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The Power of Storytelling: Lawyer, Caregiver, and More

Diversity and Inclusion

Employment and Labor

Skills and Professional Development

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Cheat Sheet

- **Not everyone will understand.** Sharing your story is not about persuading everyone to agree with you. While it may sometimes be about advocating for something, such as law, sometimes a story is just one step in a journey.
- **Be authentic.** Even if people don’t agree with you or can’t understand your story, be honest about your experience and lessons. It will help them get closer to you and will help you in your journey.
- **Your story continues.** Listen, pay attention, and grow from what others tell you as they discover your experiences.
- **Choose a manager who lets you be you.** Being able to be yourself will help you grow and thrive.

They say that a parent is born with every child. It feels like it. The changes, challenges, and lessons I have experienced through my kid being in our life changed me forever. And as we recognize

Lissencephaly Awareness Day September 8 every year, I have come to realize how important it is, as a lawyer, working parent, caregiver of a kid with a rare disease, and more, to share my story in the hopes that it will help others. You can do the same.

1. You can't plan everything

I learned the hard way. I used to have a clear-cut plan for everything I wanted to do in life. But some things can be planned, and the plans will work out as intended. Some will change somewhat. Much will change completely. So, let it go, and stop worrying about the future or ruminating about the past.

In my situation, caring for someone with rare disease and severe disability, it's super easy to get stuck thinking about numbers and probabilities that could mean life or death to the person you care for. But when you recognize that you can't control the future nor the results, you stop worrying about the challenges that await you tomorrow and focus on today.

2. Make the most of every moment while it lasts

These moments ain’t comin’ back. When you're young (like mid 20s and early 30s), it's easy to take your life for granted. A couple of years before I became a caregiver to a severely disabled child, I felt invincible. But once you recognize your vulnerability, you understand just how valuable time and health is. Don't waste it.

3. Finding your purpose helps you get up every morning

Caring for someone with a disability is tricky. Some days I feel like a superhero. Some other days I feel like hell. Stepping back and realizing my purpose keeps me going.

I find my purpose in service. The time I spend helping others in need and serving my community makes me feel alive. I started volunteering as a mentor because I believe in a world in which everyone has an opportunity to grow. I reject the prison of selfishness and individuality. I possess a radical hope others do — or will — too. Peers have joined the effort and embraced the possibilities of solidarity and empathy.

> When you're young, it's easy to take your life for granted.

Create longer tables so others can join you.

Don't waste your days being unfulfilled when you have the chance and the luxury of choice.

4. Not everyone will understand — and that is OK

One of the many comments I have heard is: “Your kid won’t appreciate your sharing about his neurodiversity and disability when he grows up.”

This continued controversy really got to me and I still waiver sometimes before sharing. I step back most of the time. I get so caught up in what the “right” thing to say is that I end up freezing.

Detractors like that think it’s wrong for me to advocate for him and his community. And believe me, I have asked myself a thousand times before I become vocal about diversity, equity, and inclusion (DEI), and disability rights if his story is mine to tell.

But here’s how I look at it:

My kid may never even grow intellectually to understand and appreciate what I do for him. Yet I do it for him with all the love and patience I can pull out, and I will keep doing it even if he never gets it. Diversity and disability are not to be shamed away. They are an intricate part of my kid. A uniqueness we applaud. I wouldn’t tell him his wobbly brown eyes are bad, so why would I imply his disability is?

That comment feeds into the idea that disability and neurodiversity is lesser than because it’s different. But I wonder, would you tell a caregiver with a kid wearing glasses or one with Down syndrome to hide their child’s disability? What about someone whose skin tone differs from yours? I never post anything defamatory that compromises my kid’s dignity, so why do I need to stop?

A detractor asked me to hide my kid because he doesn’t look disabled enough and his disability can be easily masked despite him being on the most difficult spectrum of Lissencephaly.

> I have asked myself a thousand times before I become vocal about diversity, equity, and inclusion, and disability rights if his story is mine to tell.

But there is nothing embarrassing about disability. My kid may be judged by the world, but he certainly won’t be judged at home. He will be fully and freely seen. I will meet different people who are all at different stages about being empathetic and unbiased towards everything including the disability community. And that is ok. That is their journey of evolving from resistance to embracing.

Focus on your own journey and give others the space to figure theirs out. You can’t make everyone happy and that isn’t your job. You can, however, approach every single issue with an overabundance of empathy and grace.

I don’t expect everyone to know or understand the perfect thing to always say. We are all on different journeys and have different experiences that play into our choices.

And if anyone disregards him or me because of his disability and neurodiversity? Good. We will have avoided the wrong fit for us. But I pray every day that authenticity and honesty is never something my kid or I grows up to hate, and that we both grow old holding both virtues with pride.

But ultimately, if anyone disregards my kid or me because of his disability and neurodiversity? Good. We will have avoided the wrong fit for us. But I pray every day that authenticity and honesty is never something my kid or I grows up to hate, and that we both grow old holding both virtues with pride.

5. A personal brand is where you tell a story that is authentic, original, and straight from the heart

There is a lot more to storytelling than advocacy. Storytelling is an opportunity to learn from each other’s experiences. Stories shape, strengthen, and sometimes even challenge our opinions and values. And the beauty is that sharing our stories is not only about us — they are also about the individuals who take time to listen to or read them and where those stories take us from there.

6. We can create the change we crave and the community we need to support and life each other

While at Gartner Crew, I learned how storytelling can help you feel you are in the company of others with similar challenges, even if different in many ways. It can reduce the feeling that your life is overwhelming and complicated — it can simplify and enrich it. You can broaden your perspective and evolve. And those you share with may become closer to you, become lasting connections, friends, helpers, and more.

> Stories shape, strengthen, and sometimes even challenge our opinions and values.

7. Your diversity and frankness are your greatest assets

I always tell my mentees they should do more than choose a company — they should choose their managers. Choose someone you will enjoy working with, who will develop you, and with whom you can show up authentically every day, be your individual, diverse, self, and with whom you can be frank. Showing up authentically every day is critical. Inauthenticity is not self-care. Working with someone who is clipping your wings daily is … well, painful!

8. Caring for someone with a disability is not an inability

It has been astonishingly difficult that I have not heard of a single word spoken about Disability Pride Month outside of our community. The bitter reality behind this is that most people have never heard of it, or simply don’t care.

I used to disagree with the whole concept. Now I am super grateful for it. I am saddened thinking back to the shame I once endured, too afraid to admit that my son’s disability is a part of who he is — and now is my story too. The idea that I could feel anything but resentment towards the condition my son is struggling with was alien to me, so pride was not the emotion that came to mind.

I refrained from using the label, “disabled,” for some time. Shamefully, I thought a month dedicated to celebrating something so painful felt forced and unnecessary.

But my perspective changed immeasurably.

Experiencing my son’s disability during the turbulent COVID-19 lockdown, dealing with glares later on, degrading comments, and intrusive questions, forced me to confront my identity as a caregiver and his identity as someone with a disability instead of shying away from it. I later began speaking to other people in the community and realized how sheltered my view of disability was. I was finally able to interact with people who didn’t live with shame, but with a sense of pride and community in support of each other. I realized the humiliation I felt was not because of how I saw my son’s disability and my capacity as a working caregiver, but of how I feared others see us.

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I discovered through Disability Pride Month the importance of spotlighting those who need to be heard. The voices of those with disabilities are valid and valuable, and they deserve to be treated as such. Hopefully awareness of Disability Pride will grow and make this a reality.

9. Rest

I enjoy being a DEI and disability advocate, but sometimes I wish I didn’t have to teach so many and make needs known. In my world, advocacy is the air I breathe.

Perspectives are challenged, redefined, and reshaped. It is not something I got into because it is fun, although parts of it brings joy and fulfillment. It is something I do because I have to believe in the world as “it should be,” where differences are celebrated.

Now for something much simpler, but imperative. Take a break. Rest is not flashy. It flies in the face of everything that tells us we should always be hustling, doing, and being “on” as a measure of our worth.

For the disability community and their caregivers, there is a deeper desire to keep pushing forward and advocating even when we have reached our limit. Every day, both publicly and privately, we confront ableism, indifference, bureaucracy, prejudice, and a society that questions our right to exist equally on the same playing field as anyone else that belongs to the non-disabled community.

My kid, myself, and everyone else in our community, when we share our stories, we are seen as either inspirational for having “overcome” these many hurdles or pitied for having to “struggle.” There is no middle ground. There is no in-between. What we overcome is not about disability nor the challenges of care, but the barriers of societal ableism and inherent inaccessibility we confront every minute of our day.

> The voices of those with disabilities are valid and valuable, and they deserve to be treated as such.

While there is power in storytelling, there is also power in rest. Sometimes, we can rest in celebration of our powerful stories. By taking time out to recharge, I promise you will get the chance to articulate even greater ideas to share with the world.

10. Celebrate every win

Something all parents of kids with disabilities understand, is the joy of sharing and celebrating every single win.

Milestones come in all shapes and sizes. They may not be the typical sitting, crawling, first word milestones but they are just as important and often even more exciting!

We have always felt very privileged to be “forced” to slow down and enjoy the little moments. The moments that come along with the challenges of caregiving. Those moments that quickly pass other parents by.

Maybe all of us need to take a minute to slow down and celebrate ourselves too. Celebrate the little things we do, make, achieve or overcome. Sharing your story doesn't always have to always be about achieving or overcoming something big. The uniqueness of our stories is about those very little things we do, make, achieve or overcome every single day.

Why am I writing this? Well … because sometimes we share stories for a wider purpose

One of the resources that made a difference throughout my personal and professional journey is learning from others’ experiences. I have had great mentors throughout my life. I enrich myself even more by listening to audiobooks and podcasts. I am grateful to those people who are generous enough to share their stories with the world. Regardless of who that person is or how famous they are, I am always left with food for thought with every unique story.

Here’s an example from “The Rare Life” podcast when a guest said something about their kid that I wish the world understood. “It is not sad that he can’t walk. What is sad is the inaccessibility of the world around people of disabilities.”

Those words felt so close to home. The belief that accessibility only benefits a small slice of society is not only negligent but is also wrong. For starters, about 15 percent of the world's population lives with some form of disability. But the number should not matter. Accessibility is not a favor. It is a human right. And it is unreasonable that the community of people with disabilities still must advocate for basic services, health care, schools, job opportunities, and even facilities to be built and adapted to accommodate them in a way that promotes their integration and full participation as human beings in society.

Consider someone who is deaf/hard-of-hearing, blind/visually-impaired, color blind, dyslexic, or someone who is physically or cognitively impaired? — among other differing abilities — who wants to interact with others but can’t, because we have shut them out. Imagine approaching a restaurant only to find it has no door to enter it. You know people are inside, but you cannot join them. For individuals with disabilities, this is how interacting with the world can feel when we do not prioritize accessibility.

We cannot exclude them forever

I am not brave by putting myself out there writing this article, sharing a story so personal and living a truth positively. We all have a demon. I share my story because representation matters. I want to inspire change for this community. We need more of us out there. We need more relatable, authentic, raw, and real stories, stories that resonate. And some stories need to be of people who look and dress like us, who live in similar countries, and go through similar challenges. And we need stories of people who can be part of our community and can help us drive positive impactful change.

Walking and talking will never be my family’s “we made it” moment. And I feel like it should go without saying that we are not limiting my kid or giving up just because we have accepted that this may never happen for him. We will keep pushing him to be the best version of himself. But for us, he does not have to achieve something to be a success. He, and everyone in this community, are already whole. Our “we made it” moment is when they are treated with equity, when they are seen, when they have equal opportunity, when their voices are amplified, and heard, and when their basic needs of accommodations and accessibility are met in a seamless and affordable way.

> We need stories of people who can be part of our community and can help us drive positive impactful change.

My ask of everyone reading this is to take the time to share your own story to inspire change. It takes one person to make a difference. The saying “You have not because you ask not” is so real. If you share your story, advocated for change and the answer is not acceptable, then change to reach more, but keep going. Do not give up. There will be light at the end of the tunnel one day.

Check out ACC?s Resource Library.

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Gartner

Yosr Hamza is a known champion of DEI, women empowerment, and creating opportunities for others who come from under-represented backgrounds (especially for those who are most marginalized and cast aside) to thrive throughout their career journey through mentorship, sponsorship, and authentic storytelling. She co-leads Gartner Legal and Compliance DEI Council and serves on Gartner’s Middle East CSR Board Committee, the Board of Mosaic at Gartner, and Women at Gartner Employee Resource Groups (ERGs). She serves on the leadership of Small Law Department Network, New to In-House Network, and International Legal Affairs Network.