been creative enough as a society to come up with ways to integrate people with autism without setting impossi-ble expectations. Without access and visibility we can't show people our capability. (Paul Kotler, personal communication, September 25, 2018)

Conclusion and Closing Thoughts

So in closing I would like us to apply some of what we learned in our time together. This shift from a deficit to a strengths-based lens doesn't work with piecemeal instruction and infrequent practice. So let's practice. Back to Grant. When asking for his permission to use his quote that was from a conference he did with us, I asked him if he had any specific thoughts based on his experience with OT and ableism. He stated: "OTs should stop giving out sensory toys for dysregulation due to systemic oppression" (G. Blasko, personal communication, February 8, 2022).

If we are curious, we may be shocked initially but then ask ourselves, what is a day like for nonspeaking autistic students in a self-contained classroom where staff, including OT practitioners, may not presume competence? What is it like to fully understand what is being said to you without a means of expression? What is it like to have a full day with a wide range of emotions and experience potentially reduced to "He did not listen when it was time to come inside from recess"?

Sure, a sensory toy may be helpful, but does it impact a very low-functioning environment? That is why this will be hard, because we will get defensive and say "Wait, this is a good thing." It may be, but if you are curious, you will also see it is not enough. You will see what Grant is talking about without the defensiveness. You will listen, and you will do differently. And this will require us to look at our profession with humility and, as Steele (2011) describes, "It takes humility to reconsider our past commitments, doubt to question our present decision and curiosity to imagine our future plans" (p. 14). Let's imagine our future plans together, in partnership with disability communities and activists. Let's build occupational therapy on our strengths, not our remediated weaknesses.

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