



Meeting of the Minds

Two doctors, one the Director of a center and the other an addictionologist, met serendipitously years ago through a mutual acquaintance. Diane Wiener, PhD, LMSW, and Ericha Scott, PhD, were introduced through independent encounters with Ramona Johnson, a retired nurse and world traveler. Dr. Wiener met Johnson on a plane; Dr. Scott met Johnson in an airport shuttle. Then, the magical thing happened: Johnson said to Scott, “I have met someone I think you should meet,” and handed Scott an article written by Wiener, published in 1998 in *The Arts in Psychotherapy*. Scott laughed at the synchronicity, telling her, “I am writing an article for this very same journal, right now.” Eventually the two future doctors met. Scott referenced Wiener’s work in her article; the two articles were published exactly a year apart. They’ve been friends and colleagues ever since, and for a period of time worked together as faculty for Prescott College’s Tucson Center.

Today, Wiener is Director of the Disability Cultural Center at Syracuse University (SU), which is the first of its kind in the US to be housed within Student Affairs instead of Disability Services. She is also a Research Associate Professor in SU’s Department of Cultural Foundations of Education. She teaches Disability Studies and has published widely on subjects related to diversity, social justice, inclusion and empowerment. Scott, who is also an author and artist, interviewed Wiener via Skype on her seminal role as SU’s director of the Disability Cultural Center (DCC), on what disability means and why it matters to all of us.

Dr. Ericha Scott: Welcome, Diane! It’s so good to see you. To begin, what thrilled me personally when I heard that you had been hired for your role as the Director of the DCC at Syracuse is how perfectly matched the center’s goals are with your personal values, your vision of the world, and your dreams. I think very few of us make such a perfect match between career and our personal

and professional goals. How do you see that?

Dr. Diane Wiener: I appreciate what you just said. You’ve known me a long time, so your comments mean a great deal to me. I hasten to say without egotism that I agree with you. I just wrapped up with all of my colleagues and with many people what I would consider to have been a very productive and meaningful series of events for Disability Awareness Month, which as you may know is October.

As is the case with Earth Day, which is every day, not just in April when it’s designated, Disability Awareness Month is every month at Syracuse University, as I hope it should be, everywhere. But in October, we have more attention paid to it because of the structures that are in place. We had an incredibly complicated, nuanced, and painfully obvious set of interactions around why disability matters, as some of the undergraduates might put it. It’s hard for me to explicate how meaningful it is to me. I feel honored, privileged, and deep gratitude about it. As you know, I’m the only person in the world in this role. I think it is a rare, complex gift.

Scott: We are facilitating this interview with you because you are the director of the DCC at Syracuse and also because your role and work are a good match for ABILITY Magazine. We all have our assumptions about what “disability” means. Some of us have disabilities, some of us don’t; many of us will develop a disability as we age. We’re all on a continuum, even those of us who have disabilities at this moment. How would you define the meaning of “disability”?

Wiener: I think disability is best defined as an interaction between a person’s physical, mental, intellectual, emotional, psychological, possibly spiritual and other experiences with their environment that may not always be an easy interaction, largely because of the environment’s structures. I know that certain disabilities



have a component that's individualized and individualistic, and arguably all disabilities are specific to each person. So even if I could name 76,000 people who have cerebral palsy (CP), each of those individuals would have a unique experience of CP.

Nevertheless, I think these interactions are interdependent between the individual and the space. So while I can define "disability" in part by what it isn't, I also can try to define it in terms of what it is. That is my short answer.

The things that are described as impairments are disabling only insofar as the environment is not designed in such a way to anticipate and expect and welcome an array of people from diverse emotional, psychological, cognitive, physical, and other kinds of points-of-view and backgrounds. Even if environments are designed with the greatest array of human experiences and conditions imagined, they can never be completely inclusive because we may not be able to imagine the totality of human experience. But in imagining a world in which we have the greatest variety of human experiences in mind, as we design spaces, that makes it less likely that people will experience what is called a disability.

When individuals, including myself, are interacting with our environments, including you and your interaction with your environments, those with disabilities will find ways to participate (not be undermined), because disability should not have to do with being undermined. Disability can and often does have to do with an identity, as a location of pride, like any number of other expressions of human diversity that are not always easy.

So, for example, we live in a racist world, but people might nevertheless insistently feel pride in being identified as individuals of color. We live in a misogynist world, and individuals might nevertheless necessarily and assertively be proud of being gendered female. And we live in a world that's anti-Semitic and Islamophobic and frequently oppressive to many other groups of people who are seen as so-called "Others." And who is the norm against which those people are being imagined? I don't know who those people are, but I don't hang out with most of those quote-unquote "normal" people. Ha!

Scott: (laughter)

Wiener: Disability is the interaction between the individual and the environment when the individual's so-called impairments are not always able to be experienced or negotiated comfortably, because the environment may not be very welcoming, or the so-called impairments are able to be experienced or negotiated comfortably. Stephen Kuusisto, often with patience and perhaps with some challenges—because the environment and the people within it are not disabling.

Scott: I'm thinking of a book Lyall Watson wrote about a young man from South Africa who had epilepsy (Lightning

Bird: The Story of One Man's Journey into Africa's Past, 1983). *He walked into the bush as a young man and was welcomed, rather than scorned, into an indigenous tribe as a healer. His epilepsy, for them, rather than being perceived as an illness or a disability, was in fact considered to be the mark of a medicine man. His story was verified because the tribal elders gave him several rare, ancient artifacts in order to provide evidence that his reported experience was true. He brought these artifacts back to his contemporary culture and used them to help tell how his epilepsy was revered rather than used as a way to misperceive him as weak or something different than how he perceived himself. He came back to his own society of birth empowered. That story may fit into what you've discussed about contextualizing disabilities.*

Wiener: I think it does. In many ways you're highlighting what is sometimes called the sociocultural model of disability. There are many models of disability, and there are also different models in different countries. Some of the countries I'm thinking of don't necessarily use the word "model," but there are different conceptual frameworks that may be used in different spaces. Notions of disability, like many other social identities, are not transhistorical and not culturally universal, as you're describing. I agree very strongly.

In a similar way, I think what often happens is that people with so-called mental illnesses have been seen as very creative, very spiritual, and as amplified in their wisdom in some way. And while I respect that point-of-view, I also worry that that set of perspectives, at least some of the time, makes it seem as if people with deep depression are managing some spiritual enlightenment, when in fact those individuals are often imperiled as well. One of the points I often emphasize, which pisses off some people, is that I'd rather Van Gogh had lived. I'm sorry that some people seem to think the paintings are more important than his life. My understanding is that his life was very devastating to him oftentimes, and that if he had received a certain kind of emotional attention beyond his profoundly complicated conversations with his brother Theo, who loved him dearly, he might not have had a violent and tragic death, apparently by suicide.

The same could be true of other artists with very profound mental health concerns. So I'm not delighted by what is sometimes a romanticization of certain disability identities, which makes ahistorical the suffering that those individuals endured.

It does sometimes happen that someone with a disability is welcomed and feels safe even in some space where it might not be easy if they were somewhere else, but I'm cautioning against the expectation that we should be delighted by the link that allegedly exists between creativity and what is sometimes referred to as "madness." I remember many years ago when you talked with me on your cable television program about this topic. The



main point is that for me, right now, disability is contextual, it's culturally specific, it also varies from person to person and family to family and environment to environment. It's not like one culture has one monolithic view of disabilities.

Scott: Disability can also be idiosyncratic and variable within one individual, within short periods of time, and of course, over the entire life span. Those differentials of perception and experience may vary as the disability varies, social context changes, and/or as a person's self-perception of those disabilities changes, regardless of whether there are emotional, intellectual, or physical changes.

Wiener: Agreed. There are a number of examples. Some people in the Deaf rights movement might argue that cochlear implants are designed by the medical establishment's protagonists to eradicate the linguistic and cultural identity of Deaf community members. But simultaneously there are many people in the Deaf community who have elected to get a cochlear implant and think of it as a tool. Professor Wendy Harbour, a friend of mine, has a blog in which she talks about this topic very candidly: "Wendy's World." One perspective is that d/Deaf people who get cochlear implants are becoming like hearing people. They're not hearing people; they are d/Deaf people with cochlear implants. They're not erasing their deafness, they're utilizing another approach. I'm sure there are a variety of opinions within the Deaf rights movement about this, and some people may think that my friend Wendy is a sell-out for getting the surgery.

There are lots of different cultural issues, contextual issues, temporal issues, and there's variety even in one particular culture across individual perspectives as well.

Scott: From what you're saying, it sounds as if denial and shame can manifest on either side of the continuum.

Wiener: Yes, and I think there are a significant number of people who have a great amount of pride but also are tired of being perceived oftentimes as a triumph narrative. Harilyn Rousso's memoir, *Don't Call Me Inspirational: A Disabled Feminist Talks Back* (2013) addresses this subject.

Scott: (chuckles)

Wiener: What I'm talking about is countering that "overcoming discourse" that many disability rights activists who study media in particular have highlighted as happening in so many Hollywood movies. One of the most famous examples, of course, being *My Left Foot* with Daniel Day-Lewis. It's all about the person with the disability being there to help everybody else feel inspired, when the person's life is not about inspiring other people or overcoming their alleged adversity in order to be triumphant. The counter-discourse to the triumph narrative reminds me of other social justice illustrations provided by disenfranchised people talking

back to our oppressors. For example, in the civil rights movement and the anti-racist movements, many activists have highlighted famously, "I'm not here to help you white people learn about my life. Why don't you do some research and think about the oppression that you participate in causing, still?"

This is all quite complicated, because it isn't appropriate for people who are not members of disenfranchised groups to speak for other people. It's also not appropriate, in my opinion, for people in disenfranchised groups to think that they ought to be seen as representative of a group, when their own opinion is their opinion and not necessarily a collective opinion. Yet, people are not only put into tokenizing positions, some may choose to self-tokenize, and others may want to speak for other people. It's a tricky business.

Scott: Agreed. How do you navigate it? You're in the center of all that.

Wiener: I was recently asked to nominate myself for an award. One of the criteria for this award is that the nominee has to self-identify as a person with a disability. I don't always identify as a person with a disability. I identify sometimes as emotionally disabled. I've increasingly come out to the undergraduates as "crazy." I've used the word with my tongue in my cheek as a critical insider. You know that for many years I eschewed that word, and I've recently come to use it in a disability-prideful way, but I'm using it as an insider, as I use the word "dyke" as an insider. Calling myself a "dyke" is different than someone yelling at someone out the open window of a moving car, "Hey, you dyke!" An insider reclaiming a word, using the word "queer," the word "mad," the word "crip" or any of these other words that are allegedly able to be reclaimed, is rather different from someone else using it as an admonishment of me or as an attack against people in a group of which I'm a member.

So should I nominate myself for this award? I can't let anyone else nominate me because the procedures require that you nominate yourself. First of all, I don't suffer from hubris, and I don't love the idea of nominating myself for something. I also feel conflicted about the ethical implications of saying that I'm disabled or that I'm a person with a disability when I do in fact use the word "intermittent." So, I was talking about this issue with a few mentors of mine, and they said, "This isn't about you. It's about the students."

Scott: (chuckles)

Wiener: The students said the same thing, because we were discussing it, and because a number of the students had been talking about this idea in a loving way behind my back, as they'd been plotting to recommend me for this award and wanted me to nominate myself. So, some of the people with whom I talked about this informally,



whose idea it was (it was the students), also brought to my attention that I should do this for them. (*laughs*)

Scott: Wow!

Wiener: Again, what are the ethical implications of calling myself a person with a disability when I identify that way sometimes, but not 24/7? So going back to this inspirational thing—I think it’s very important to imagine, like with all identities, that this is not one thing when we talk about disability. It’s important to talk about the intersections that exist between and across social and cultural identities—disability in relation to identities connected with race, class, political affiliation, ethnicity, sexual orientation, gender expression, religion or its absence, age, size, veteran’s status, health status, country-of-origin, etc., in addition to not simplifying often marginalized identities as being about overcoming or about feeling pride always. I don’t know anyone who’s happy 24/7. If anyone does know such a person, I’d like to meet them. I think that includes the people with disabilities who are not happy 24/7. So rather than saying that people with disabilities are struggling and look at the inspirational overcoming triumph of their life as a modicum of joy for all of us to follow, yay, I’m unhappy sometimes, people without disabilities are unhappy sometimes. I’m glad I’m inspiring, but I’m not doing it for inspirational purposes.

Scott: What I think is important is your interest in and dedication to supporting Mad Pride and combating what you refer to as “mentalism.” Could you elaborate on that?

Wiener: Sure. A number of years ago, Rebecca Ribeiro, Kurt Warner and I wrote an article that was published in *Disability & Society*. There was a special issue about *Brave New World* by Aldous Huxley. We speak explicitly in the essay about Huxley’s work, and we also highlight the movie *Gattaca*, a 1997 science fiction film by Andrew Niccol about genetic discrimination. We talk about the complicated and sometimes uneasy relationship between disability rights and the anti-psychiatric rights movements.

The word “mentalism” is used in the title of that essay to emphasize the ways in which certain states of mind are seen as normative, and that states of mind (again, using culturally-specific definitions) that exceed or don’t match up with, that are too long-term, short-term or temporary in all the ways that they are those ways, if they don’t match up with what’s seen as quote-unquote “normal,” that’s a form of oppression. Because people with those states of mind, including myself, are seen as “crazy” and are often perceived to be experienced by people in a mainstream context as needing psychiatric intervention.

The only reason I’ve never been locked up is because I haven’t said certain things to certain people at certain

times, and if I had I would have assuredly been repeatedly locked up. Now, I’m in no way suggesting that people who have managed to try not to be locked up but still are less important than I, or weaker than I, or less clever. And I’m also not saying that people who needed to be psychiatrically assisted ought not to have received that assistance. Another thing about this mentalism discourse is that some people have misapprehended my position as being against medication, medicine and biologization of any kind. If I thought a pill would help me, I sure as hell would take it. If I really thought that I was at risk to kill myself, I would want help, I imagine.

If somebody chooses to have therapeutic intervention that other people think is not okay, that goes back to this notion about the choice about one’s own body. There’s often an uneasy relationship between the disability rights movement’s members and the pro-choice movement’s members, because there’s a wish by some to eradicate any kind of difference. For example, some people think we need to not have women over 40 being at risk of having babies with Down syndrome because we don’t want more people in the world with intellectual disabilities. That’s an oppressive, violent point-of-view, in my opinion.

Simultaneously, if a person wants to have an abortion because their baby is going to be born with Down syndrome, I ought not to be telling them what to do and neither should the government, but I do think (and this is one of the ways in which my politics as a die-hard feminist are challenged, because I’m a disability rights activist) it would be immoral for a woman to abort a fetus because it was probably going to be born with Down syndrome. I think that would be reprehensible, and yet it’s her body, not mine. So it’s complicated. The “Ashley X” story, as described recently at the bioethics and disability rights event that we hosted at Syracuse University, highlights many of these subjects around the rights of people with disabilities that are often disrupted and violated by family members, medical practitioners, etc. The complete title of the event was “Disabilities as Ways of Knowing: A Series of Creative Writing Conversations, Part Three: Lives Worth Living.” The event, featuring William Peace and Stephen Kuusisto, was video-recorded, and a captioned video will soon be available on the DCC’s YouTube channel.

So I don’t think mentalism is all that different from other forms of ableism—the idea that children with disabilities are a burden on our society, that adults with disabilities are wasting money that could be spent on other purposes, that disabled people are sucking the life out of the mainstream cultural minds because we shouldn’t be preserving “their” right to have access to education and employment, because “they” don’t really learn anyway and can’t ever be truly productive members of society. Mentalism is a kind of ableism that highlights the psychological, emotional, and cognitive elements of ableism. Because oftentimes ableism focuses on a disability that’s physical



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and visible, and I would argue, which might offend some people, that even in the disability rights movement—this is not original, but I do agree with this point of view—there’s a hierarchy of disability narratives, and the people with emotional, psychiatric (or labeled as psychiatric), cognitive and intellectual (or so-called “developmental”) disabilities are at the bottom of this hierarchy, while people with visible physical disabilities are at the top of the hierarchy.

When you adopt a cross-disabilities perspective, but you want to make sure that you’re highlighting invisible disabilities that are physical, and mental health complexities and emotional variances that are often invisible, the word “mentalism” helps us do that. The oppression against people whose states of mind are not deemed normative is an oppressive act that is no less important in our analysis and struggle for justice than the discrimination against people with disabilities who can’t access a building because the stairs (and the absence of a ramp) don’t make it possible for them to access the building.

Scott: This discussion is an important one for war veterans who are returning home with multiple injuries and often a diagnosis of post-traumatic stress disorder. This dialogue could, interestingly enough, integrate very diverse people from diverse groups. Also, I’m thinking about an experience I had as a person who is now wearing two hearing aids. I wrote to you about this recently, when I was part of a training seminar as a participant, not the teacher or trainer. I signed up for the second seminar in a series with no concerns that hearing would be a problem with my hearing aids—because for the first seminar they had people (trainers and participants) speak from a microphone. Apparently, for the second seminar, unbeknownst to me, the group leaders felt it was advantageous to have participants speak up out loud as a way to encourage self-assertiveness. I asked if we could have a microphone because I was missing probably 30% of the dialogue. I was asked to have the group vote for my request, and the group voted yes to additional microphones. So the leaders brought in two microphones, but at each break they kept moving the microphones out of reach, which was a little surprising to me. Historically, I don’t think of myself as someone who has overtly run into issues with regard to my own disability. Granted, I’ve had a hearing loss my whole lifetime, but possibly my own denial, my family’s denial, whoever’s, but in some way I was insulated from overt public self-identification as a disabled person. But I really felt it in this event, and I owned it, not because I want to identify that way, but as a pathway to gain understanding and empathy for other people who have disabilities and who deal with discrimination on a daily basis. The power of the slight and neglect was riveting to me. Even though I kept bringing the issue of the microphones back to the attention of those in charge, there were many reasons, excuses, and justifications, some of them valid, for why they were not using the microphones, even after the

group had elected to bring them to the seminar.

What I realized is how common this mentality can be. Is this part of what you’re saying when you talk about mentalism?

Wiener: First of all, I am aggrieved that happened to you, but I’m also not surprised. I think the complexity of what you’re highlighting relates to a concept a lot of people call “universal design.” If we create situations with the broadest possible array of people’s experiences in mind, although we can never meet everyone’s needs simultaneously, we still will have competing needs that exist. One person wants a mic, another person finds the mic disruptive because they’re sensitive to noise. Someone wants to do group work; another person thinks group work sucks. People want to use techniques that are kinesthetic; other people are auditory learners. People who need to have audio captioning for a video will find that people in the same room with them are feeling undermined by the audio captioning.

Nevertheless, I think some experiences are not just about opinions and perspectives, they’re requirements. You need to have captions on a video because you can’t hear the video, and someone’s going to say, “Your captions are messing with my concentration,” and that’s really an exclusion of people. That’s not just some point-of-view compromised. So universal design is always imperfect, but there are certain aspects of universal design that I think are minimal and basic and ought to be practiced. One of those is honoring people’s different learning styles with the acknowledgment that not everything can always be perfect for everyone, that people ought to have videos that are captioned, documents ought to be screen reader-accessible, a microphone should be available. If someone’s overstimulated by noise by virtue of a microphone, they can excuse themselves. They might feel that they’re being excluded from the conversation. It’s a complicated situation, and people who cannot hear and cannot see and cannot access spaces physically and have a need not to be endlessly overstimulated because of negotiations of Autistic identity, they, we, need to find ways to work things out with each other.

I think that Communication Access Realtime Translation (CART) is one of the things that could have been utilized to help in that situation—so that there’s live captioning underneath or next to what’s being spoken. People who are visual learners, with or without learning disabilities, people for whom English is not a native language, people who are d/Deaf but who don’t use American Sign Language (or who just prefer CART), people with hearing challenges who might identify as disabled, or who sometimes identify as disabled, etc., can all use CART. So, maybe you and I need to start an intermittently disabled self-identifier club.

Scott: I like it.



Wiener: I'm not ashamed; it's just that I don't always identify that way. CART (sometimes also called Computer Aided Realtime Translation) is expensive, but it's a civil rights issue. I have used CART. I don't have a learning disability, I'm not Deaf, and if I were Deaf, I am already fluent in American Sign Language (ASL). I have a story about using ASL as a hearing person, which I'll share shortly.

So...mentalism is discrimination against people whose mental, emotional, and psychological states of being are perceived to be outside of the norm of mainstream society.

Scott: Well done. Clear. Thank you.

Wiener: Recently, I was physically ill and am still having multiple medical complications. On Facebook, I came out as having a mysterious and invisible ailment of a physical nature. My voice was so shot that I was beginning to identify as having a short-term vocal disability. Because I'm fluent in ASL, and because I didn't want to have to work with an augmentative communication device when I have other options, I arranged with the university, for the two weeks that I was really in trouble, to have sign language-to-voice interpretation services when I was going to be in a big meeting.

I therefore, being hearing, was signing during these meetings and had sign language interpreters voicing for me, as they would for someone who is d/Deaf. (Note: Not all d/Deaf people know or use ASL; some d/Deaf people voice for themselves.)

I had a first-hand experience the likes of which I've never had in my life, even though I've signed for 30 years and I've been part of the Deaf rights movement for 30-plus years. I actually had an insider glimpse into what it was like to have hearing people dominate a conversation to such a degree, that I had to feel like I was interrupting to get my point across because I couldn't use my speaking voice. I was raising my hand and signing, "I want to say something, I want to say something!" and the interpreter's voicing for me, "I'd like to say something, I'd like to say something." And even my most clued-in, activist, social justice-oriented colleagues at some of these meetings didn't realize that that's what they were doing—talking over me, and not sharing the floor.

Scott: That's powerful. Thank you! What is a typical day like for you as a director? Also, since I know people are trying to replicate your program across the world, please tell us about that.

Wiener: A day in the life of what I do is difficult to describe, but sometimes, for example, I'll receive a call from a parent whose son is Autistic and who wants to know if there are places where their son could feel welcomed at the university. I would tell them about the ways

in which I do not provide accommodations, but I'm glad to help refer them to the Disability Services office. If their son wants to hang out and come to the Disability Student Union (DSU), which is a new undergraduate organization, for which I'm proudly the advisor, that individual would be welcome to come even if the son didn't identify as Autistic, because the students who are in the DSU are students with and without disabilities.

The DCC is strongly connected with the Autistic Self Advocacy Network, which takes as its premise the notion that autism is a cultural identity—that there is an Autistic culture, if not more than one. Many individuals involved with the Autistic Pride movement, of which the Autistic Self Advocacy Network (ASAN) is an illustrative example, often think of Autistic culture and Autistic pride as parts of the fabric of what's referred to as neurodiversity. So, I'm supposedly neurotypical. I'm allegedly an "NT," a neurotypical (not Autistic) person, but, if I was Autistic (thus, neuroatypical), I might just call myself Autistic. As in, "I'm an Autistic person," or "I'm an Autistic," not "I have Autism." Again, language choices are not unilateral or monolithic. Lots of people don't like that language, use other language, or have different points-of-view.

SU's DCC has a language guide that was written by the first DCC Graduate Assistant, Alex Umstead, in consultation with me, and is called "An Introductory Guide to Disability Language and Empowerment:" (Note: This guide includes content on the ways capitalization is often used to express identity and pride, as happens throughout this published interview.)

Within the first five months of being at SU I was asked, "Diane, are you Autistic? Are you on the spectrum?" I was amazed. I'd never been asked that before. And one of my colleagues, whose child is Autistic, and I were talking about this, and she said, "Well, you know, it's a compliment." And I thought, "You know what? You're right." I discussed these experiences with Alex (Umstead), who happens to be Autistic. Alex promptly went online and found a rainbow-colored infinity graphic, connected with a neurodiversity site. The rainbow infinity sign (a horizontal figure eight) is a symbol of the neurodiversity movement. He added text and designed an infographic (information graphic) for the DCC. The image is on the DCC Facebook page. We would love for the infographic to go viral. It says: "No, I'm not Autistic, but thanks for the compliment."

Another thing that might happen in my day is that I'm in a meeting where people are asking me why we should have sign language interpretation at an event. Should people have to request an accommodation? Should there be a sign language interpreter, just in case, if it's an event that is open to the public, so that people who are Deaf and are ASL users could just show up and be welcomed, instead of having to identify themselves and say, "I'm Deaf and I need an interpreter"? Sign language



interpreting services are expensive. Discussions about that, people’s opinions about that, civil liberty issues around that, I’m sometimes in the middle of those conversations.

In the course of one day, I could meet with an undergraduate who has never before realized that there might be an array of experiences that are connected with what it means to identify as having multiple sclerosis or muscular dystrophy or an Autistic identity or a so-called psychiatric illness, and the student is sitting there asking me questions because they have a paper due for school and they want to talk about this stuff. So they’re interviewing me, as often happens, and they want me to tell them about what it’s like to be disabled, and we wind up talking about spectral issues. Or, we talk about diversity within disability movements. And, sometimes, they’ve never thought that being disabled could be something someone would be happy about. I watch the student’s head light up like a bulb and this “Holy shit!” moment a 19-year-old has in my office.

Or, I might have an experience where I have someone from another university call me up and tell me the latest on the Center that they helped to create, which is modeled in some ways on our Center. They’re hoping that their Center will some day get approval to hire professional staff, because we have professional staff, and they want staff too. The DCC at SU was the first—and remains the only Center of its kind in the world—to have a full-time professional director. We are no longer the only one housed in Student Affairs, as there are now other Centers like ours that have been and are being established in Student Affairs.

So, my advice for people who want to do this is that the students should lead, but they shouldn’t be burdened with doing all the work. Students, administrators, faculty, staff, community members, including alumni, should work in collaboration to identify supports, constituents, etc. Is there a Deaf Studies program at the university? Is there a Disability Studies program at the university? Are there people committed to issues of multiculturalism and diversity? Are there people who are dedicated to social justice and anti-oppressive values? Those people are your allies. Go see them or interact with them in some other way. Maybe you’re not sighted, but you’re still going to see them, symbolically, some might say.

Have interactions with people and foment. Think about budgetary implications. Maybe you have a small space. I have a small space. What I tell people when they visit, and they want to experience our extremely accessible, paradigmatically inclusive furniture, multiple-level-hung coat hooks, every single thing in that office—the lighting, the hypoallergenic furniture, the dimmers, all of that—people want to experience. They say, “Oh, this is cool.” Architects come and want to see how it works. People remark, “But it’s not very big.” And I know it’s not very big, but it’s there.

And, so I say, “We are modest in size, but not in scope!”

Scott: (laughs)

Wiener: A small space is better than no space. It sends a message to the community, students and campus. And without being obnoxious, I think it sends a message to the world. I’m going to look back in ten years and these kinds of Centers will be all over the country and all over the world, and we were the first one that was separated from Disability Services, that was put in Student Affairs, and that had a full-time professional director.

I mean, it’s really magical! I’m actually working with some people, including students, now, to put together a handbook on how to establish DCCs. I would like to start an international organization on the establishment of DCCs. I was inspired to do that by Ann Luetzow, who was one of the key people who started what is called the D Center at the University of Washington. And they named it the D Center—of course, that’s a nice pun and play on words. The name acknowledges simultaneously capital-D Disability pride and capital-D Deaf pride, as many d/Deaf people do not identify as disabled. The “D” thus addresses both points-of-view (Deaf pride and Disability pride).

There are lots of people who would be interested in joining such an organization, to get it started and to help it to grow. The Disabled Student Cultural Center (DSCC) is a registered student organization at the University of Minnesota, and was the first Center of its kind. In many ways, SU’s DCC was modeled after the DSCC in Minnesota. However, while the DSCC had been connected historically with accommodations and services provisions, SU’s DCC is completely separate from the Office of Disability Services, although there are strong partnerships between the offices. Also, as noted, all disability cultural centers, except for the one at SU, are operated by students.

The DSCC’s students and affiliates, the students and others who together with Ann created the D Center, and the students at Georgetown who are starting a disability cultural center would all be on board, I imagine, with wanting to create an organization like the one I’m discussing. Lydia Brown, an undergraduate activist and leader in the Autistic Rights movement, and a staff member of the Autistic Self Advocacy Network, is leading the Georgetown initiative. She is amazing. Everyone needs to read her blog, Autistic Hoya.

I also wanted to mention, in terms of the relationship between disability culture and the field of Disability Studies, that there’s a great article that was just published in the *New York Times*. It’s called “Disability Studies: A New Normal,” and SU is discussed in the piece.

Scott: *One of the ways you and I connected 15 years ago was through our mutual interest in the arts. Thinking*



about disability rights, civil rights, and your interest in the arts, please tell us about your participation in the arts, how and why that is important to you, and how the arts interact or intersect with everything we've discussed today. Of course, with my background as a Board-certified Registered Art Therapist and as an Internationally Registered Expressive Arts Therapist, this interests me.

Wiener: It pleases me to hear you say the words "15 years," and I have hope and clarity that we'll know each other, always.

Throughout the 15 years that we've known each other, we have always talked about the arts. I do, of course, as you know, identify myself as a writer and an artist, and as a poet, in particular. I think that the arts are vital to these conversations.

We had an event last spring, "Disabilities as Ways of Knowing: A Series of Creative Writing Conversations, Part Two: The Disability Experience and Poetic Verse," and Jim Ferris, Laurie Lambeth, and Steve Kuusisto read their poetry. This poetry is not just by people with disabilities who are poets. These are poets who happen to also have disabilities. I just went to an event which featured Steve (Kuusisto) and another poet, Ilya Kaminsky. I think Ilya identifies as hard of hearing. Someone identified him as deaf; another person identified Ilya as hearing impaired. I don't know how he consistently or maybe doesn't consistently describe his own experience. And Steve is blind. So people asked them after the reading if they felt this was a circus thing, like they were being put on display, the deaf poet and the blind poet. They talked about how that's not what it was about. How do you simultaneously negotiate the truth of these experiences and how they inform your poesis without putting yourself on display or exceptionalizing yourself?

Poetry is a form of creative writing, and creative writing is informed by disability. How is disability a form of creative writing? That's interesting. The first "Disabilities as Ways of Knowing: A Series of Creative Writing Conversations" event was hosted in the fall of 2012. We named the series in this way because of Steve's and my conversation about that topic, and Anne Finger came and read creative nonfiction to the audience. Some of what she shared was very much about disability as a positive experience, as a negative experience, as a neutral experience, as words that are neither positive nor negative, or any other clear, one-sided aspect of identity. We subtitled that first event "The Disabled Body in the World."

In terms of visual arts, what happens when there is a blind painter, blind photographer or a deaf musician or sound engineer or someone who has an array of experiences about their own neurology that makes them want to, for whatever reason, describe that in some synthetic way or some organic way? There are lots of examples of that aesthetic complexity in art. There's a

new collection coming out on b/Blind culture that talks about some of that. Many people have talked about this issue. There's actually a movie from a number of years ago called *Proof* (1991), about a blind photographer who walks around with a Polaroid camera. There are a lot of people who have collected and made shows of paintings done by people with disabilities. Some people will then say that's putting people on display. "Why should it have to be artists with disabilities? They're just artists, right?"

Another argument is, "Because we want to show that people with disabilities are often also artists, instead of assuming that people with disabilities are unproductive and incapable of expressing themselves and are worthy of admonishment because they.... blah-blah-blah." There have always been artists with all kinds of disabilities. And also, when people are dealing with distress and trauma, as we both know, the arts are a way to enhance other forms of communication. How is art itself a form of communication?

At a dance that's hosted annually as part of the Society for Disability Studies conference, people have been known to throw themselves out of their wheelchairs and dance literally on the floor. In 2012, I saw people at this dance do just that—throw themselves out of their wheelchairs and dance the way that they dance, because they're not dancing the way anyone else dances. All of these individuals danced their own ways—I'm not saying they danced the same way, because the "they" in that sentence is already a problem. What might have been described by some people in mainstream society as people with so-called "significant" disabilities dancing. Which I think is awesome (the dancing, not the labeling).

Scott: I do too!

Wiener: And it disrupts what's considered "normal" dancing. So whether it's dancing, music, visual arts, or poetry, there are many examples of how people with disabilities are artists, how artists happen to sometimes have disabilities, and how the arts can be used as an expression of experience, including what it means to live in the world with a disability. ■ ABILITY

This interview is dedicated to Ramona Johnson, who passed away in 2013.

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artmanna.com — Dr. Ericha Scott's website

