# **Disability Unity Community Convocation**

Tuesday, November 15, 2016 AIChE Annual Meeting San Francisco, CA Funded with a grant from the AIChE Foundation

AIChE's first Disability Unity Community Convocation set out to raise awareness within the AIChE community regarding the professional needs and unique contributions of people with disabilities, with deep insight and personal anecdotes provided by chemical engineers and chemists living and working with disabilities and associated unique abilities. The program featured panelists from AIChE, the American Chemical Society's (ACS) Chemists with Disabilities Committee, and other organizations, and was funded by a grant from the AIChE Foundation. The session was spearheaded by AIChE's ChemEs with Disabilities Taskforce, a working group within the Institute's Societal Impact Operating Council.

# **Speakers and panelists:**

**Session organizer: Chris Pope**, PhD, chemical engineering; independent researcher / consultant in chemical engineering; Chair of AIChE's ChemEs with Disabilities Taskforce

**Bill Byers**, Vice President and Technology Fellow (retired), Industrial Water, CH2M; Former AIChE President (2004); Member of AIChE's ChemEs with Disabilities Taskforce

**John Johnston**, PhD, food toxicology; U.S. Department of Agriculture; Chair of ACS Chemists with Disabilities Committee

**Cathy Kudlick**, PhD; Professor of History, San Francisco State University; Director of Paul K. Longmore Institute on Disability

**Ashley Neybert**, chemist; Curriculum Specialist, Independence Science; Member of ACS Chemists with Disabilities Committee

**Henry (Hoby) Wedler**, PhD, chemistry, University of California, Davis; member of ACS Chemists with Disabilities Committee

**Moderator:** Lucas Landherr, PhD, chemical engineering; Northeastern Univ.; Member of AIChE's Societal Impact Operating Council and the ChemEs with Disabilities Taskforce

The following pages contain a slightly edited transcript of the panelists' presentations, supplemented with additional commentary based on questions posed by the audience and the moderator.

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# **CATHY KUDLICK**

Thank you so much for having me. I am not a chemist, I'm a historian. But I am going to try to put disability into perspective for everybody.

I often start my talks these days with something I've been thinking a lot about. It's a little figurine of pirate. And I invite people to think with me for a minute, and ask yourself if you've ever thought of a pirate as a disability action figure.

If you think about it, the peg leg, the prosthetic arm, the eye patch, all of that — yet nobody ever thinks of pirates as people with disabilities. And I'm going to ask you to think about why. And understanding why will help open doors for considering how disabled people have much to contribute to STEM fields — not just to humanities and history, but many of the things that you're all engaged with.

As an overview, there are two competing views of disability and disabled people, and this shapes our perceptions. The older one is known as the medical or pathology model of disability. And basically, here, disability is something unfortunate that happens to someone — an accident, an injury, a disease, or you're born that way. It's rooted in an idea that disability is unfortunate, and it needs to be fixed so that the disabled person can function as much like a "normal"/non-disabled person as possible. Consider the example of someone with a mobility impairment, although this would apply to all sorts of other kinds of disabilities. For someone with a mobility impairment, this means avoiding using a wheel chair for as long as possible; if you have a mobility restriction and you don't use a wheel chair, you're considered a hero. You've triumphed over your disability. Even when it involves great effort, basically you want to avoid defeat at any cost, because using a wheel chair makes you seem more like those other people, and you want to be seen as the quote "normal" people.

Essentially, in this medical/pathology view, your body does not function as it's supposed to, and the most appropriate response to this is pity. You feel sorry for the person, and you want them, and you, to do as much as possible to manage and counter the situation, so this poor, helpless person gets what they need. That's the medical view.

The competing view has been known as the social or minority model. This says it's environments and attitudes like prejudice and discrimination that shape disability. The model shapes ideas about disability much like you might think of other minority identities, like LGBT or race. And that means that for someone with a disability, say, with a mobility impairment, facing a flight of stairs is your problem, rather than something inside your body that doesn't work. So, the problem isn't your problem to overcome, but it's our collective problem as members of society to fix this wrong and make it better. In this view, someone who finds using a wheel chair easier knows they can get places quicker and efficiently as long as there are ramps and elevators. That's just better for them. And the appropriate response here is not pity and sadness, but actually to take action, wake people up, get things fixed, and get people to think differently about disability. Educate them, engage them. And to say, "it's not me. I don't need to get 20 surgeries. I want to make an environment that has me in it."

Now, when we fail to understand the pirate as a disability action figure, it's because we're shaped by the medical pathology model of disability. And a pirate, of course, historically, is this dynamic figure that functions fine, and in no way would a pirate inspire pity. You just can't go there. You never think, "poor Captain Hook."

A lot of people are trying to rethink this stuff about disability. There's an interdisciplinary field of scholarship known as critical disabilities studies —to really study the history, the society, psychology, policy, and all the things that go into making us think about disability the way we do. It's mostly social scientists and humanities scholars trying to understand and shape attitudes and responses to disabilities so

it becomes much more of an open conversation, that's not just grounded in this medical place where you feel sorry for people. Disabilities studies have been around since the mid 1980s. There's lots of people who major or minor in it across the country, growing numbers of programs in universities. And there's lot of pre-meds getting involved, and all sorts of people in the STEM fields find it an interesting way to engage with the humanities. They come in thinking, "I'll learn about medicine," and then find they're learning about medicine in ways they didn't bargain for. So, it's a very interesting set of conversations.

I direct the Paul K. Longmore Institute on Disability at San Francisco State. It's named for a scholar-activist named Paul Longmore, and he worked hard to change the outdated medical idea of disability and to change hearts and minds. That's what we try to do — to switch people's thinking so that they can think of a pirate as a disability action figure. And we want to change ideas of both disabled and non-disabled people alike. The idea is to change all the thinking.

We run the Superfest International Disabilities Film Festival, with films by and for and about people with disabilities, where we bring allies and all sorts of people together. It's really fun. We co-host it with San Francisco Lighthouse for the Blind — which is not something that people automatically assume would be a film-related thing, but we show people different forms of access and ways of experiencing film. It's not just about watching something passively and taking it in. We also did an exhibit that's traveling around the country called Patient No More, about people with disabilities securing civil rights. And it's a really cool history of a time when 150 people with disabilities, in 1977, took over a federal building for 26 days to demand civil rights and get the precursor to the Americans with Disabilities Act signed in 1990. And until the recent standoff in Oregon, it was the longest occupation of a federal building in U.S. history. It was right here in San Francisco. Yet nobody knows the story. It's not in a single history book.

At Longmore, we're promoting a view of disabled people that goes beyond the medical and social models of disability to promote disability as having a positive and far-reaching impact and implications for everyone — not just people with disabilities, and not just to be nice, but actually to engage people in really exciting ways around disability. And in this view, everyone at this conference has that person in the wheel chair to thank for things like the curb cuts that help you roll your suitcase up to the hotel. There's a reason all these spaces are accessible. And those rolling suitcases are accompanied by mothers with strollers, deliveries, bicyclists, everybody. And it's a thing that people didn't want to put in initially, because they thought it would be too expensive and would only help a few disabled people.

There's probably 20 other things related to disability that could have the same impact on society that we haven't thought of yet. So, we can't say, "We can't really justify doing this major accommodation for people with disabilities. It only benefits those people and it's too expensive." Instead, you want to get in the mindset and say, wow, something that we offer to people with disabilities might have unexpected benefits for everyone.

So, what about chemical engineers? I expect we'll learn on today's panel that people with disabilities are resourceful, great innovators. And that's in part because we with disabilities, by necessity, have to size up our environments, figure out how things work, and figure out different ways to work around a system that's not made for us. Talk about a perfect recipe for innovation, at every single level! We have these really great opportunity for discovery and innovation.

I want to close by acknowledging one of chemistry's greatest disability pirate action figures — and it's a man who had a profound impact on every person in this room. Louis Pasteur. Now, Pasteur had a serious vision impairment that forced him to hold things very, very close when he was looking at them. And he thought about things small-scale, in tiny pieces that made sense to him visually. I would venture to guess, that shaped his thinking about particles and systems, and the ways he thought about small things in relation to wholes. I think his disability shaped that. He also had a series of strokes that paralyzed him. He

also did much of his scientific research, including directing a lab, and was quite a profound contributor to science and all the things we care about in STEM fields. Now, I can't help but think that Pasteur was a great scientist not despite his disability but precisely because of it.

I think what we need is to create frameworks that allow us to think of people with disabilities as making contributions because of those disabilities, and not in spite of them. And this is why I urge everyone here, if you're ashamed of a disability, if you're embarrassed by it, draw your inspiration from people who actually made a difference. And if you don't have a disability, think about the people in front of you with disabilities as having something really amazing to offer, because we've thought a lot of stuff through.

# **CHRIS POPE**

I'm a 20-year member of AIChE and a five-year member of ACS. I have a doctorate in chemical engineering. And today, if I were qualified, I'd be talking about inclusion of highly skilled STEM professionals with disabilities. But realistically it's more like "I never thought I'd be giving a talk about *this*."

Twenty-three years after my doctorate I thought I would be a full professor somewhere, maybe a department chair, maybe not. But, as I found out, anyone can become disabled at any time. Some of you might have read my commentary in the January 2015 issue of *Chemical Engineering Progress* entitled "Our Most Important Tool," in which I say that, among the resources any chemical engineer has, if the mind and body are not working reliably, then success is really not possible. And, yes, I know about this first hand.

First off, it's not recently that I've had disability. It's only been recently that it's kind of hit me in the face. Looking back, I've had several health problems since childhood, including anxiety and depression. They got dramatically worse when I was in graduate school, including some chronic pain issues that came up. Fortunately, I had a very patient advisor — the late professor Jack Howard a MIT — and eventually his patience was rewarded. I did receive my doctorate. It did take a while. But even then I noticed how I had to work my way around health limitations, especially ones that could leave me incapacitated rather quickly. For example, I wrote the first draft of my doctoral thesis in six weeks. All 300-plus pages of it. So, in many ways, I like to think of myself as a Jaguar that's been in a bad crash or two.

When I'm working, I can do some things that really are impressive. But when I break down, that's not quite the case. But I finally caught a couple of disabilities that I could just not work my way around. I came out to the Bay Area for a post doc position in the beginning of 1999. Five months later, I went out on a date with somebody in the woods, and I came home with a tick on me. Found out that I had caught Lyme disease. And about seven years later, I found out that that tick also gave me another pathogen, called Babesian, which is similar to malaria. And my ability to produce went downhill.

What I did do was great. I went to a conference in Edenborough in 2000, the National Symposium on Combustion, and, according to everybody else, I gave a great talk, My boss made a point of telling me that, as did his boss, and his boss, and his boss. Also, my MIT advisor came over and said I did a great job, and even one of his students said "Wow, Chris, I heard you gave a great talk today." And then, when I got back to Livermore, I found out that my position was going to end. It was a post doc — two years with the option of a third. But it ended, not quite by my choice, in 2001.

Since then — well, to give you an idea of what my disease does, it's a spirochete that attacks everything it can, especially the weakest parts, but also in my case the lining of the brain. So much so that there were times when I had to remind myself — "where am I? Like, geographically, where am I? Oh, I'm in California. How did I get here?" — because I grew up in the Northeast. And I would have to piece back

through my life — okay, I went to grad school there, the post doc in France — oh yeah, I'm here in California. It was to the point that — I ran into a friend who is a mathematician, and there was this one unresolved problem in an article I'd written and I wondered if he could help me with. He couldn't quite understand my paper. And then I read it, and neither could I. And I *wrote* it. That's how scary things were for a while.

To say that I had lifestyle changes would be a gross understatement. The physical part — to give you an idea — I wrote down a page and a half full of symptoms that I did not have before that tick bite. And the cognitive and emotional parts — I've mentioned some, but also I've seen five different spec scans that show encephalitis. The last one, about seven years ago, showed a lot of progress, but it also affected me more emotionally. I was more emotional than guys are permitted to be — especially out there in Livermore, in cowboy country; and especially at an NNSA nuclear weapons lab.

So, one good thing that has come of it is that I'm a recovering wallflower. The stereotypical lab rat — even though I was not very good in the lab; there's a reason I'm a ChemE and not a chemist. But I am less inhibited, which is enabling me to talk in front of audiences. And that is a very mixed blessing, I can assure you. But it's still, in many ways, an asset.

Once I lost my job — yes, I was a PhD: Pizza-hauling Dude, for eight years at the Domino's in Livermore. But even then they found out right away I was their fastest driver, by a good two minutes. I ascribe that to having lived 13 years in the Boston area. And, it was a big struggle staying connected with the profession. The single best thing that came out of it professionally was that I started going to the local NorCal Section AIChE meetings — which I had never really thought of before. Of course, part of it was pure self-interest — I wanted to find a job, because I wasn't even on disability yet.

Actually, it was my thesis advisor, Jack Howard, who advised me to go on disability. And at first I was quite offended, thinking it was a vote of no confidence in me. But it was probably the best piece of advice he'd ever given me, minimal though the stipend is, around \$15K. And, looking at the *CEP* surveys and finding that people with my experience and training usually make a \$100K a year more than that, there's definitely some incentive for me to return to working in the field. Not just because of the money, but because I want to work with my favorite molecules and equations again. I'm good at it.

Recovery's definitely not guaranteed, but it can happen. For the past three years, I've been going to the community college near Santa Cruz, and taking mostly computer science classes but also classes in French and German. I know French already, but it's also to broaden the range of places where I could work, because I know it might be an uphill battle. But I've gotten two certificates in computer science — because my work was about 95% modeling work. And I know that computers have changed dramatically since 2000.

One thing that people say, especially for people who are high achievers, there is this notion that if you work hard enough anything is possible. It sounds almost like a new-age guilt trip. "If your life is not the way you want it, you're not visualizing hard enough." But that's not entirely true. Having a disability is really not one's fault. It's not a moral issue. The level of functioning or the extent of recovery is not something that a person can decide or will to happen. Failure to attain complete recovery is not an indication of lack of will or any other character failing. It's definitely not a vacation. I've had people say that to me.

Those with mental or psychological conditions are not, *ipso facto*, a safety risk. As an aside, I've worked with people in the mental health care community, as a peer counselor, and people with mental diagnoses are much more likely to be victims of violence than perpetrators of violence. Nor can they recover merely

by looking on the bright side of life. And, somebody who has more insight than I though he did wrote that: Me.

And the reason we are here today — about three years ago, inspired by the existence of ACS's Chemists with Disabilities Committee, which has been in existence now for over 25 years, I wanted to produce the same within AIChE. Not just for feathering my own nest, but also in a sense of service that's saying that if I can get through this, I want to be of help to other people out there. And part of that, also, is that I've been in 12-step recovery programs since 1980. My first time in college, I partied my way out. Which was a considerable achievement seeing that it was at Princeton — and that's really not a party school.

I know I'm not the only one out there. So I've gotten involved with AIChE's initiatives on diversity and inclusion in general. I'm now a member of the Societal Impact Operating Council. The Chemical Engineers With Disabilities Task Force was officially created this year, and hopefully will pave the way for the creation of a standing committee in AIChE. Sunday, we had the fourth annual ChEs with Disabilities Forum. Today, there's the Disabilities Unity Community Convocation with Dr. Kudlick and three members of the ACS Chemists with Disabilities Committee, including their chairman, John Johnson. And also Bill Byers, an AIChE past president, who actually attended that first forum three years ago, here. He was the only one, besides me, there, and he's inspired me to go on since.

And that's where numbers are not so important initially. It's that something has started. And this first session here I see as the first hit of the wrecking ball toward whatever needs to be cleared out for people to be seen as equals.

And also, I've learned a lot more about disability and inclusion in general. Shortly after I came to California, they found that California was the first state in the nation in which white people are no longer the majority. The best headline I saw about it was in the *Valley Times*. It said: We're All Minorities Now." And in some ways, that is reality.

And so, diversity and inclusion benefits everybody — not just rainbow butterfly unicorn kittens. It shows there's a lot of creative people out there — some, perhaps, with too much time on their hands. And this event was made possible by a grant from the AIChE Foundation.

Behaviorists defined intelligence as the ability to learn and the ability to adapt. Therefore, those of us with a history of disability are brilliant. We're very intelligent. I've had to adapt in a lot of ways I've never though of. And a new asset to me — I'm less inhibited; I am capable of talking in front of an audience. I've relearned how to learn. I had real cognitive challenges in learning — not only computer languages but also human languages — with short-term memory problems and difficulty focusing. I'd look up a word in German, and then go to the screen to type it and then forget, sometimes having to go through two or three iterations. But also as a tutor, I've learned how to explain things to people half a dozen different ways. And I am persistent.

Some people might think that, since it's now mandated, there's this terrible obligation to hire people with disabilities. That it's really a chore. When in reality, it's a chance to change. It's a terrific opportunity to include our colleagues with disabilities.

# **HOBY WEDLER**

Thank you very much, to Lucas for moderating this, and a special thanks to the American Institute of Chemical Engineers for putting this together and inviting us from the American Chemical Society – and to so many young chemical engineers with disabilities for being here today. It's really an honor. We just love what we see. And we love the development of this movement you're putting together.

Before we get too far, I want to think about *what is a disability*? That question is one, I think, that we can ponder a lot. What does it mean to be disabled? Are disabilities really a burden or a hindrance, or can they be beneficial? And the message here — I think it's good to point out — is that every one of us in this room is good at something and not as good at other things. We all have things that we are better at and things that we can't do. Are those things that a run of the mill person can't do so well considered disabilities? Well, in some ways I think that they are. And we can make an argument, effectively, that all of us in society have a disability, and have different ways of looking at problems, or different ways of doing those things that we're less good at. Some people are not good spellers. Well, they use spellcheck. That's why that was created.

Let's think about, as well, the idea of how we overcome disabilities. Well, there's many different ways. But it all boils down to developing tools to achieve results differently, and to achieve sometimes the same results in a slightly different fashion. Some people might take the stairs to get from here up to the 25<sup>th</sup> floor. Some people might take the elevator. So, it's the same thing — some people might read a book in braille to understand information, some might read it in print. It doesn't really matter — the means in which you go about solving a problem, as long as a solution is approachable and intelligent and useable.

So, I think if we can come up with the right solutions to solve problems, as people with disabilities, we may have an advantage. There are abilities that we gain by having to think about things and having to do things differently.

Professor Kudlick talked about curb cuts, and I think that's a really good point to bring up; the fact that so many of the adaptations that we see, the adaptive methods that people use to accomplish things, are created by people with disabilities and that need those resources.

So we with disabilities are some of the best creators of the adaptive tools that we need to thrive and succeed

How many of you know how the typewriter was created? The standard typewriter in the 1800s, and the QWERTY keyboard?

People were writing everything by hand. And there was a group of blind people who realized that writing by hand wasn't going to be very easy. Braille was just being invented, there really wasn't much of a code of bumps to use. And blind people wanted to communicate with the world as well. And essentially a movement came up where blind people said we need a way to write. And, along with others, they created the first typewriter, including the QWERTY keyboard that we all use.

Along these lines, can we do long algorithms of mathematics in our head? Can we run calculations that computers do for us everyday? I certainly can't. And I'll bet no one in this room can run an algorithm to figure out some mathematical solution to solving a problem of, say, squaring a five digit number. Something as simple as that for a computer would take us a lot of time to do in our own mind. Some people can do it, but not when the math gets very complicated. I'm not a computational chemist by training — and, as all the people in this room know, the only atom we can solve for, the exact energy and position of electrons exactly, is the hydrogen atom. Everything else, the math is too hard for us. We need to approximate. And the way that we approximate is generally using quantum mechanics and other techniques that are available to us. And none of us can do this in our mind. So, we all are disabled in that sense.

But what we've put together is a tool that we can all use. And that's the computer. And the emergence of the computer in the last hundred years — and the technology leading up to the computer over the last

century — has made it much easier to solve problems and, frankly, revolutionized what we can do as a society.

But the truth is none of us can do in our mind what a computer does. So are we all disabled in that regard? I think it's important to think about.

I'll tell you just a little of my story. I've been totally blind since birth. I began really loving science when I was quite young. As a child, I always wanted to know how things worked, how things fit together, why water could travel from a water treatment plant through city waterlines into our house and get everywhere it needed to go. Plumbing, electricity, electrical systems always fascinated me. And these things led me to really enjoy science, and enjoy asking the "why" question.

So, I decided to attend school at UC Davis, with encouragement from blind friends of mine, my parents of course, colleagues, and many others in my life. And I ended up receiving a chemistry degree at UC Davis. I didn't know how science was going to work, as a blind person, so I also received a history degree. I took a couple of classes with Professor Kudlick at Davis, which was great. And I graduated in 2011 with a BA in history and a BS in chemistry. Didn't really know that I could go to grad school, as a blind person in chemistry, until during my undergraduate tenure I met my advisor, Prof. Dean Tantillo, who was a computational chemist. The main reason I didn't know if I could go to grad school was because I did not want to work in a lab with an assistant looking over my shoulder as I used actual chemicals, day in, day out, for my research in graduate school. I was confident that the thought process, that the cerebral nature of chemistry was not necessarily going to be the challenge, but really the act of accomplishing the research and getting the results.

When I met my advisor, he really had more belief in me than I had in myself. He told me that he was confident that we could come up with adaptations in methodologies for me to study chemistry at a level equal to my sighted peers. We ended up doing so in my first summer in his lab as an undergraduate. We got great results. And Dean basically kept convincing me, and after a year and a half I accomplished enough in his lab to believe that graduate school might work. So, I took a shot in the dark and applied to graduate school, and ended up getting in and thriving in Dean's group, and really enjoying the work that we do. And I'm just now terminating my graduate career, and entering the real world and figuring out a niche for what I want to do.

But what I would say is most important to my graduate career were people who understood that, as a blind person, that's not a complete hindrance to one's ability to do chemistry. And people who really saw in me what I didn't yet see in myself. I think that's a quality in great mentors — that ability to see in the people they are mentoring a future for them before the people they are mentoring see that in themselves.

And a big part of inspiring anyone, including those people with disabilities, is being a great mentor, and being there to say "this is all possible." You might do things differently, but anything is possible. Anything is doable.

As a member of the ACS Committee on Chemists with Disabilities, I'll be the first to say that having a committee that is aware of disability issues, working hard to advocate for those in the society with disabilities, is of utmost importance. Because it reminds everyone involved that change can be made, and that people with disabilities offer just what people who are not disabled offer, just in a slightly different manner.

So, seeing this forum get together at AIChE is really incredible for all of us. I understand that this is the first meting of its kind in AIChE. And I believe that with more awareness, and more knowledge of disability, and of what people with disabilities can do, really anything can be achieved. And people with

disabilities gain the confidence in fields like chemical engineering that they lack because people always tell us that a disability is going to hold you back and that it's an impractical career to study because it has so much technicality and so many hurdles that can be inaccessible to anyone with a physical disability, all the way to those folks who might have mental or psychological disabilities. And having a group like this that motivates and supports and promotes the work and the great accomplishments that have developed from the disabled community is paramount and so incredibly important.

I'll close by talking about the method that I think is the quintessential way that disability works, and how a disability revolution and understanding takes place — so that changes take place for folks with disabilities that can help not only those of us with obvious disabilities but everyone.

The first idea in this is awareness. Being aware that there are people in our field with disabilities and that they are just as capable as anyone else. And that's what I think that a committee or society dedicated to disability resources and disability advocacy is so good at — creating that awareness.

Once we're aware of folks with disabilities, and aware of the fact that what we do and the discussions that we have might not be as accessible as they could be, change takes place. We start to think about how we can put things together differently, how we can think about things differently in order to make change, and make the environment more approachable to folks with disabilities, and more accepting.

And once this change takes place, I think progression is what happens. We need groups — like the Committee on Chemists with Disabilities, like the disability action network that is being developed here — to promote and remind people that, though change has been made and though we're working hard to accomplish what we know is possible, we need to keep thinking and keep chipping away at that iceberg and at the barriers that some of us face. Just because of a lack of understanding of what folks with disabilities, and folks of any minority, can accomplish.

So, again, those pillars are awareness, change, and progression,

Finally, I think it's very important to think about what I said at the very beginning, which was — people with disabilities are very good at creating tools for accomplishing what they need and for making their lives accessible. And I think that as chemical engineers, and as scientists in general, our calling is to develop these ways of solving problems, as well as the critical thinking skills that we need to revolutionize how we think about engineering and how we think about the world at large. And if we put that perspective onto this framework of folks with disabilities developing their own skillsets and tool sets that work for them, we can see a crystal clear image of why having a disability is by no means a disadvantage, but most likely an advantage when approaching scientific problems, and approaching the thought process that we undergo when we talk about science and the scientific method at its core.

# JOHN JOHNSTON

Good afternoon everybody. I'm John Johnston. I have a speech disability. I was the student who sat in the back of the class petrified that the teacher was going to call on me. I was the student who never raised his hand and asked a question in class because I knew I would just stutter my way through the whole question, and embarrass myself.

When I gave my dissertation seminar, I stuttered multiple times through every sentence. I completed a U.S. Department of Agriculture Leadership Executive program, and my final presentation was a similar mishap.

So, at this point in my career I realized that regardless of what I had accomplished — earning a PhD in food toxicology, earning an MBA and finishing first out of a class of 240 students — that my career was going to be extremely limited because of my speech disability.

So, I took some speech therapy, and I've been participating weekly in Toastmasters International, a public speaking organization. And some 30 years later, at least I can stand up here and share my story — and to be honest, it feels great.

And, as the chair of the American Chemical Society's Chemists with Disabilities Committee, one of my projects is to increase the awareness of the capabilities of people with disabilities. And I've coined the phrase "people with disabilities are people with unique abilities." Is the glass half empty, or is the glass half full? And there are many examples of people with disabilities who have become scientific superstars.

We have these bookmarks that I can share with you, and there are posters that we display at ACS meetings. This series features world-renowned scientists — one has a speech impediment, one is blind, and one has a hearing disability.

So, the individual with the hearing disability — Thomas Edison — has said that his disability aided him in many of his great discoveries. It helped him concentrate. It helped him get in the zone. It helped him eliminate all the distractions.

Our next set of posters features three more scientists, one of whom is Albert Einstein. Albert Einstein had dyslexia. We've all heard the stories about how, in elementary school, Albert Einstein struggled — typical for a student with dyslexia. Wouldn't it have been horrible if his opportunities and education ended there?

And it doesn't take too much thought to garner the perspective that perhaps Albert Einstein's dyslexia gave him such a unique way of looking at the world and science that he revolutionized how we think about energy and mass. And perhaps without his disability he never would have come up with that world-changing point of view.

Now, every scientist with a disability is not going to become a Thomas Edison or an Albert Einstein. It would be unreasonable to expect that. But if I use myself as an example — just a regular, Joe Schmo scientist — I've been fairly successful in my field. As a researcher in my research center, I have authored or co-authored more than 130 peer-reviewed publications, and I have brought in more grant funds than any researcher there. And when I look back and think, do I have an advantage because of my disability? Perhaps I do.

As the kid sitting in the back of the classroom who never raised his hand, when the teacher called on me, you'd better believe that I wanted my answer to be as short and concise as possible. I perfected going from point A to point B to point C as efficiently as possible, because I wanted to give the answer and be done. And I think that serves me well as a scientist; to go from point A to point B to point C as efficiently as possible.

Another thing that served me well in my career is that since I did not want to have to raise my hand and ask a question, because I did not understand something, I listened. I listened intently. Because I didn't want to miss something, because I didn't want to have to ask a question. And I think that has served me so well in all of my scholastic courses, in professional meetings, etcetera.

So, yes, having a disability has in some way given me some unique abilities.

Two more examples I'd like to share with you. I read recently that some tech firms in the South Bay of San Francisco have discovered that hiring programmers who are on the autism scale is serving very well, because they have a propensity to program efficiently and not be distracted. Stellar employees. It's about matching someone with a disability and unique ability with the right job. I think that is something that employers and people with disabilities should strive for.

And my last example goes to World War II. In World War II, soldiers who were colorblind were eliminated from officer training school and all sorts of promotional opportunities. They were relegated to being infantry. Then, someone stumbled on the fact there was a bomber that was so much more successful than all the other bombers. And it turned out that their spotter was colorblind; he'd kept it a secret. It turns out that camouflage, as we would expect, is designed for people with so-called normal vision. And camouflage is basically ineffective against people who are colorblind. So every bomber wanted to get a colorblind spotter. And those who did had higher success rates.

So, pairing people with disabilities-slash-unique abilities with the right job is something that can really be a win-win; a win-win for the individual with the unique ability and a win-win for the organization as well. It's not going to fall into our laps, it's going to take some work and planning. But there is a great opportunity out there for all of us by hiring from the community of disabilities.

# **ASHLEY NEYBERT**

I enjoyed Professor Kudlick's talk about how it's really society that disables people and not the disability itself.

I like to think of that in terms of computers. When you think about it, it doesn't mean that there's something wrong with you when you have a disability. When I turn my computer router off, my internet is disabled. Does that mean that my internet is somehow less valuable now than it was earlier? No. It just means that there's something preventing it because it's not sending a signal. Turn the router back on and it works. For people, if you have a physical impairment, maybe the set of stairs is disabling you. Put a ramp there and it's fixed. So, it's something you can get around if you put your mind to it.

I've had a history of disability, in a sense, that probably many people have suffered with. I have Asperger's syndrome. And my family always knew that I was disabled. However, I performed well in school, and it was considered shameful to be disabled. So, "let's not announce that you, for example, don't have a social life; it will work out as long as you're doing well in school." So, I grew up trying to hide that, and trying to be quote-unquote normal. And that caused me issues when I got to college and there were suddenly lots of timed tests. Because, for autistic people, you know really well the answer for things, but as soon as you put a time frame on that, my reaction was "oh-oh, I don't know anything because suddenly there's a time scale and I can't do this in the next 20 minutes. Sorry. I don't know anything. I'm going to turn it in and fail."

I was lucky that I had an advisor who figured that out — when I went to office hours to ask, "what is wrong with me? I seem to be doing fine on the homework" — because the homework wasn't timed, and I didn't have someone yelling out, "fifteen minutes, ten minutes, five minutes." So, that was something that I needed to figure out how to deal with.

And so, I got over that, or worked through it. But I've now dealt with both mental and physical disabilities. As I finally got the Asperger's syndrome dealt with, I began to go blind halfway through my undergrad career. And so I continuously had to adapt, because blindness is a spectrum. At first I started reading large print. Then, I had to do things more tactilely. I had to try to learn braille, all while trying to finish my chemistry degree. And every time I learned how to adapt to what vision I had, it changed again.

That's something that's similar to a lot of mental disabilities. You say to yourself — I solved this problem. I finally thought I could overcome depression or anxiety in this scenario, and then it strikes somewhere else.

So, I'm constantly trying to put out fires, in a sense. I think this fact is looked at, in a sense, as a weakness—but frequently, if you can fight those fires continuously, that itself is a strength to go on.

I got involved with a company called Independence Science that makes laboratory equipment for blind and visually impaired people. And it could make things more successful for a lot of people.

# [Performs demonstration]

[Paraphrased extract] It's a completely accessible thing for blind people. When the device is set on temperatures, it will read aloud any sort of temperature. It interfaces with 75 different probes to basically come up with any sort of measurement that you might need in a laboratory. This allows me to work independently. If I press a key, it will start collecting data. It automatically generates a graph and statistics or data tables. And if I'm interested in specific points I can get a read out and take notes.

At Independence Science, while working with other students, we found that the tool was more helpful than we were aware. At first, it was designed for blind and visually impaired. Its screen has large print lettering. You can use it with a touch screen, or you can use it with a keyboard interface. But we learned from doing that that several students who were not in the blind or visually impaired category got jealous of our equipment. Some students started asking us — "hey, can I have this? I'm dyslexic" — and as many of you know, if it's 69 degrees C or 96 degrees C, that makes a bit of a difference when you're running your calculations. So, those students like it for their own purposes.

And then, there's the common proverb of "if you teach me one way, I might remember. Teach me two ways, I'll remember it more. Teach me three ways and I'll remember it for my life." Well, if I am teaching a laboratory based on a lecture, that's my second time learning the material, using my experiments. But if I'm also getting an audio output at the same time – even if I can see and hear – I'm able to gain an additional way that I'm learning it, and I'm able to process that. So, students can potentially remember things better. That's something we stumbled across by accident.

We also put in three different languages. We realized that when you have students that come from foreign countries, who don't know English well enough yet, you can just switch the language to help them learn, or switch back and forth. This is another example of giving people multiple ways to learn things.

And that's an example of something that, without the problem of "how does a blind student operate in a science lab" we wouldn't have come across. So, that shows you how a tool for disabled people can be a benefit for all.

#### **BILL BYERS**

AIChE has been my professional home for well over 40 years. I have a ton of friends here, and AIChE is a big part of my career success because I've used the Institute's various meetings and relationships as a laboratory for how to be a professional. And, if I felt uncomfortable about leading a group a work, I could lead a group within AIChE and then I could apply that in the workplace — and them I'd be a better group leader than I would have been if I didn't have AIChE as my professional home.

And it's been mutually gratifying. In 2004, I was president of AIChE. And at the end of that year, thanksgiving weekend, putting up Christmas lights, I fell from a ladder and injured my spinal chord —

which commenced a year of rehab. After that year, I started back to work part-time. I was able to return to AIChE meetings. And it was really important that I had the friendships that I had in AIChE and the professional society — relationships that I could return to. My workplace colleagues were equally glad to see me returning to work. They saved a place for me. They couldn't have been better. But I could break the ice with my good friends at AIChE in ways that maybe I could not at work. And I could try new things.

And so, being a member of the Institute, and being an active member of the Institute, helped me reenter the workforce and reenter the profession after a bit of trauma.

So, I'd returned to the status quo — life's good, I'm back to work, I've got my friends at AIChE, and I've got my career going for me. And then, three years ago there was a note in the AIChE meeting program that someone had reserved a room for chemical engineers with disabilities. I hadn't heard about it. I hadn't really thought about it. And I didn't have anything else to do that evening, so I thought I'd go see what's up.

And Chris Pope was there, and Chris and I had a room bigger than this, and we had about a 90-minute conversation. And I learned Chris's story and it occurred to me that we probably weren't unique within the 30,000 to 50,0000 members of the Institute. And in the chemical engineering profession at large — whether they belong to the Institute or not — there were people who could benefit, perhaps, if the Institute had programs that were welcoming and supportive of chemical engineers with disabilities.

I was a member of ACS as well, and I knew they had a Chemists with Disabilities Committee, and so did Chris. And Chris has really carried the ball the last three years to get AIChE where we are here; another small step along the road.

I'm so pleased and thankful for the members of the ACS Chemists with Disabilities Committee for joining us today, and for Dr. Kudlick for joining us today to give her perspective. It's been inspirational to me to spend some time with these people these last few days. I want to thank AIChE's Societal Impact Operating Council for establishing the Taskforce, as well as the AIChE Foundation for financially supporting the travellers to this panel. That's been very important.

And it would be my dream that AIChE helps chemical engineers with disabilities find a professional home like I've had throughout my career. And that they would look to AIChE meetings and feel welcome to come to meetings knowing that they will have a great time. And knowing that the profession, as supported by the Institute, supports them in whatever unique way will help them be a more fulfilled professional. And, with the breaking of the ice for people with disabilities to get past the embarrassment, if you will, of being somewhat different, we can help people step past their disabilities and enter the profession fully and ably."

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# **Questions and Answers**

**Question from the moderator:** Comment on the Americans with Disabilities Act and how it has impacted your lives.

**KUDLICK:** The Americans with Disabilities Act was passed in 1990. Prior to that there was not much in the way of regulation for everybody, in terms of architectural access or educational access. The protests that I mentioned at the very beginning, in 1977, ensured those forms of access in anything that received

funding from the U.S. government — universities, hospitals, schools, post offices, things like that. And once that become law in 1977, and they started making people comply with the law, that ensured that organizations that were federally funded would follow it. What was missing was the fact that private enterprises — stores, hotels, etc. — were not required to make their places accessible, until 1990 when the Americans with Disabilities Act came in. So, if I was going to school in the early 1970s, I would not be able to ask or know to ask that I could have accessible materials for me as a person with low vision. If I was in a wheelchair, I couldn't assume that there would be a way for me to get somewhere. And with these acts — in 1977 and 1990 — at least the regulations were put in place.

The thing I will say about the ADA is that it should be viewed not as a thing to aspire to, but as the lowest of the low to which we will not go. So, still, there's a lot that's not accessible. And what we should be thinking of is not just meeting the requirements of the ADA but surpassing them, and really thinking about ways that we can better the environment for everybody.

**JOHNSTON:** We all learned in school about Brown v. the Board of Education, and when it came to education and students of color, separate was not really equal. That ensured public education for students of color in the United States. It's a great thing. But about 20 years after Brown v. the Board of Education, students with disabilities were still routinely excluded from schools on the premise that a wheel chair would be a safety concern; they couldn't get out if there was a fire, and so on. So, having joined the disabilities community about a decade ago, there's a lot we can learn from these different disabilities groups, and I feel that we have not yet had our 15 minutes of fame. We are definitely not on the radar for most people.

**BYERS:** If I might add — we can only go so far through litigation and legislations. Education is really what matters most. And it's my experience that my more fully-abled colleagues want to know how to interact with me in the smoothest and most caring way. And, I know the members of the Institute want to know how to interact with people who have clearly evident disabilities in ways that will break that ice and get through that discomfort, to being people together. So I think that that's an opportunity for us — to educate and to go beyond the litigate-and-legislate stage.

**WEDLER:** I think that's true, Bill. And one thing that I've found to be true, at least in my field and the work that I've done, is that people really want to help, generally. Obviously, there's going to be litigation and certain circumstances and issues that cause us not to be able to achieve what we believe and dream of achieving. But in 90% of cases, I would say, people really want to help. And, Professor Kudlick, I think that's pretty true historically, isn't it? People often don't know how to help, and if we can show them what we need — and we speak for ourselves — it lets people know how they can help, and how we advocate for ourselves. And the bottom line is that we are the only ones who have the power to make a difference.

**KUDLICK:** There's a statement in the disability community that says "nothing about us without us," and that's a great way to start when you think of any kind of inclusion of disability; don't just assume that you're going to know exactly what needs to happen just because you've read up on it. The idea is to get the feedback of people with disabilities and build it in from the beginning. And make them part of the process from the beginning.

**POPE:** And if I may, I was going to reiterate the same thing. Because, I have also been involved with mental health advocacy, and scenarios where there seems to be a fair bit more cause for concern, especially in a time when we need to be aware of terrorism. Chemical facilities are targets for that. I got a chance to review what happened in Bhopal, and how the actual incident itself started with an employee who had gotten fired and wanted to get back at the company. So he hooked up the water hose to the methyl isocyanate tank, and we know what happened.

One thing I've mentioned along those lines is, there are probably more people than who will probably admit it, that have some kind of psychological condition.

Among the things I've learned in the trainings I received is something called trauma-informed care. Basically, trauma is where an event overwhelms the individual's response to cope with it. And there are three typical outcomes for people who have dealt with trauma. Initially, trauma overwhelms them and they end up continuing to have trauma and degenerating into psychosis conditions. The three outcome choices are mad; bad (they end up being rebellious and possibly criminal); and the third one is grad, where they focus their energy into scholastic achievement, and continue along those lines. And I know that I was one of the latter ones, because — although my family history isn't one you'd see on Oprah — school was an escape for me. And I must say that a lot of higher education in general, especially grad school, is almost designed to be traumatic. And I suspect that there are a lot of people who are, in that sense, walking wounded here. It's important to recognize that, and to recognize that adaptation to an unhealthy environment is not necessarily indicative of achieving health.

**Question from the moderator:** One comment that Hoby Wedler made in an earlier forum was that low expectations are easily exceeded, just by showing society what they might be missing. What is the best way to communicate to others to make sure that, whatever your disability is, you're not going to be treated differently and that you'll be understood? How can those of us without disabilities, help in that communication?

**NEYBERT:** I think there are people who don't like to be asked questions. But there are also people who have been told sometimes that it might be insensitive to ask questions. I've found that being asked questions helps, because for people with disabilities, you don't necessarily want to get in someone's face and say, "Hi, let me educate you about my disability."

Sometimes, you can just try talking. For instance, on the way here, I was sitting in the airport, waiting for my flight, and I'm texting, checking emails. And someone had seen my cane and walked over, and he announced "Hi. I've been watching you for several minutes, and I was wondering, if you're blind, how on earth do you use a phone?"

So, there's two ways you could have reacted to that. I could have reacted with "I need to go, because you just came up to me and told me, I've been watching you for several minutes." Or, even though the guy's comment wasn't phrased quite correctly, it was better to inform this guy about how it worked than to be offended by it — because he was genuinely curious. And I explained the voiceover feature on the phone and how it talks. And he said thank you. So, I think if you're curious about something, asking questions or get to know someone. See them as any other person. Talk to them. And then, once you get to know them, feel free to ask questions such as — "if you don't mind, how do you do this? Or, how is it best to handle that situation?"

**JOHNSTON:** Having joined the Chemists with Disabilities about a decade ago, I have found that, dealing with colleagues with a wide range of disabilities, it's often nice to just offer assistance, if it's accepted. And if people say they're fine, to just back off. I think that is something that people without disabilities, or people who aren't around people with disabilities, can find to be a tenuous situation; do I offer to help? Is that condescending? I have found that offering to help, in 99% of the situations, is appreciated, or tolerated. So that's what I do. I err on the side of offering assistance.

**WEDLER:** I'd just add, the only way to educate is to communicate. And if we don't know that someone has a question, we won't be able to answer that question correctly. So I encourage people to ask questions,

no matter how awkward they are — such as in Ashley's situation. I have my own slew of stories there. But if we have an opportunity to explain things to people, and we're not willing and open minded about it, they're not going to learn and they're going to make the same judgment calls they've always made. And we're not going to make the progress that we need.

**POPE:** Actually, I've found myself on both sides of this situation. For a while, when I was in the Boston area, my girlfriend worked at an institute for people with cognitive and developmental disabilities. And I had to learn how to help people out and how not to. I learned that the hard way when I tried to help somebody put their shirt on and got a hostile response. It is a learning process, and some of the people, especially those who have been on the receiving end of some kind of condescending treatment, can be touchy, which is understandable. That's where I have to know that, if I'm truly helping somebody it's for *their* benefit, not mine. It's not like I'm being especially heroic if I'm helping somebody. And, again, they might not need it. I agree, the communication part is important. That's why I've put myself center stage here in this whole process. Some might think — aren't you totally blowing your chances for being employed by presenting yourself as "here, there's something wrong with me." But on the other hand, my career has already been destroyed, so it's all uphill from here. And, in that sense, that gives me the freedom to be able to present honestly what's happening.

Regarding people having low expectations — I don't think I've ever encountered that in this profession. Usually it's the dead opposite — that you have to be beyond perfect. And that anything that gets in the way of being able to produce prodigiously is seen as a quote "personal issue" and therefore totally irrelevant. And that's where, as I mentioned, I did have a doctoral advisor and post doc advisor who was able to see past my limitations. And anybody who would hire me would need to do the same, since I can't guarantee you physical presence reliably. When I have pain issues, sometimes they hit immediately and I'm down for a couple hours or a couple days. Last night, for example, I was just about to go to some of the receptions, and in the course of five minutes I knew — "I'm not going to go anywhere." Now, to do that in a setting, especially an employment setting where, usually, prospective employers are looking for reasons to reduce the pool, reasons to exclude — there needs to be reasons to include, too.

**NEYBERT:** Adding to what Chris said, in terms of saying that "something's wrong with me" being a reason to not hire you — I've found quite the opposite experience in many cases. In several cases I've gone into interviews, and where my other colleagues are being asked "what is your research" and "what's your alma mater" — things that would matter for teaching positions and things like that — I've found my interviews more along the lines of "how do you light a Bunsen burner?" "Can you stand in a classroom with that many students?" So, it's a balancing game. You want to tell them how you do things — but in interviews, people always tell you that what you're going for is being the one they remember. So, the disability thing can be turned around as a bit of a positive in that, in some instances, it's not a bad thing to announce that you have a disability, as sometimes your employer would much rather know ahead of time rather than find out later and not know how to handle it. Whereas if it comes out ahead of time at the interview there's the potential to be the one that's remembered. Is it risky? Well, you have the potential for ending up answering endless "how do you do this" questions that might not change their minds. However, what might change their minds is catching them off guard; when they say "how do you do this," you might way "why does it matter, just know that I can. And here's my qualifications that show that I can do this based on my past experience." So, sometimes you can point to things you've done before, and you can shatter that stereotype.

**Question from the moderator:** All of you talked about how disabilities allow for unique abilities and the different opportunities that would allow for. Would each of you share one positive aspect and one negative aspect that your disability has allowed for — and highlight that unique ability that you're able to contribute.

**KUDLICK:** As a teacher, this was kind of a terrifying moment. I was just starting to be more open about my vision impairment, and I was teaching a large lecture course in women's history, and I brought a bunch of slides with me. And for some reason I didn't look at them closely enough before I went, and I was putting slides up and I had no idea what they were. It was terrifying; here I've got this whole room full of people waiting and expecting me to illuminate them. So, what I ended up doing is being forthright about my disability, and I said, "okay, talk to me about what's on the screen there." And this room of about 75 people started talking about the slide. And I said, "let's describe what's up there." And somebody said, "well, there's a tree, and I think there's a snake next to it, and a woman is sitting there." And then somebody else said "no, that's not a snake." And pretty soon the class was having a conversation. I knew what the slide was once they started talking about it — and what was great about it was that I knew from the readings they had done for the course that there were certain elements from the reading that they were picking out from the slide, so that I could say "Oh yeah, remember that in the reading there was something about snakes. What did you learn about that? What was its relation to witchcraft?" And what happened in that room was magical because, instead of me being the one who gave them the information that they passively took in, the students were engaged — not just with me but with each other.

And to get back to the point that Ashley was making about knowledge and how it comes to you; knowledge that you arrive at and that you are solidifying — either explaining to someone else or engaging with someone else to prove or disprove something — that knowledge sticks with you. And I knew that when I left that day that my class had learned far more than if I had just stood up there and said "that is a snake and you see it wrapped around a tree. So I'm sure there is a scientific correlate to that — but there was a moment of panic, and then something in me kicked in and allowed me to go to that creative place. And it happened because I couldn't see what was going on.

**WEDLER:** You know, as a blind chemist, I often put up an image at the beginning of talks where I show a very complicated map of, say, Mexico City. And on the map there are streets that run every which way, and commotion and it's very confusing. And when a sighted person looks at it, it looks very confusing. And there are two stars on the map — point A and point B. They're not very close together. And I ask, well, how would you get there. And the paths just don't look clear. But imbedded in all these paths, and all these routes and trails and buildings that go in every direction, there are set streets that are very grid-like that run between them.

So I replace that map with a very clear map. I say, we're going to start at point A. We're going to go due north a half a kilometer on this street, then we go due east, then we cut to get around a building slightly northwest, then we go south, and that's going to take us right to point B. There's five simple steps, with none of the other commotion involved.

And I use this to talk about how I see the world in a very clear way. In fact, when I do chemistry, and the reason that I love organic chemistry so much, is that I use the same skills — the same spatial skills that I use for my survival as a blind traveler.

Sometimes when we look at a big complicated molecule on paper, it's hard to see that two points in the molecule that might be reacting with each other — which in the two dimensional representation are way far apart — are actually quite close in space. So as someone who was born blind, I visualize things around me. I visualize the banquet tables in front of us. I know how to get from here to the elevators to get up to my room. I know how to get from here to the nearest bus stop. These things are visual images in my mind. And why not make distances of meters and feet very small, on the order of angstroms and nanometers, and use the same exact skills to think about how atoms fit together to form molecules? And that's where I feel that one of my advantages is from my blindness.

The biggest disadvantage to being blind is not being able to drive. It's a hassle. Honestly, disability is just a little bit of an inefficiency. And that's an example of an inefficiency.

**POPE:** I mentioned some of the things that are pluses. One is the ability to do things quickly. I am taking a public speaking class, and part of it is critiquing other speakers. There was one essay for that, a bit over 800 words that I wrote in 45 minutes. And when I did the spell check, which I usually have off because it keeps telling me that a lot of the technical terms are wrong, it was perfect. So, there are times — like that Jaguar — when I'm on, I can easily go 90 miles an hour. And this was an asset from before the Lyme disease, but it's also more true now.

There's also the ability to think of problems from a totally different perspective. I'm giving a talk on my research Thursday, and it's about a new kind of group additivity method for estimating properties. And it's something I thought of 20 years ago, but have been carrying through with it. So, I've always had that outsider's detached perspective, seeing things that other people haven't seen before.

Another thing that is an unfortunate necessity is that I've learned to ask for help. I've learned to ask for accommodations. Part of it is financial. I've had to learn that for survival. Fortunately, I'm in a metastable state, usually, where I'm not having to worry about whether I am going to be able to eat at the end of the month, but instead about resources, which are quite limited — especially for attending events like this.

The limitations I have — with the chronic pain issues that can hit unpredictably, it's hard for me to really commit to be somewhere. I still use an old paper calendar, and it's full of cross-outs, many times of things I wanted to do or actually had committed to do that I missed, or that have been extended. And that's something I really hate. The thing with that is, I'm able to make it to what is the most important thing — like here. I knew I was going to be here today. There are ways to push back, against stress and my body's reaction to it. I can't handle overwhelming stress, and the worst thing about that is when I feel I am alone. Which in many ways I am, professionally. I'm not associated with any institution or anything. So what it comes down to is doing a lot, and then sometimes having to recover from it. Where, if you're looking for a vehicle that can reliably go 40 miles an hour all the time, that's not me. But I've also been able to have some pretty impressive successes too, even with my cognitive and physical limitations. And in my case the two are strongly coupled, because of the neurological damage from the Lyme.

**JOHNSTON:** A disappointment associated with having a speech disability — in my research center I set my sights on being the director someday. And it seems like the general trend historically has been that the most successful researchers had the opportunity to move into that position. And I was clearly that in my center. And to increase my chances even further I went to night school and earned an MBA and kicked butt, and figured — I'm competitive here. And I applied for the job and didn't get it. And I found out from some colleagues who were on the inside that there was a perception among some people on the selection committee that someone who stutters really can't be the director, the outward face of an organization. And such is life, I guess. Life goes on and because of that I left the center, and I'm in an even better place now, and probably making more money than I would have as the director. So, you never know what's going to happen. You have to roll with the punches.

Something else I've thought about recently as an advantage —I talked about the unique abilities that I've developed because of my speech impediment, the coping mechanisms that have an up-side. And then there are the unique abilities that I think are associated with the multiple phenotypes of the genotype that leads to your disability. Just like every personality has a positive and a negative side. Or, you look at a certain breed of dog and they look a certain way and they tend to have behaviors that you expect for that breed. And so — I am musician. I don't make enough money at it to support my family, but it is a successful undertaking. I'm a blues musician. My recent CD was named best blues CD by two state blues

societies. And in my historical readings about bluesmen, I've discovered that some of the greatest blues players — Muddy Waters, John Lee Hooker, B. B. King, Sonny Boy Williamson — they all stuttered. And so, I wonder maybe if there's a phenotype associated with my genotype in addition to stuttering that gives me an advantage as a blues musician. Who knows?

**NEYBERT:** My disadvantage is — with the Asperger's syndrome — a quality trait seems to be taking things in a very different manner than most people would. So, for instance, when I was younger I got a card for a national parks pass. And on the back of the card it said, "this card is awarded to a person determined to have a medical disability for life." 99% of the population would read that as "a doctor determined that this person has a medical disability and it's not going away." But my reaction to reading that sentence was — "I am NOT determined to keep this disability, and if anybody would like to take it from me, please do." So, that trait has put me in some interesting situations, because sometimes I won't read or understand right what someone is telling me, and then answer a completely different question. So, that's a disadvantage I'm still working at.

One of the advantages of that, as well as the advantages of being blind, is it causes you to think even more differently. So that can be an advantage for me in that, when I run a laboratory classroom I have students announce "I have a beaker of sulfuric acid and I'm going to walk behind you," and they have to continue repeating that until they get to wherever it is they're going in the lab. And that has made labs run by me more safe than other labs — because I'm not the only one who might not be seeing. Someone who's sighted might space out or be focused on their work and take a step back and not realize that someone is behind them. Not only that, it eliminates the safety concern of, if that beaker does spill, I know exactly what was in it. I don't have to worry adding something to the spill that could make it worse. I know what spilled and where it was when it happened. So, that's made laboratories safer and better, and it's an advantage for me.

**BYERS:** I think that folks involved in chemical process safety could take a lesson from Ashley's comment. It made me think that if chemical processes were operated in a way where people who had certain disabilities were able to operate that plant well, the plant would be safer.

I enjoy golf. I was never very good at it, and the injury played hell with that. So, I'm even worse but I like to once in a while get out to the golf course. And I like to hike in the wilderness, and I do that less and for shorter distances. So, it's had some impact. But I've learned not to try to do everything myself. So, I'm a better teammate. It would have been in prior years that, given an assignment, I would work for the next 16 hours straight until I got it done. Now, I will work with others and I will say that, sure, I can do that, but I need these people to do this part of it. And to accept help — I've learned that when someone offers to help me, it may actually make them feel good to help me. And for me to prove my independence by rejecting their help is to actually give them the cold shoulder. So, I'm more open to being helped, and don't feel like I need to be this island and this rock and this independent entity that I would have tried to be before.

**POPE:** I applied for faculty positions for about seven years straight after getting my doctorate. I sent applications to about 2/3 of the schools in the U.S. that have chemical engineering, and had some interviews in England — and the single biggest reason that I was told I didn't get the job was that I wasn't dynamic and forceful enough. Usually the person telling me that wasn't exactly Harrison Ford either. But it leads me to note that, especially in this culture, both speed and dominance are very highly valued — possibly overly valued. The best creative insights that led to my work were not done in that way. Granted, like most of the ideas for my doctoral thesis — basically about a chemical mechanism for describing fullerenes formation in flames — about 90% of that mechanism came to me one Thursday night after dinner. And then the rest of it took two years to put into action. So there is a place for work and persistence. But just the idea that the kind of person who would be a successful executive, for example —

you don't want a team full of people like that. And that's where you're talking about permanent disability, and having something for life.

One of the things that AIChE does, if you've been a member for ten years, you can get a national dues waiver for disability. There are two categories. The first is for two years, called temporary disability. And then after that they call it a permanent disability. And I resisted saying that I was permanently disabled. But a friend of mine actually talked to someone in the national office about getting me on permanent disability status. So, that nomenclature might require revisiting. Maybe call it long-term disability, because, as my being here shows, whether I have these conditions for life or not, I don't plan to be disabled for life.

**Audience question**: [Regarding the concept of independence]

# **KUDLICK**:

I don't believe in independence. I think it's fake, it's unrealistic, it's an impossible ideal that's created in American history — and even the so-called glory days of independence are nonexistent. And I think independence with respect to disability is even more of a fallacy.

I want to give you an example of a job description, and you tell me where independence is here. I found a job application — they're looking for somebody that can run errands, drive you places, feed you when you need to be fed, buy presents, run out and get you stuff at the store, take notes for you ... Think about that job description. What is that job description for? If you frame it one way, it's a job description for an assistant for someone with a disability. An attendant how will help them and take care of some basic things. Framed another way, it can be an executive assistant for a CEO. Neither is independent. The biggest, toughest, highest achiever on the ladder of success is not independent at all. And the rest of us are scurrying around at the bottom, pretending we're independent when we're not. We need each other. We're a society that is really interdependent. And that's the word I would like to stress in relation to disability, in relation to scholarship. When you write a scholarly article with six co-authors, that's an interdependent relationship. Somebody brings this to the table, somebody else brings that. And you're enhancing each others' knowledge. Thinking "I'm going to do this by myself, and I'm going to be proving something" is not a healthy model. And it's not a very interesting or intellectually engaging model. I would much rather be thinking in terms of interdependence and getting feedback and ideas from others.

**POPE:** Independence really is a myth. As a postdoc, I wrote parts of three grant proposals for my advisor, and one of the biggest things that funders look for is the resources you have and the institution you're affiliated with. So right away they're not assuming that you're an artisan, doing the work on your own. And personally, while it can be useful for me to do things for myself, I can't do everything for myself. And this myth of independence can lead to isolation, especially in this society. Americans spend more time alone than do people in any other culture in the world. And I think that's quite unfortunate. So I agree that interdependence needs to be balanced with independence. It's really a yin and yang sort of thing. And in a culture that appreciates the yang a bit too much, there needs to be some change in vision.

**NEYBERT:** I have to disagree a little bit on the aspect of independence, but that's also because my definition of independence is different. When I think of independence, it's not about being able to do everything by myself, it's about achieving what I can while operate at the highest efficiency. And so, being independent might include my having an assistant so I can do things faster. But I'm still doing things independently because underneath it, it's still me understanding that I could do this myself, even if it takes a long time, or I could delegate and make things faster. So, for me, independence can be a reality.

However, I see independence as doing whatever it takes to realize and understand how you can operate at your highest efficiency, not based upon reliance of others.

**Audience question:** [on different approaches to achievement and alternate abilities among disabled people]

**POPE:** Each person has his or her set of resources available, and that's where the difference lies. We have the term co-dependence — a term which is probably overused — but basically it means relying on other people to do things for you that you can do for yourself. And that's where its best, for me, to recognize my capabilities but also recognize that I have limitations. Which, in and of itself, doesn't mean that I'm disabled but makes me human. I'm a mere mortal.

We were talking about 3-D visualization — I've had that gift, perhaps from my mom, who's an artist. And it was something where I did not need to use a molecular model through organic chemistry — not until a few years later into grad school, where we were talking about shapes of fullerenes. So that was a gift I was blessed with. On the other hand, there are mental things that I'm not quite so good at. But I was good enough to get where I got to, and hopefully a lot farther.

**NEYBERT:** If the question is whether one approach is better than another, as an independent variable instead of being dependent on other things, I'd have to say it totally depends on the scenario. For instance, when I was losing more and more of my sight, there was a point when I was in this awkward halfway world between seeing and non-seeing. And it was an advantage to be able to use my sight to be able to identify a Starbucks coffee sign or a Walmart sign. However, it was a disadvantage if I was trying to walk without a cane, and was staring intently at my feet so I didn't trip on curbs. And so, you have to be able to assess the specific situation and go from there to figure out what is the best approach.

#### Additional and closing comments:

**POPE:** One thought I had was why not get a grant to study this? That's not a joke. It's a real possibility that we could get outside funding to aid the disabilities initiative. And since AIChE will be the first engineering professional society to have gone this far in awareness of our members with disability, it would be good to take care of other resources, ones that I know nothing about yet. I suspect, Professor Kudlick, you might know more about what's available.

**BYERS:** There is a foundation of the engineering founder societies, and that would be an interesting thing to apply to them to study.

# WEDLER:

If we don't have a certain ability, then it's hard to imagine what it would be like to have it. For me, color—since I've never seen it—is very much something I imagine scientifically. Green light is around 500 nm electromagnetic radiation—that's the best frame in which I can think about it and perceive it. It's really nothing more than that. But, as a blind person who's fascinated with optics and color, I've learned a lot of the theory of color, and appreciated it. And when I visualize things, it's not like I'm making up how they look. They're more just entities in my mind. A lot of people think blind people spend time imagining what people's faces look like. I really don't. It's not a big thing for me to focus on. On the flip side of that, art, and things that are very nicely put together, is at least equally impressive to us. Especially tactile things. I love, for instance, feeling the intricacies of different shells and how they fit together, and thinking about the nature or bizarre intersection between art and science.

I like to say, in my sensory work, that sight is sort of a first-response sense. But to another extent, I believe everyone in this room, no matter what senses you have or don't have, needs to be sensory literate. A lot of people are visually literate. Something comes into our mind and we see something and we know what to do. And we can thoughtfully process that information. When you're driving and you see a red light, you'd better know to stop, for instance. You see a picture of a cat, and you know it's a furry thing that sometimes scratches and goes meow, and you know that's a cat. Now, with our other senses — touch, audio hearing, smell or taste — I feel that we should also be aware of the data coming into our mind from those senses, just the same as we are with visual data. And the answer here that I'm giving you is trying to put into perspective the way you see the world versus the way that we can all see the world through all of our senses.

**POPE:** We are always learning. We are always strengthening our abilities in different ways. And for me, learning to be a community organizer and a leader is totally new to me. As I mentioned, I'm a recovering wallflower.

But then, just so far as asking what exactly is a thing — I'm reminded of Jacques de Vaucanson, an 18th century French inventor who made a mechanical duck. And there's that saying that goes, "if it walks like a duck, and talks like a duck, and looks like a duck, then it's certainly a duck." But I ask — what if the duck can't walk? What if someone can't see to tell what the duck looks like? Or what if the duck can't talk? And along those lines, we need to redefine what constitutes being a person.

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