Congratulations to Jeiri for winning a Starbridge 2018 Community Award for her advocacy!

Voices | A View from Where I Sit

Merriam-Webster defines ableism as discrimination or prejudice against individuals with disabilities. I define it as an everyday adversary who can and may defeat me multiple times a day. As a person with a physical disability, I recognize ableism is everywhere. It’s in every business, every school, in every movie where the casting director chooses to hire a non-disabled actor to play a disabled character, and it’s even in church.

In our society, there is no stone untouched by ableism and once you see it, you can’t unsee it. Hopefully you don’t ignore it; you point it out, and educate those around about it.

As advocates, it is our job to educate people about the struggles people with disabilities face; specifically we should all be discussing ableism as it is one of the most prominent struggles.

Below you will find interviews of advocates in different positions discussing their experiences with ableism.

Voices | Conversations about Ableism

What is Ableism?

Ableism is defined as the practices and dominant attitudes in society that devalue and limit the potential of persons with disabilities. It assigns inferior value to people who have developmental, emotional, physical or intellectual disabilities.

Ableism may be invisible to those who do not have disabilities. It is sometimes not intentional, but in certain circumstances, it is very intentional.

An ableist society is said to be one that treats non-disabled individuals as the standard of ‘normal living’, which results in public and private places and services, education, and social work that are built to serve ‘standard’ people, thereby inherently excluding those with various disabilities.

Adapted from Stop Ableism, www.stopableism.org/p/what-is-ableism.html

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Adapted from Stop Ableism, www.stopableism.org/p/what-is-ableism.html

Q: Tell me about yourself. Where are you from? What do you do?

SS: My name is Stacy Schuyler. I am from Rochester. I work for the city school district and also SWAN (Southwest Area Neighborhood Association) community center.

LD: I am Luticha Doucette. I work for the Mayor’s Office of Innovation. I have been an incomplete quadriplegic for actually 33 years this Memorial Day and at the time I also acquired a brain injury which makes me neurodivergent. Woohoo neurodivergent, awesome.

SL: My name is Steve LaDue. I am a teacher/advocate coach for students with disabilities and their teachers in the Rochester City School District. My title is Behavior Support Specialist, which means I’m primarily working with students with very intense social emotional behaviors that aren’t typically dealt with in most academic settings.

continued on page 2

*This interview is a transcription and some answers are edited for brevity and clarity*
I grew up having a disability from the time I was born until probably 12 or 13; I was legally blind with very minimal corrective lens working. I couldn’t participate in life typically like everybody else. After puberty, my vision changed dramatically to the point where now I can drive.

Q: Why are you passionate about disabilities or advocacy?

SS: I have a cousin that has Cerebral Palsy and I was always around him. When I first got my assignment with the city school district, a few of my students had behavior issues and then little by little I was transferred over to students with various disabilities. I kinda looked and saw how kids were treated, and a lot of kids were very, very hopeless, and that bothered me. The kids were very dependent on me as an adult, and they didn’t seem to have a lot of friends. That really bugged me. A lot of kids without disabilities would ask me questions, and I would say, “Don’t ask me, ask the kid with a wheelchair.” I would run away and the kid would look at me like, “Oh no, come back” and I would say, “No, no you go talk to them; have a friend, be a friend, make a friend for life.”

LD: I’m really passionate about this because it impacts my everyday life and now that I also have chronic pain on top of being in a wheelchair, accessibility and ableism really impact me even more and it really exacerbates the pain that I am in on a daily basis.

SL: Having a disability helped me understand how a person internalizes their own value and their worth in reaction or relationship to the people around them. And what does that do for them psychologically and socially emotionally? I never felt as though I was a part of anything until, well after college, just feeling like an outcast. As of recently, working with the students and families that I worked with a number of years, understanding that anybody who has something in their life that makes it so they can’t interact with the world in a way that the world wants them to interact with them, puts them in a deficit and automatically puts them into a situation where they have to start planning things differently.

Having these experiences has benefited me so much, not only as an advocate, but also as a special education teacher.

I’ve really learned how to understand people as people and listen to them and their needs when developing plans.

– Steve LaDue

Q: How do you define ableism?

SS: I think that I am so trained to constantly look for ableism because even when I go in a place I think, “Oh I couldn’t bring this person here or that person here.” So it’s hard for me to define other than to say, it’s just something I am looking for... I’m always planning three steps ahead.

LD: So ableism is not just something that’s structural; everything that’s built is built for those who are not disabled. So any building, anything in this world that we interface with has a standpoint of someone who’s not disabled, but it’s also attitudinal. So how we talk about those who are disabled, how we write about those who are disabled, “confined to a wheelchair” and their “suffering.”

SL: I think it’s just people making assumptions about the people around them. That’s the bottom line, especially if those assumptions affect people in a negative way.

Q: How do you combat or experience ableism?

SS: There’s a lot of depression among my teenage kids; none of them have friends. On a couple of my school assignments you would see all these little kids with disabilities and you’d see the other kids and they’d all have friends and they’d go to each other’s houses. But it becomes so hard for families with kids that have various needs. What’s so hard about calling and saying, “Hey, can this kid come over?” You know, even if the family needed a ramp for the kid, just call and ask if the other kid can come over instead. Ask if we can meet you somewhere. You know, nobody ever does that. There’s almost no such thing as playdates for kids with disabilities.

The children with disabilities don’t know that they could live in their own house, that they can take a bus somewhere, they can go sit in the movies by themselves, they could have a boyfriend or a girlfriend, they could have a job. A lot of kids don’t understand that there’s a future, and they don’t see active adults within the disabled community doing anything, and the pictures they are getting aren’t positive images.
**My job and my goal is to allow kids to grow.**

– Stacy Schuyler

**LD:** So for me, I think I’m in a unique position than other people because I work for the system. So therefore, in my office I have the ability to really influence those who are the decision makers to think about things in a different way. Our mayor is literally the first mayor to really address accessibility and to talk about disabled people if you actually go back and listen to her inaugural speech. Like those were my words that she was using. So she listens and she gets it and you know, it allows me to make change within the system for betterment of our citizens, which is great.

The issues are that the system still tries to work against you and there’s a lot of bureaucracy, a lot of trying to convince people... yes they may be supportive, but you have to also work within how they view things in order to get things done. And that’s super, super frustrating.

I call ableism a macroaggression because it’s in your face all the time. And especially when you are a disabled person trying to work.

**Not only are you trying to interface with a building or parking...that’s not meant for you, you’re also then trying to break down the attitudes that people have.**

– Luticha Doucette

I had an experience where I went by myself for a meeting, and I was waiting in the lobby and the executive I was to meet walked right past me, and he’s looking around the lobby and then goes to the secretary, “You said the person was down here waiting for me. Where are they?” And like the secretary’s eyes got really big and she’s like, “She’s right there.” And he did a double take. And you know, you have to be professional, you can’t go wild on people. I wanted to curse that person out because I dress on point, you know, I’m dressed when I leave this house and that’s because I have to be presented just as the same as others without disabilities or perfect. And even when I’m at my most on point, like Rihanna level, right? I’m not even seen, like, “You don’t see this Fenty (make-up) on me? What’s your problem?”

**SL:** I think in some situations, people just have to be cognizant that the world that they interact with is not being seen the same exact way as the person they’re talking to. Regardless of what challenges that person has, whether it’s social, emotional, or it’s someone with a physical disability, you can’t assume. Making assumptions about anybody or any situation is to the detriment of our community. We as people can’t just say, “I’m going to hold this event and people are just going to show up.” Well, let’s think of the 15 reasons why they wouldn’t show up, whether it’s light and sound issues because they’re very sensitive or whether it’s their visual spectrum or auditory spectrum. Allow yourself to actually be put in that situation where you can humble yourself and just allow the conversation to happen; ask people about what they need.

**Q: What piece of advice would you pass down to someone who may be dealing with the effects of ableism?**

**SS:** I would tell them to be very vocal; you know your craft and/or you know your child. Encourage anyone—children, adults, families—to network. Networking is important because a lot of families feel that it’s just them; the most important thing out there in the world is knowing someone that’s like you. To not be able to see yourself or your child, represented in society is damaging.

Understand that everybody’s a regular person underneath; you’re a regular person that may need a little help or you may not want help. You’ll just have to say that, have open communication.

**LD:** For me, I think it’s about one, creating a great network of individuals around you, and that’s your crew that you can rely on for whatever it is that you need. You need to be very selective in who you let into your life. I think a lot of it is trying to connect with other disabled people. If you’re the only one, go on the internet, look for your people, put it up the call, like a batman signal, and we’ll be there. We’re looking for that too.

Two, somehow there needs to be a way to educate and know about all the resources that are available to you so that you could actually move out of poverty and into self-sufficiency.

**SL:** I think that parents advocating for their children and/or folks becoming self-advocates: you have to be in environments where people are going to have open, candid conversations, otherwise you’re never going to move anyone’s thinking forward.
Ableism in Language

“Always respect an individual person’s preference for identifying or describing themselves, even if that is not what the majority in a community prefers. Not every person with every disability is personally upset or hurt by every term on this list, even ones that reference their specific disability. That’s why this list is meant as a learning/awareness/consciousness tool, not a litmus test or a censorship guide.”

By Lydia Brown, autistic activist and blogger

Examples of Ableist language

Blind to ____ / turn a blind eye to ____ / blinded by ignorance/bigotry/etc.
Refers to Blind, low-vision, or sight-limited people.

Confined to a wheelchair
Refers to people with physical or mobility disabilities.

Deaf to ____ / turn a deaf ear to ____ / etc.
Refers to Deaf or hard of hearing people.

Invalid
(as a noun, as in “my neighbor is an invalid and never goes outside”) Refers to people with physical or mobility disabilities or chronic health conditions.

Manic
Refers to someone with bipolar (used to be called manic depression)

Suffers from ____
Can refer to any person with a disability.

Insane or Insanity
Refers to people with mental or psychiatric disabilities.

Examples of Non-ableist language

For describing people with disabilities/disabled people in general:
Disabled, has a disability
With a chronic health condition
Neuroatypical, neurodivergent

For describing people on the autism spectrum:
Person/people on the autism/autistic spectrum
Autistic person/people
Person/people with autism

For describing people with intellectual disabilities:
With an intellectual disability
With a cognitive disability

For describing people with sensory disabilities:
Blind, low vision
Deaf, hard of hearing

For describing people with physical or mobility disabilities:
With a physical disability
Uses a wheelchair, uses crutches


I am more than an empty wheelchair

I am a complete human being who sits between a set of wheels and I deserve to be spoken to directly.

By Emily Ladau, Words I Wheel By blog, wordsiwheelby.com/2014/04/speak-up-against-ableism/
Consider the Following When Confronting Ableism in School

- Everyone has strengths and limitations
- Children with disabilities are still children
- Accentuate strengths instead of problems
- Don’t make assumptions about competency
- A little accommodation can make all the difference
- Students with disabilities have rights
- Accessibility should be built in, not tacked on
- We should celebrate our differences

By Brianna Flavin, adapted excerpt from What is Ableism? Teachers Share 8 Things They Wish the World Understood, 8/7/2017, www.rasmussen.edu/degrees/education/blog/what-is-ableism/

Presuming Competence

First, people’s expectations matter. When teachers expect students to do well, they do even better than expected.

Second, I.Q. and other tests that aim to measure human capacity are terribly flawed. They usually tell us what students can’t do rather than what they might do if they had good instruction and high quality supports. Basing a student’s whole educational career and future on a test score just seems filled with potential harm.

Third, a growing body of research shows “unexpected” abilities in people who had been identified as intellectually disabled until they were provided with a means to communicate. Think Helen Keller or Larry Bissonnette.

Fourth, to presume incompetence could cause irreparable harm to our students if we are wrong.

And finally, even if we are wrong about presuming a student’s ability to learn and to communicate in ways that are on par with his classmates without disabilities, being wrong about that isn’t as dangerous as the alternative.

By Cheryl Jorgensen, adapted excerpt, www.swiftschools.org/talk/five-reasons-why-presuming-competence-is-always-a-good-idea

Accessibility Should Be Built In, Not Tacked On

Accessibility should be a priority of any educational system that seeks to offer positive experiences for people, regardless of their ability level.

It should be built in as a “norm” rather than a special accommodation.

When you look at a group of children working in a classroom, you shouldn’t be able to readily identify the children with special needs.

AnnMarie Johansson, State Road Elementary School Teacher, Webster, NY
How Inspiration Porn Promotes Ableism

Inspiration porn, in a nutshell, is when a disabled person is viewed as “inspirational,” “brave,” or “special” for achieving ordinary, everyday tasks. Inspiration porn is particularly evident on the Internet, where it takes the form of simplistic memes branded with absurd slogans like “The only disability in life is a bad attitude.”

Inspiration porn is a form of objectifying and Othering disabled people. It sends a signal that we do not deserve to live life like everyone else, so it’s cute or heartwarming when we do.

It also reinforces the myth that disabled people are eternal children. Even when they don’t realize it, nondisabled people often talk to disabled people as they would talk to children, in syrupy, high-pitched tones. If we’re adults, talk to us as though we’re adults. If you’re talking to a disabled child, make sure you’re talking to that child in the same way you would talk to a nondisabled child, regardless of their cognitive or verbal ability. Presuming competence is the best thing you can do for a disabled person.

By Cara Liebowitz, adapted excerpt, Everyday Ableism and How We Can Avoid It thebodyisnotanapology.com/magazine/everyday-ableism-and-how-we-can-avoid-it/

Normalcy is an Ableist Concept

We are expected to “work hard” – starting when we are toddlers – to be what “mom, dad and the whole wide world dreamed about”. We are not allowed to simply be. Being “normal” is the goal. When we cannot “be normal” we should, at least, “act normal”. If we don’t or can’t, we are failures, not good enough.

This is why normalcy is an ableist concept. I reject normalcy. I am not normal. I don’t look anything close to typical. I am very disabled and I don’t try to pretend that I don’t need help. I am not ashamed of being disabled.

By Amy Sequenzia, excerpt, Normalcy is an Ableist Concept, ollibean.com/normalcy-is-an-ableist-concept/

Invisible Disability Project Offers Ableist Card

The Invisible Disability Project is offering an easy way to simply and quickly call out ableist bias. The Invisible Disability Project defines itself as “a social/cultural movement and an educational media project that consciously disrupts ‘invisibility’ imposed upon unseen impairments at the intersections of race, class, gender, and sexuality.” Their solution? A printable card (available for download online) that explains ableism, and why the actions of the individual receiving the card might have been ableist. The card is intended for those with invisible disabilities, but can be easily modified to apply to ableist remarks about visible disabilities as well.

By Emily Pate, excerpt, Rooted in Rights, The Invisible Disability Project is Making it Easier to Call Out Ableism, www.rootedinrights.org/the-invisible-disability-project-is-making-it-easier-to-call-out-ableism/
Accessibility Confronts Ableism in the Community

Challenger Miracle Field, specifically designed for individuals with physical and/or cognitive challenges, is made with a rubberized surface that is fully wheelchair accessible. For baseball, bases and pitching mounds are painted onto the surface so that there are no raised obstacles and the dugouts are enlarged to accommodate wheelchairs and other apparatus.

The Play with Possibilities Playground – the only one of its kind in Monroe County – will allow typically developing children to play alongside children with disabilities with full accessibility and sensory benefits to create a truly inclusive, ADA-approved play space. All kids will be able to participate in elevated and ground-level play, with ramps, transfer points, and sensory-rich play opportunities throughout so that the play space is friendly to all children and parents as well as other caregivers, such as grandparents and service animals.

Adjacent to the field will be a pavilion, fully accessible ADA-compliant restrooms and concession stands. The entire complex will be centrally located in the northeast part of Monroe County at the Ridge Park Athletic Complex at 1000 Ridge Road in Webster, adjacent to Webster Town Hall, and less than one mile from New York State Route 104. The facility is accessible via public transportation and para-transit lines. For further information, please see rochestermiraclefield.org.

Examples of Ableism at Work

- Not being granted reasonable accommodations
- Being passed over for promotions simply because of a disability
- Being paid less than non-disabled employees
- Not understanding that boundaries need to be respected
- Not seeking consent of people with disabilities
- Being surprised that a person with a disability is hired

Adapted from Quora, www.quora.com

Ways to Eliminate Ableism

- Think about your own attitudes and actions
- Become informed about disability issues. An excellent resource is Rooted in Rights, www.rootedinrights.org
- Avoid assumptions
- Treat and speak to everyone in an age-appropriate way
- Treat everyone with respect and compassion
- Join an empowering organization such as SANYS (Self-Advocacy Association of New York State, Inc.) www.sanys.org or New York State Partners in Policymaking www.nyspip.org

“Dear Friend,

That thing you just did — that was ableism.

I am sure you did not realize this when you made/laughed at/agreed with that ableist remark, or behaved in that ableist manner. Like racism, sexism, and elitism, ableism is a cultural bias that impacts disabled peoples’ everyday lives. For example, being called a “retard”, “lame”, or “crazy” is offensive to people like me and my friends. Instead, we need safe and accessible spaces in the absence of ableist assumptions for those with no seemingly obvious disability, like mobility, hearing, visual, or affective impairment or chronic illness. I can’t always alert or educate people about my non-visible disability. If I do, it is often considered malingering or controlling, so, instead, I distribute these calling cards to signal when ableist remarks/behaviors arise.”

By Emily Pate, excerpt, Rooted in Rights, The Invisible Disability Project is Making it Easier to Call Out Ableism, www.rootedinrights.org/the-invisible-disability-project-is-making-it-easier-to-call-out-ableism/
Answer:
There is a great resource for you to explore that provides NYSED testing accommodations and what can and cannot be used on the different tests (including elementary and middle school state tests and Regents). It also provides some guidelines for administrators for when to consider different accommodations:

Testing Accommodations for Students with Disabilities – Policy and Tools to Guide Decision-Making and Implementation, February 2018

- Kara Olds, Family Education Specialist

Do you have a question for one of our advocates, a topic or issue you’d like some guidance on? Submit your question on our Facebook page or email mschaertel@starbridgeinc.org - we’ll choose one or two to include in the next issue!
“Your other children will grow up and leave you, but this baby will never leave you.” The elderly woman’s tone at the grocery store was sweet and comforting, and I’m sure she was well-intended in her comment. She shared what she perceived was a positive thought in what was clearly to her a negative situation: confronting a child with a disability.

How did this stranger know what Nick would or would not do in the future? I wish I would have known back then that ableist thinking was at the root of her comment. She shared what she perceived as a positive thought in what was clearly to her a negative situation: confronting a child with a disability.

Nick and I have heard other voices through the years as well: the voices of family members who fully expected him to play alongside his cousins; teachers with high academic expectations; neighbors who respect and welcome him; church members who value his dignity; and professionals who treat Nick in an age-appropriate manner.

Unfortunately, ableism is alive and well. Hopefully this issue of Bridges has helped all of us to better recognize ableism, understand that it ultimately undermines lives, and do what we can to reduce and stop it.

From the Editor:

That’s great!” “He has his own phone? That’s wonderful!” Again, people are well-intentioned. But they would never make such remarks about any other teen or young adult.

Maria Schaertel