

I'm not sure about you, but when I was a little kid around the beginning of elementary school, I was taught some basic life lessons. These were things that, I was told, I needed to remember in order to get along with other people. Some of the most important lessons, drilled into me by parents and teachers and reinforced by peers, included:

*Keep your hands to yourself.

*If somebody touches you and it doesn't feel good, tell them to stop. If they won't stop, tell an adult.

*If somebody says "no" or "stop" to you about literally anything, you must listen to them. It doesn't matter if they're older or younger, bigger or smaller than you, you need to accept "no."

*Don't record people, take pictures or videos of them without their permission.

These are basic sociocultural rules about boundaries and consent. All humans, even the newborn who cries for milk when hungry and pulls away from mother's breast when satiated, are exercising their boundaries and consent. Consent is equally important to all humans regardless of race, gender, creed, age, socioeconomic status, sexual identity, or physical or mental ability.

Yet I have noticed that because I have a disability, seemingly universal rules about consent get broken all the time. Strangers regularly grab, pull, or steer my body without so much as a hello. I'll be out minding my own business, then suddenly feel a tug on my shoulder or my purse. If I react in self-defense, by pulling away or saying "don't do that," I am often chastised for being ungrateful because "they were just trying to help." I regularly get asked if I know where I am going on the street. People question my judgment and get upset if I say "no" to an unsolicited grab or an invasive question. And in many ways, I am privileged. I only have a sensory disability. For people with cognitive or communication disabilities, violations of consent go much further. They are regularly left out of decisions about their lives and their futures; their attempts to communicate pain or dissatisfaction are ignored or punished; their parents or caregivers share personal information about their lives with the public; they are denied opportunities for intimate relationships. And for all of us with disabilities, nondisabled people often police the way we define and express our disability identities.

Today I'm going to share a bit about my own disability identity and what inclusion means to me. I will also mention research that can guide us as we work to build an inclusive world. As I speak, I want you to keep this concept of consent and agency in the back of your minds. For me, the essence of inclusion is honoring everyone's fundamental humanity, whether they have a disability or not.

I was born in Phoenix 33 years ago. When I was a baby, my parents soon noticed that my eyes wouldn't focus on anything. When I was almost 6 months old, an eye doctor performed an electroretinogram, a test that showed my retinas didn't respond to electrical stimulation. The verdict was that I had Lebers congenital amaurosis, a genetic condition that kept my retinas from developing properly. Then, my pediatric ophthalmologist gave me a great gift, and it's not what you might think. He told my parents, "Arielle is blind, and there is no treatment." To many people my eye doctor's proclamation would have seemed callous, cynical, hopeless, even cruel. But I realize now how much of a gift it was. Because not only was it the truth, but it was also the certainty my parents needed to raise me as a blind person

rather than a broken sighted one. It saved me from needless surgeries and other attempts to make me into someone I was not.

I went to the preschool at the Foundation for Blind Children (anyone heard of them)? Where I learned fundamental skills I would need to do well in public school: braille and cane skills. Some of my fondest early childhood memories include the joy I felt when I read my first book aloud in contracted braille, the challenge of deciphering new braille contractions, and the sense of security and connectedness I felt when I took my first steps with a white cane in my hand. Unfortunately many people view braille and canes as symbols of dependency or surrender to blindness. For me, braille and cane are, and always have been, symbols of independence and freedom. I'm not the only person with this experience either. Studies have linked braille literacy, in particular, with academic success in high school and positive adult employment outcomes, and a study I recently published found a connection between braille literacy, particularly learning braille early in life, with life satisfaction and self-esteem. Unfortunately, many educators and service providers see braille and cane training as "last resorts" reserved only for individuals who have vision loss severe enough to preclude print reading or visual navigation completely. The consequences of such a mindset are tragic for many people with low vision, who are forced to struggle with visual methods of doing things when nonvisual methods, or a combination of the two, would be far more effective.

Because I got the key blindness skills early, and since no one tried to fix or treat my blindness, it never occurred to me that blindness could be a bad thing. It has always felt as normal to be blind as it does to be a female. But, the one and only time that blindness ever became a problem for me was when it was a problem for other people in my life.

Around the early elementary grades, I started to experience exclusion by my peers and over-protection by adults. I also became aware that my blindness was a characteristic I didn't share with any of my family members or kids at school. But it took me a while to connect those two things. I didn't realize, until around the beginning of puberty, that at least part of the reason for the exclusion and condescension I encountered was related to my blindness. Like my budding breasts and body hair, my awareness of discrimination came on gradually, until it reached a point when I could no longer deny its existence. Around the time I was struggling to figure out training bras and how to shave my legs, I struggled to learn how to manage increasingly frequent encounters with naysayers who treated me differently because I couldn't see. Sometimes the exclusion was hostile and blatant. But most of the time it was dressed up as kindness. Teachers would exclude me from class activities, they said, for my "safety" or "so I wouldn't get hurt." And often kids would include me nominally, but showed a kind of fake niceness they didn't show with our other classmates.

Many people think of disability as merely a medical problem. Under a medical definition of disability, my blindness is an unwelcome thing to be cured. My experience of blindness as normal defies the medical model of disability. Instead, my experience more closely approaches what is known as a "social model" of disability. I experience the consequences of my disability not as a given, but in the context of my social environment. Undoubtedly the worst aspect of many disabilities is ableism-the negative societal reaction to disabilities paralleling racism, sexism, heterosexism, and other "isms."

In many ways, my experience of disability parallels that of many other minority groups, and my awakening to discrimination was similar to that of many children growing up with other minority identities. There was one important difference, though. About 80% of disabled children grow up as the

only disabled person in their family, having what Andrew Solomon would call a “horizontal identity.” I was in the 80%, as no one in the recorded family history has my eye condition. Thus, unlike an African American child who can discuss racist encounters with their parents, I could never really commiserate about my ableist encounters when I got home from school. My parents tried to be supportive, but they couldn’t really teach me how to stand up for myself, or how to counteract the temptation to believe what others believed about my disability. The scariest thing was that, over time, I started to wonder if what I thought I knew about myself was wrong. Maybe there really was something wrong with the way I was born. I discovered that when I tried to stand up for myself, people didn’t seem to like me much, but when I acquiesced and played the nice blind girl, people didn’t seem to respect me much. I feared I would have to choose between acceptance and respect.

There was one thing that saved me, though. Remember the FBC? I started going to their summer day camp and weekend rec programs with other school-age blind kids. When I was with them, I was no longer the token blind girl. I was just another member of the group. As I moved into my teens, some of those kids became my best friends. I had my first serious crush on a boy there. And eventually, some of the older kids became my first blind mentors. When I was around “my kind,” I experienced all the normal ups and downs of teen relationships. I also found that it was impossible to feel sorry for myself for my disability when I knew people with the same disability whom I liked and respected. In the safety of my blind peer group, I got to practice many social skills I could later transfer to my interactions with nondisabled people. Eventually, in a desire to give back to the blind community, I joined the National Federation of the Blind as a young adult. In fact, I just flew in last night from my sixteenth NFB national convention. A funny thing happens sometimes at our conventions. Someone will get up to speak, and say that “I have retinitis pigmentosa” or “my daughter has Lebers” and you’ll hear a scattered cheering from the crowd. Not everyone cheers, but more than a few people do. A few years ago at a convention, when someone said they had Lebers, I cheered too. I did it because I felt like I had just gained a new sibling. It felt good to meet someone sharing a seemingly rare experience with me. And, I felt proud of who I am in that moment.

Even today, I continue to seek the affirmation of the blind community by attending regular local NFB meetings and I still keep up with some of my FBC friends. Today, I feel a real kinship, an almost family connection, with all the blind people I meet and, to a slightly lesser extent, all disabled people.

Research is starting to reveal a connection between a positive disability identity, high self-esteem, and happiness. Sometimes disabled people may be inclined to minimize, hide, or try to overcome their disability. In fact, we are constantly pressured to do this, in a myriad of ways. Those of us who can hide our disabilities are usually treated better when we choose to hide than when we don’t. And people who “overcome” disability by doing great things are glorified in the media. The alternative, identifying disability as a positive source of pride, is a lot less sexy. But people who do this are consistently happier with themselves and their lives. Some of the factors linked to high well-being include believing that disability is an important part of who you are; feeling a sense of belonging in disability communities; having friends with the same disability; and getting involved with advocacy to make the world more accessible.

My disability story is just my own. And in many ways I am privileged. I’ve been blind my whole life and my disability is severe enough that escaping or hiding was never an option. I don’t associate my disability with loss. For some of us the story is quite different. Some of us are disabled from diseases,

trauma, or abuse. For some of us our disabilities stem from painful ongoing medical conditions. Or we may have psychiatric disabilities where negative emotions are core symptoms. Disability pride may not come naturally to many of us. But, we can still work to promote a positive sense of self in the people we know and the people we serve. One of the greatest gifts we can give our clients, our colleagues, our friends with disabilities is to introduce them to peers and mentors who share their disability experience. We can show them role models, teach them about disability history, and invite them to join in activism.

Another gift we can offer is to create communities where people with all kinds of bodies and minds are valued. It is in these kinds of inclusive spaces that people with disabilities can truly contribute.

So, what is inclusion and how do we build it together?

In thinking about the meaning of inclusion, it is helpful to first define what inclusion is not. Inclusion is not giving pity handouts to disabled people. Nor is it putting disabled people on a pedestal and glorifying our every action. It is not treating us like amazing superheroes nor helpless victims. When done properly, it should not necessitate changing standards, compromising integrity, or risking the bottom line.

In explaining inclusion, my colleague Lisa Handelman from the Jewish Federation of Greater Washington wrote,

As a society, we strive to shift from a focus on kindness to a demand for justice; from the idea that inclusion is about helping others to the knowledge that it is about strengthening the collective; from creating particular programs to making all opportunities accessible.

Inclusion, then, is a mindset that goes beyond helping disabled people or making accommodations on the fly when a disabled person wants a place at the table. It starts with a set of core values; most critically, valuing a diversity of approaches. We can be most inclusive when we recognize the value that people bring whose bodies or minds differ from the norm, and that there is more than one way to accomplish a given task. In a world where up to one in five people has a disability, we must not be surprised and flustered when we encounter disability. Instead, we need to expect it. We must anticipate that people we encounter in all walks of life, in our workplaces, schools, families, communities and social groups, will have disabilities. We need to anticipate the involvement of disabled people with an openness toward what they bring to the table.

Universal design is the concept of building things so that people with a variety of abilities can use them, instead of building something only for the norm and then having to rebuild it later when a disabled person comes on the scene. A good example is the company Oxo, with their Good Grips line of handheld kitchen tools. For the same low price as competing brands, you can buy a can opener or vegetable peeler that happens to work well for people with hand dexterity impairments, and is also generally easy to use. As another example, Apple products have a huge array of software built into them that makes them usable by people with visual and hearing impairments, as well as apps and features that can help people with cognitive impairments, all out of the box. Disabled people can buy these products without having to pay a disability tax for access. But more importantly, these universal design features make mainstream devices more usable by everyone, as you know if you've ever used Siri. Of course, specialized assistive technology will always have its place; universal design is unlikely to make

wheelchairs obsolete. But by making mainstream environments as accessible as possible, we can reduce the overall cost burden of assistive technology and the loss of autonomy that can result when disabled people must rely on others to procure essential technology for them.

So, part of inclusion is an attitude at the systems level, an attitude of openness to what people with differing bodies and minds can bring. But inclusion also depends on one-to-one relationships across ability lines. Student-teacher, provider-client, employer-employee, or personal relationships can span ability lines, either with one nondisabled partner or two people with different disabilities. Good relationships depend on trust, and sometimes disability can challenge trust. The nondisabled partner may be uncertain about what the disabled partner can do, and the disabled partner may worry about being discriminated against.

So how do we solve the problem? First, we can start with the premise that disabled people know best how their own bodies and minds work. They can help resolve uncertainty if they are invited to express their own accommodation needs, and if their expressed needs are honored. Again, as I mentioned at the beginning, this idea is obvious but is not always followed. Too often, disabled people are questioned or doubted when we articulate what we need or don't need. Sometimes people don't even speak directly to us, asking questions of a companion "what does he want?" etc. It's important to remember that two people with the same impairment may need different things, or one person may need different things on different days.

Another cornerstone of inclusive relationships is the idea of "ordinary treatment." That is, treating the person, in most ways, how you would treat them if they didn't have a disability. Usually a disability affects only one or a few aspects of a person's life. Said person still has interests, strengths, and desires unaffected by their disability. And they still have fundamental humanity.

To illustrate the broad principles I've described, I want to close with an inclusion success story I recently had the privilege to be part of, and we can look at the active ingredients that made it happen.

I serve as deputy coordinator for a pre-employment transition program for blind and low-vision teenagers. One of my roles is to organize work experiences for these students, paid jobs or unpaid internships, mainly during the summer. I had zero experience with job development before I took this position, and I was a bit overwhelmed by the demands of the job. But I also knew how vital early work experiences are for young people with disabilities.

We had the students prepare resumes and cover letters to get an idea of their talents and previous experience. For some of our students, setting up internships was just a matter of introducing them to our colleagues who had openings. For others the process was much more individualized.

There was one student, we'll call him L, who lives in a very rural part of the state, barely in the service area for our program. L is a talented musician. He is on the autism spectrum in addition to being legally blind from retinopathy of prematurity. Although L has some impairments in written and spoken language, he does not have an intellectual disability. He plays chess, and has an extensive vocabulary, yet for much of his education he has been placed in segregated autism classes with kids who are completely nonverbal. L can only read print if it's blown up to double-sized font or placed inches from his face, yet his educators insist he does not need to learn braille. His Individualized Education Plan (IEP) evaluations are full of statements like "L struggles to stay focused and on task," "he perseverates on

things and needs redirection often,” “L does not allocate his time effectively,” and “he struggles to complete tasks independently.”

On top of this, L’s mother has diagnosed him with multiple chemical sensitivity. She says that when he is around common cleaners and other synthetic chemicals, he has trouble concentrating and thinking clearly. The mother still controls many aspects of L’s life, and for a work experience, she needs to serve as L’s driver. So, we needed to find a job that the mom would approve, ruling out many common jobs in places with chemicals. The family is also military, they move frequently and have few connections in the local area. Between all these perceived and real limitations, L has had few chances to interact with his peers or build job skills.

But as I began working with L in the pre-employment group meetings and individual conversations, it became clear that he enjoys being around people, and wants to become a contributing member of his community. And, despite her fears, the mom does want him to gain job experience. She even gave me a list of pre-approved small businesses to contact. The trick was that neither I nor the family knew anyone at these small businesses.

One day I sat down and called all the businesses on the list, one by one, asking managers if they would be willing to set up a paid or unpaid work experience for a high school student. I introduced myself as a job developer in a transition program for teens with disabilities. Most of the business owners either missed my call, or told me they were too small to set up this kind of experience. Remember we’re talking rural Virginia. A few of the business owners bordered on nasty. One even said their insurance policy wouldn’t cover them if our student slipped on the wet floor in their kitchen, and that they wouldn’t have anyone to “watch over” the student. Feeling discouraged, I took a break from my phone marathon at one point to text my husband and said, “I’m hating the world right now.”

The very last business on the list was a small-town music center offering music lessons and instrument repairs, among other things. By the time I got to them, I was depressed and exhausted. It took all my strength to make that one last call. After being transferred to the manager, I went through my spiel one more time. The woman on the other end of the phone said “we’ve never done something like this before, but we are wanting to increase our partnerships with the community. Let me talk to the owners and get back to you tomorrow.” Then, the next day, something even better happened: she called me back and we set up an appointment for L, his mom, and me to visit.

Our initial conversations focused on L’s strengths and interests. I told them that he plays the piano and drums, and wants to learn more about the technical side of music production. At the visit, I came early and met the couple who owned the business. We brainstormed activities where L could job-shadow and work. The owners explained that they had been in business for six years. They were growing, but wanted to forge new connections with the local community. Only shortly before L arrived did I explain his specific disabilities.

At the interview, L was clearly excited to be around so much music. He was asked about his prior musical experience. The owners recognized that L’s enthusiasm can energize their students and customers. They agreed to set up a part-time, eight-week unpaid internship for L.

On the first day of the internship, L was introduced to one of their drum instructors, B, a guy in his mid-twenties who shares L’s interest in electronic dance music (EDM). B took L into the drum room and

asked him to play, saying he wanted to find out where L was at musically. The two young men sat down and just drummed together for a good half-hour. I sat outside enjoying the free concert. Soon I noticed they were playing the same beat over and over again. I remembered what the IEP had said about perseverance. But then I heard B asking L to play it again. He wanted to learn the new EDM beat. Quite literally, he was following the beat of L's drum. And the result was that a bond of trust was formed.

Later that day, L collaborated with one of the owners to advise him on lighting choices for an upcoming show. After working together, the owner said "He's a bright guy, he catches on quickly, he's musically talented and creative." As I mentally compared those words to the words I read in the school evaluations, it made me think of how the same person can be seen quite differently in different settings. In a setting based around his strengths, L was able to shine.

On the second day of internship, L began learning how to tune guitars. In the coming weeks he will help maintain and repair instruments, volunteer in the summer camps, configure lighting and sound for shows, and have the chance to compose and record his own music. L will gain several transferrable skills. But more important, L is finally in a place where others accept and value him as he is. Where the employers see assets where others have seen problems to be fixed, where his strengths can be converted to benefits for the community. Instead of trying to "redirect" him, they followed his lead and helped him build upon his strengths. And L is responding to the combination of acceptance and high expectations. At the end of his first day he said to the owner, "Thank you, this changed my life forever." And, really, that's what it is all about.

So, what can we learn from this success story? And what can we do to change more lives?

It's interesting to note that this was a small business with zero prior training related to inclusion. And, as much as it pains me as an inclusion trainer to say this, sometimes it's the organizations without prior disability experience that intuitively make the best decisions.

This success started with an employer who valued community connection. They recognized that including this student would benefit them as well as benefiting the student. As a result, their motivation ran deeper than merely a sense of charity. They recognized that they would gain a return on their investment.

Another factor was the consideration of L's strengths when creating the work experience. This speaks to the value of customized employment and job carving. While creating a fully customized job is not always possible, any worker is going to be more effective when doing tasks they are naturally skilled at than when doing tasks playing to their weaknesses.

Finally, this employer treated L as an expert on his own needs. They strived to learn from him not only about his musical interests, but also about his preferences, learning style, and any accommodation needs. By following his lead, they are able to develop a supportive environment for him. They also respect him as a human being, which is what creates mutual trust.

As I come to the end of this talk and transition to Q&A, I want to challenge each of you to change someone's life. Maybe today, maybe this month or this year. Maybe directly as a service provider. Maybe indirectly by busting someone's misconceptions about disability, or making a system more universally accessible. Think of the opportunities you can create, the bridges you can build, the identities you can transform. The ripple effects of inclusion can transform the world in ways we may not even

imagine. Let's work together to build an inclusive world where everyone's humanity is affirmed, and where everyone belongs. Thank you.