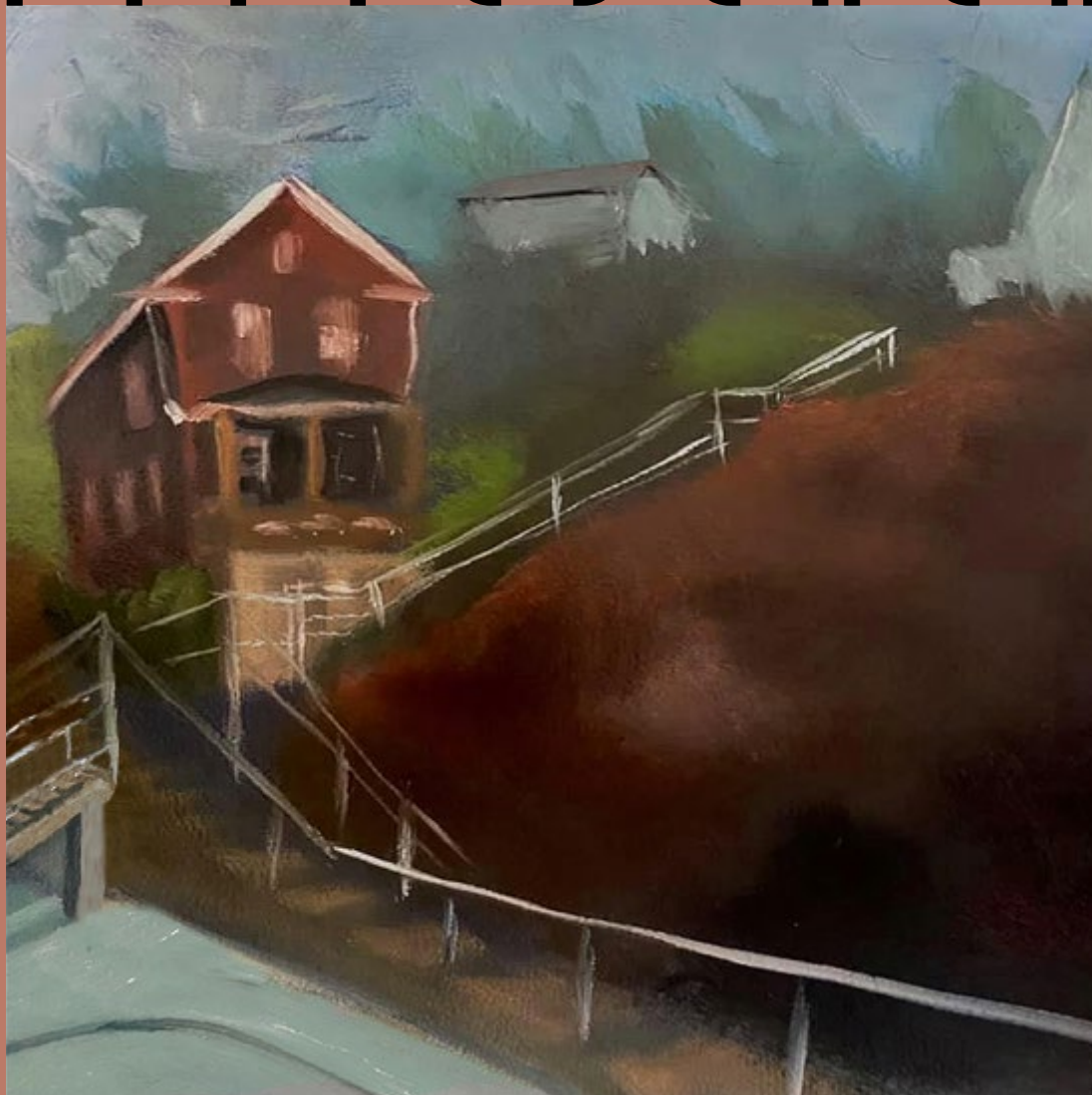


PITTSBURGH



LIVE / ABILITY

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ENCOUNTERS IN POETRY AND PROSE



# PITTSBURGH LIVE/ABILITY

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**City of Asylum**  
Pittsburgh, Pennsylvania

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# On Trigger Warnings

*All bodies are unique and essential. All bodies are whole. All bodies have strengths and needs that must be met. We are powerful not despite the complexities of our bodies, but because of them. We move together, with no body left behind. This is disability justice.*

—**Leroy F. Moore, Jr.**, chair of the Black Disability Studies Committee for the National Black Disability Coalition, cofounder of Krip-Hop Nation, author of *Black Disabled Ancestors* (2020), and activist against police brutality

As voiced by Leroy F. Moore, Jr., all bodies matter, and it is vital that we recognize, honor, and support the needs of everyone in our community. This includes you, the reader. *Pittsburgh Live/Ability: Encounters in Poetry and Prose* is a dynamic, creative, and engaging collection of writing that amplifies the experiences of disabled folks living in Pittsburgh. Conversations about disability are multidimensional, and, in this work, the storytellers are inviting you to share their transformative memories and moments, their defining struggles and successes, the power of their laughter and their pain.

The majority of disabled folks experience discrimination and trauma as they navigate a world that was not built with them in mind. Living in an ableist society can come at a cost, whether people are hindered by

physical barriers or limited by prejudicial attitudes, due to our cultural tendency towards marginalization and our narrow definition of worth. Stories surrounding discrimination and trauma can be difficult to hear, but it's important that we amplify these narratives to build a better understanding of what disabled folks experience and how nondisabled allies can work with the disability community to not just create safe and inclusive spaces, but build a world in which disabled folks can live their everyday lives with acceptance and belonging.

In this collection, trigger warnings will be provided for two pieces: "Learning to Dream Again: Anne Alter's Life with Schizophrenia" and "A Swirling, Lingering Storm: Corporal Kevin Craig Nixon." These pieces explore the emotional and physical

consequences of living with a mental illness in an ableist and sanist society, including such issues as sexual assault, suicide, and being the victim of violence. Trigger warnings help readers prepare for potentially distressing content, providing an opportunity to pause and emotionally protect themselves so they can engage safely with a piece. As you begin to explore these candid, authentic, and vulnerable narratives, it's important that you acknowledge what your brain and body need so you can

comfortably and safely access these stories. Check in with yourself. What do you need? A glass of water? A comfier chair? Do you need to take a break and walk around your neighborhood? Do you need a hug from a friend? Do you need to process your feelings with your therapist? *Pittsburgh Live/Ability: Encounters in Poetry and Prose* is a collection of writing that builds community for authors, collaborators, and readers by celebrating and centering all bodies and championing everyone's needs.

As you read *Pittsburgh Live/Ability: Encounters in Poetry and Prose*, we urge you to do so safely. Below is a list of resources that can provide support if you experience any distress or discomfort. It's important to be aware of these resources as well as share them with others so we are all equipped and empowered with information that helps all of us stay safe.

- **Suicide Prevention Lifeline: 1-800-273-TALK (8255)**

- **Suicide Prevention Lifeline: 988 (as of July 16, 2022)**

*For TTY Users use your preferred relay service or dial 711 then 1-800-273-8255.*

- **Allegheny County Peer Support Warmline Service: 1-866-661-WARM (9276)**

*Peer specialists are trained to actively listen to their peers, empathize with their concerns, and empower individuals to choose their path to wellness and recovery.*

- **PAAR (Pittsburgh Action Against Rape): 1-866-363-7273**

*Access text/chat via: [paar.net](http://paar.net).*

- **RAINN (Rape, Abuse, and Incest National Network): 1-800-656-HOPE (4673)**

*Access TTY: 1-800-799-4TTY (4889)*

- **Substance Abuse and Mental Health Services Administration's (SAMHSA) National Helpline: 1-800-662-HELP (4357)**

- **National Domestic Violence Hotline: 1-800-799-SAFE (7233)**

*TTY: 1-800-787-3224*

*Live chat: [thehotline.org](http://thehotline.org)*

- **National Alliance on Mental Illness (NAMI) HelpLine: 1-800-950-NAMI (6264)**

*Web chat: [www.nami.org/help](http://www.nami.org/help)*

- **Resources for veterans**

*NVF Lifeline for Vets: 1-888-777-4443*

*Stop Soldier Suicide: 844-317-1136*

*Veterans Crisis Line: (TTY)711+1-800-273-8255 #1; or text 838255.*





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# Introduction

**Ellen McGrath Smith**

*Project Director and Editor*

In the fall of 2020, my laptop screen filled with faces, some of which I'd never seen before. They were the faces of nearly a dozen Pittsburgh-based writers, half of whom identified as disabled, and an equal number of Pittsburghers with disabilities who had agreed to take part in this project sponsored by the City of Asylum, with funding from the The Heinz Endowments, the FISA Foundation, the Queequeg Foundation, and the Staunton Farm Foundation. But "faces on a screen" doesn't fully describe this first gathering of participants in the Pittsburgh Live/Ability: Encounters in Poetry and Prose project. There were faces as well as the bodies of DeafBlind participants, their hands communicating in protactile with protactile interpreters. There was the sound of a Dynavox speech generating device. There were ASL signers on the

screen, and there were captions (for which I, as a hard-of-hearing workshop facilitator, was grateful). We were a diverse, multilingual, multiply disabled, and multiply abled group.

When City of Asylum cofounder Henry Reese and I first discussed this project, we both imagined our first initial workshop gathering to be an in-person event at Alphabet City, the performance venue and multipurpose headquarters of City of Asylum on Pittsburgh's North Side. We imagined refreshments, touch, chairs and wheelchairs, handshakes. Then came the global pandemic that has stayed with us longer than most of us could have predicted.

So a Zoom meeting it was. But a very busy one. Some of the writers already knew their partners, but many of the pairs were meeting for the first time to determine how

to carry out the project going forward. Some partners decided to collaborate. Others planned on a series of interviews, with the writers producing a piece—in poetry, prose, or a hybrid of the two—that their counterparts would then write a response to.

A central purpose of the project: to create a literary collection that reflected what it was like for Pittsburghers with disabilities to try to live their best lives in this city and region. Another purpose: to voice, to give voice, to listen to one another. And still another purpose: to call forth all our pens, keyboards, vocal chords, assistive devices, and signing hands to give a dynamic, textured testimony to the diversity of the lives pursued in our city. In this collection, you'll get to know State Representative Jessica Benham, former Pittsburgh ASL instructor and current Gallaudet Professor Kenneth DeHaan, longtime attorney and disability rights activist Paul O'Hanlon, business owner Alana Gibbs, U.S. Marine veteran Kevin Nixon, singers Anne Alter and Sidria Williams, retired psychologist Dr. Avis Zawadi, recent college graduate and business professional Mark Steidl, blogger and Pitt outreach coordinator Heather Tomko, and DeafBlind interpretation instructor and advocate Rich McGann. After reading this e-book or listening to the audiobook, it would be impossible for anyone say that there is such a thing as "the disability experience." Whether one is born with a disability or acquires a disability later in life, the experience is always nuanced and unique. And literature is nothing if not the language of nuance and uniqueness.

The history of disability literature is long and rich, but has all too often been drowned out by the voices of the abled talking *about* those who are disabled, or speaking *for* them. Our writers include disabled and

nondisabled Pittsburghers, some who have received national acclaim—including Katie Booth, whose *The Invention of Miracles: Language, Power, and Alexander Graham Bell's Quest to End Deafness* was longlisted for a 2022 Pen America award in biography, and Cameron Barnett, whose *The Drowning Boy's Guide to Water* was a finalist for the NAACP Image Award—, some with one or more book publications—including Selene DePackh, Rick St. John, Sheila Carter-Jones, Ava C. Cipri, Jason Irwin, and Jennifer Matesa; Matesa, along with Patti Murphy, has a long track record in journalism as well. Emerging writer Cristina Hartmann has numerous essay and story publications to her name, and U.S. Marine veteran Emilio Rodriguez continues to produce stunning poetry and prose that should be receiving much wider attention.

At our first workshop, the folks who had agreed to share their stories and thoughts with writers met in Zoom breakout rooms to discuss their concerns about such a project. Then we discussed these issues in the large group. Representation is key, particularly when it comes to the ways in which marginalized groups are portrayed in our culture, and for those of us with disabilities, there is a lot of negative representation out there, as well as well-intentioned representation that nonetheless fails to meet the demand of "Nothing about us without us." One pitfall of such representation is a tendency toward "inspiration porn," a phrase that Australian writer, comedian, and disability rights activist [Stella Young](#) introduced in 2012 to characterize the ways in which individuals with disabilities have often been represented as exemplars of overcoming hardship for abled audiences. Well-meaning though many of these representations may be, they often fail to truly *see* individuals

beyond their disabilities. As Pittsburgh business owner Alana Gibbs writes in her collaboration with Selene dePackh, “I do not want to be someone’s inspiration because I am sick and was able to shower myself today. I want to be an inspiration because I did something amazing.”

Over the course of several months, partners communicated, collaborated, and clarified. As an editor, I have been delighted to see the work take shape in a variety of forms—from bingo cards to mash-ups, from transcribed conversations to many-layered prose and poetry hybrids. In our second workshop, in the spring of 2021—still pandemic, so still Zoom—we were able to discuss two of the drafts-in-progress, encouraging the collaborators and brainstorming on areas to be developed. Both of the pieces we workshopped showed the unlimited possibilities for listening and telling; both tapped in to innovative forms to make it happen. And I am grateful to all of the participants, and to our sponsors and funders—as well as to everyone who was instrumental in coordinating this project and producing these books, including City

of Asylum’s Andrés Franco, R. Henry Reese, Diane Samuels, Abby Lembersky, and Alexis Jabour; along with interviewee liaison and audiobook producer Jennifer Szweda Jordan at All-Abilities Media, audiobook reader Carroll Murphy, our Afterword contributor Sheila Black, and our e-book designer Joel W. Coggins. Thanks also to Dr. Rachel Kallem Whitman for her sensitively written warnings about some of the book’s more difficult content; suggestions and resources for self-care and other support for readers can be found at the beginning and end of the book.

We make things happen for each other, for ourselves, when we listen, when we speak our truths. Whether you are reading this book or listening to it, I hope something happens to shift the way you see the disability/ability binary. Pittsburgh is more livable for some of us than for others, and our love for this city can drive us each to address that in our own way. Please share the book as far and wide as you can—to educators, legislators, employers, students, and all who have a stake in making Pittsburgh more inclusive and more vibrant.



# Sidria Sings

## Sidria Williams

Cameron Barnett

with paint and pictures posted all around  
her home; sings Disney and dancing, sings  
from the throat down through her feet  
to the beat of her roommate's tunes,  
and the living room pumps like a heart.

Sidria doesn't sing potholes—it's Pittsburgh,  
Penguins, and politics. Sidria sings *Sidney Crosby*  
like Pittsburghers do; Sidria sings because  
Sidria is Pittsburgh—you can hear it  
in her voice, as though a perfect day  
were the width of ledger lines, flat and sharp  
notes passing by with the breeze.

Sidria sings *Take Me to the King* at Sunday service.  
She sings Kirk Franklin by morning  
and Cheetah Girls by afternoon. Sidria sings  
*independence* and you know the note means more  
to her than most can grasp; sings *routine*  
while the rest of us murmur it; sings all  
the parts of songs that we take for granted.

I'm a daddy's girl she sings, and hearts hopscotch  
a beat. Sidria sings *family*: *Mom* is a beloved verse,  
and *Dad* is a close chorus, and *siblings* are  
an album so good you have to put it on repeat  
and let the names roll over you note after note.  
She sings pain too. A song of life:  
a little bit rough for my family, some people  
*passed away* and she sings their names;  
a song of healing: *I do my spiritual dancing*  
*in the living room* and her legs become ballads.

Sidria sings *we do anything* and she means her work,  
she means *return addresses, labeling, postage, stuffing,*

*folding, gluing.* She means what she sings,  
and Sidria sings a city back to itself. She won't  
hesitate to sing a song to set you straight  
if you don't see her correctly. She won't hesitate  
when it comes to voice. She sings everything.  
Love of city, family, and life—Sidria sings that too.



# Sidria Williams responds to “Sidria Sings”

*with Jennifer Szweda Jordan*

**S**idria hopped on Zoom with me with the screen name “How train our dragon.” I shared my screen with her to show her the poem. When she saw the title “Sidria Sings,” her first response was a Woody Woodpecker-like laugh. “It’s about me! It’s about me!” she told her housemate.

She read it out loud, and we had the following conversation, then we took turns singing it to each other.

**JSJ:** What do you like about it?

**SW:** I like everything about it.

**JSJ:** Is there anything you would want to, like, say to Cameron about this?

**SW:** No. I like it.

**JSJ:** Do you have a favorite part?

**SW:** The one that says, “Sidria sings . . . family, mom . . .”.

**JSJ:** Why do you like that one?

**SW:** It’s like spiritual to me.

# The Language He Dreams In

## Kenneth DeHaan

Katie Booth

Karlee Smith was about ten minutes into her first deaf culture class when she realized she wasn't going to be able to understand any of it. Her teacher, Kenny DeHaan, stood at the front of the room, in a button-up shirt with the cuffs rolled up, just once, signing away in American Sign Language (ASL). With his closely trimmed beard and his short light brown hair immaculately in place, he could easily look a touch too put-together to really feel approachable, especially if you couldn't understand his words. But his smile and the warmth in his eyes were constant invitation. The other students seemed to understand him. He signed slowly, using basic words, pivoting from the signs themselves to fingerspelling for some of the trickier signs. He would lean his shoulders back ever so

slightly as he listened patiently, even as the other person signed so slowly, even as they fingerspelled, even as they stumbled. DeHaan's hands waited; his smile assured them that everything was ok.

Honestly, there were ways that Smith *could* understand DeHaan—not his words, but essential things about who he was. She could see how natural ASL was to him, how good it looked when he used it, how clear it was that there was purpose behind it. And when he would project pictures on the screen about whatever he was talking about, she could get these glimmers of understanding. She liked these glimmers.

By the end of class, Smith wanted in, though she wasn't sure if it was possible. She wrote a note and brought it up to DeHaan. "I don't know any sign language," it said.

“Should I drop the class?”

As DeHaan read it, a look of concern gathered across his features. He looked at Smith; it was clear to him that she wanted to take the class. She may not have known the language, but she was still *there*, that porous look in her eyes. If she was interested, then he wanted to share his culture with her.

*Should I drop the class?*

He wrote: “Absolutely not.”

To Smith, his face had a new look on it. It said, *You’ve got this*. It said, *We’re gonna be fine*.

At that point, DeHaan had been teaching ASL and deaf culture classes at the University of Pittsburgh for about five years. It was a career he cherished for the ability it gave him to break down misconceptions about deafness.

“Often students have this mentality that deaf people need to be fixed, or deaf people need help,” DeHaan explains. The greatest task of a low-level ASL class isn’t teaching a language, it’s undoing prejudice. This is true at any school, but the University of Pittsburgh has a huge medical school, and hospitals are one of the most dangerous sites of prejudice that deaf people face. DeHaan estimates nearly 85 percent of his students were med students. If these students went into their professions with a more expansive idea of what deaf people can do or be, it could radically change the way they treat their future patients both in Pittsburgh and beyond. But in the beginning, they were just taking an elective, most of them with no idea what they were getting into.

Katie McGovern remembers her first day of ASL 1 with DeHaan, which was also the first time she’d ever met a deaf person. To be honest, she was nervous about it. “It’s pretty earth-shattering when you’re a hearing person walking in [to your first ASL class] and not knowing anything, and it’s just dead silent.” The classroom looked different than others, the chairs arranged in a wide circle. When it was time for class to begin, DeHaan flashed the lights to get everyone’s attention. She’d never seen something like that before. She thought to herself: *Alright. Here we go*.

Much of what DeHaan does at first is work to reduce nervousness, to create a space where everyone’s humanity is seen and respected. *You’re welcome here*, he says, and he has faith in the eventual outcome being reciprocal, that deaf people will be welcomed by hearing people too. But changing the minds of hearing people is a slow and bumpy road, and it requires tremendous trust.

At the beginning of his classes, especially ASL 1, everyone is vulnerable. Students are suddenly immersed in an unfamiliar culture and language, and in order for them to connect to that they’re going to have to connect with *him*. During week one he’s not just teaching them the ASL alphabet; he’s also teaching them about *Kenny*, the person. He tells them about his travels, about his childhood, where he went to school, what language he learned in. He communicates in ASL, in what McGovern described as a flipping of the script: “Instead of deaf people adapting to the hearing world,” she explained, “[it was] *us* adapting to him.”

But he also creates an environment where students can laugh, ask questions,

make jokes. He tries to, in his words, “make that classroom feel like any other classroom.” What he wants, really, is for everyone to feel comfortable.

“Yeah, deaf people are different,” says DeHaan, “but they don’t have to feel different. And you don’t have to feel different around [deaf] people.”

DeHaan will arrange the space in a deaf way, communicate in a deaf way, get everyone’s attention in a deaf way. He’ll go slow, really slow, making sure no one is left behind, making sure everyone is comfortable enough to ask questions, even somewhat personal questions, questions about his life. Everyone wants to ask questions. They write them in English on scraps of paper and pass them his way. They begin to learn things no textbook can teach them.

.....

Smith didn’t drop the class. When DeHaan’s eyes said *You’ve got this*, she believed him. She stayed. Because it was a deaf culture class, not an ASL class, DeHaan did use an interpreter sometimes. Smith followed all the readings and went to ASL social groups outside of class to try to learn more. In class, she often relied on the interpreter, and when she had smaller questions, she and DeHaan wrote back and forth. After about seven or eight weeks, DeHaan noticed she was signing. It was slow and unsteady, but it was enough for him to encourage her to push the notebook aside, to sign with him. She did.

Just like the students in McGovern’s class, Smith had a lot of questions. She wanted to know about DeHaan, about what his deafness was really like. She wanted to know: *When you eat cereal, can you hear it inside of you? The crunching?*

DeHaan laughed, and then made a thinking face.

Students said that asking so many questions made them feel closer to DeHaan as a person. It filled out a picture; it made him seem whole. Given the prevalence of the idea that deaf people are broken, this is no small thing.

When I ask DeHaan about this onslaught of questions, his eyes get big with feigned exhaustion and he laughs. *So many questions!* He remembers the question about the cereal—that one made it onto a file he kept of the funniest or most interesting questions he was asked. But he also points out to me that the cereal question was not so different from a misunderstanding I once had.

“In your book,” he says, “you talk about thinking your grandmother could hear *herself*, inside, even if she couldn’t hear others.”

It’s true. In *The Invention of Miracles*, I write about my childhood confusion about what my grandmother could and couldn’t hear. In fact, there were a lot of things DeHaan’s students told me that reminded me of the way, as children, my cousins and I would try to understand our family’s deafness. We poked and prodded at boundaries, always testing what we might be able to get away with, sometimes astonished at what our deaf family members *did* observe, the frustrating way they always seemed to catch us.

In a way, this is a natural exploration, and maybe on some level it needs to happen—I’m not sure. There’s a benefit and a danger that comes with the kind of openness that DeHaan encourages. Students need to feel like they are safe to make mistakes in the classroom, both with signing and with content. DeHaan is on the front lines of mistakes with content—questions or

ways of framing ideas that are riddled with ignorance and bias. When students say something biased (and they will), DeHaan looks generously at what was said. He assumes that they didn't realize the bias, and he exposes it. Often it is pity. "People think: *How do you survive? How do you live a normal life?*" He gets underneath those assumptions and challenges them or tries to reveal the thing underneath that they're really trying to say or ask.

Students ask DeHaan questions that are well known to deaf people—exhausting, insulting questions. *Can deaf people drive?* This one has an easy answer: yes.

*What about ambulances?* a student asks. DeHaan explains he can see the flashing lights.

He sends a question back their way: *What do you do when you're cranking your music? You can't really hear the sirens either, right?*

The students contemplate.

But other tests are different. Sometimes the students talk amongst themselves in English. They whisper. DeHaan knows this is happening. He reminds them: in this classroom, we don't speak in English. This is pedagogical—it makes for a language immersion environment—but it is also a deaf cultural norm of equalizing access to information in deaf spaces. When a student uses their voice in a low-stakes situation, like during class time, he doesn't usually single them out. Instead, he'll give a reminder to the whole class. If it continues among a class, he'll change his tone, become more serious. "Please," he'll say, "in this classroom we use ASL." If he has to remind a particular student, he'll sometimes use a sign: There is a dial on your throat, and you turn it. *Voices off.*

During a midterm, a student waits until DeHaan's back is turned and asks the

answer to a question. His peers shoot icy looks in his direction. *Not cool*, their eyes say.

After class, the student meets with DeHaan. They talk about what happened.

In some ways, this rule-breaking is normal behavior. Some students press at boundaries, some try to cheat. Today, DeHaan mostly works with deaf students, and sometimes they cheat too. But it's different. He still has to follow up, enforce the rules, become stricter and sterner if the offenses repeat. But it doesn't involve the same element of power.

When the hearing students do it, DeHaan says, it deflates him, makes him feel a little smaller, less empowered. The sign he uses to describe this is one in which the non-dominant hand creates a kind of shelf at the chest, and the dominant hand sits atop it, cupped like a C. The space inside of this C is heart, spirit, vitality, and the action of the sign is that it flattens out, like air let out of a balloon.

When hearing students take advantage of DeHaan's deafness, it demonstrates a lack of respect, a way of saying: the ease of my communication is more important to me than your inclusion. DeHaan knows that the default belief in hearing people is that deaf people should change to adapt to hearing expectations—not that hearing people need to be ready and willing to make some sacrifices to accommodate deafness. He knows that students respect him, that this isn't about *him*, but is a deeply engrained way of operating within their privilege that they are often not even conscious of. But it is also of huge importance that they become conscious of it.

In ASL 1 and 2, this use of privilege and hierarchical thinking is still fairly dominant. DeHaan thinks it often takes two or three

years of exposure to deaf culture to really see the shift inside of someone. “They need time to really process it . . . [time] for them to really understand that *maybe, yeah, this person is fine*. They need that constant exposure to a deaf person, to see their everyday example, to understand their life and their background.”

Once that solidifies in a student’s mind, the prejudices around deafness are no longer abstract; they’re something that has a real impact on the life of someone they know. And if they’re not thoughtful, they could become even more a part of it than they inevitably already are.

But even without that kind of insight, there are things that students can begin to see and change. If they catch DeHaan’s face when he knows people have been using their voices, if they see the soft, subtle slump of his shoulders, it changes them a little. This is a person, a person they know and like, who has been vulnerable with them and has supported them when they were vulnerable, too. They don’t need to understand anything more than: *I don’t want to be the person who makes Kenny’s face do that*. They don’t want to make that spirit, held inside the space of a C in front of the heart, they don’t want to make that deflate.

This alone is valuable, transferrable instinct.

The sign that DeHaan used to describe the deflation he felt, it has an inverse, a filling of the heart. It is the same shelf in front of the heart. The dominant hand, sitting atop it, begins flat and then swells back up to a circle. Swells with hope, with happiness, with wholeness.

Two or three years for someone’s mind to really shift.

Jayme Halfhill, another of DeHaan’s students, remembers the moment it happened for her. At the time, she was a server at a bar near the university, Hemingway’s, and she was always assigned to DeHaan’s table. (“Oh *this* is why he taught me the sign for ‘beer’,” she jokes.)

One night she was watching him and his friends from afar, down the dimly lit corridor of the cramped college bar. She knew enough ASL to be able to pick up on what they were saying—they were chatting about their upcoming travel plans, a date someone went on, who just got a new motorcycle. She was watching them, their faces and bodies alive with story, their deep friendship evident in the way they looked at each other, kidded with each other. It struck her that they were having more fun than anyone else in the bar.

She thought of her own life—she didn’t even know what she was doing that weekend. She was a college student whose friends would soon scatter around the country, and what she wanted was what she saw with DeHaan and his friends: deep, enduring community.

“There’s nothing to pity,” Halfhill remembers thinking. “They’re not pitying [themselves]—they’re *living it*.”

And she realized, “I want to be a part of this.”

.....

*Do deaf people tell knock-knock jokes?* Smith was a font of questions. She was worried that she would be judged by the deaf community for being a hearing person, and while the questions didn’t stop Smith’s nervousness, they did prepare her. They

made deafness—and deaf people—seem more understandable. *What language do you dream in?*

Difference can breed both pity and fear; students experience these emotions differently, but all of it relies on distance, on people not truly encountering each other. DeHaan works to collapse that distance. DeHaan works to bring us closer.

When DeHaan took the ASL 3 class to the National Technical Institute for the Deaf (NTID) in Rochester, N.Y., Smith worried that she wouldn't be able to communicate. She also knew she'd have to. Once on campus, DeHaan began a conversation with a group of students. Basic stuff: *Where are you from? Have you always been deaf?*

The students started signing, and timid as Smith and her classmates were, they were able to join in. When Smith didn't understand something, she was able to say so and to ask for help. And when the conversation was over, she turned around, only to find that DeHaan was long gone.

His students tracked him down pretty easily, off in the distance chatting with someone he knew. But this too was a lesson. What can you do without your teacher? "It helped us more than anything for him to just throw us in the deep end and walk away," says Smith. She began to learn what she was capable of.

McGovern experienced something similar when she had to fulfill a requirement of attending a social event in the deaf community. "I was terrified," remembers McGovern. "I thought that I wasn't going to keep up or that I wouldn't be welcome." But DeHaan was there, facilitating introductions, slowing down conversations, and helping with unknown signs.

Encounters like these aren't just perks of

the class—they are critical learning experiences, in large part because so few people encounter deafness in a sustained and respectful way. That kind of encounter takes time and vulnerability and trust, and once we do it a few times, once we reckon with our shared humanity while respecting our differences, it does change things. Hearing people, it changes us.

The rarity of these true encounters is not just a missed opportunity; it's a danger. The imagined distance between hearing people and deaf people breeds misunderstanding and, in the worst cases, dehumanization. In medical settings, deaf people are often put into life-threatening situations; ethnocide is a reality in the deaf community; the federal law allowing for the forced sterilization of deaf people is still on the books; their rights are routinely violated at the hands of the police and in the hands of the law; deaf people who are also people of color, or queer, or multiply disabled are at even graver risk of life-threatening neglect or outright murder by people meant to protect them. Hearing people turn around and weaponize these facts, saying they are inherent outcomes of deafness itself and using them to justify "cures" instead of rooting out the ableism and audism that enforces these realities. It is a broken, self-sustaining cycle. The pity, the distance, and the fear—which are so engrained in the ways hearing people encounter deafness—these destroy deaf lives. But when a hearing person has a true encounter with deafness and sign language, as many of DeHaan's students have, it can begin to transform these realities. Maybe only in small ways, but in ways that matter. Maybe in ways that initiate greater change.

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My mother sometimes tells a story of my grandfather in the hospital. One of the biggest shared traumas in the deaf community is the neglect deaf people routinely face in hospitals, and my family is far from immune. When a deaf family member is in the hospital, we expect only the least and we fight so that those we love might be lucky enough to escape life-threatening neglect. So when my mother learned that, during one of my grandfather's many hospitalizations, there was a nurse who was kind to him, she wanted to meet her.

It turned out that the nurse had taken an ASL class years before. Though she remembered very little, she could do something almost none of the other hospital staff ever did—she could encounter my grandfather's humanity. Deaf people deserve much more than this, but it's also no small thing to have someone who understands something about the greater context of deafness. This nurse could look my grandfather in the eyes and she could *try*. She could point to things, gesture, fingerspell. She requested him as a patient whenever she worked; she brought him his favorite flavor of ice cream; she visited with him. She made sure he didn't just disappear.

I was reminded of this story when Halfhill told me a story of an encounter she had on the border of Turkey and Syria, in 2014 at the height of the refugee crisis. She was at a rehabilitation center for injured orphans when she met a child, the only deaf child in the center. She wanted to talk to her but didn't know the local sign language, or even Arabic. And so she found a friend to translate from English to Arabic, and another woman to translate from Arabic into the local sign language. The four of

them stood there as Halfhill signed with this child, slowly, stilted, before she said *nevermind, nevermind*, and sent everyone away. Then she sat down with the girl, just the two of them, lifting objects and sharing their signs for them: the sign in ASL, the sign in the girl's language. At that moment, the important thing wasn't complex communication, but connection. So for three hours they shared these two languages; they connected.

"I don't know if I would have had the confidence to do that," says Halfhill, "had Kenny not been so open about his experiences growing up deaf, and . . . [about] how hearing people interact with him when they don't know him."

She had DeHaan's words in her mind, or at least the essence of his teaching: *We don't want you to be afraid of us. We don't want you to be weirded out by us. We just want you to treat us like normal people. I want to have a conversation with you.*

She still remembers the sign for Arabic. Or maybe it is Syria. She remembers a moment of connection. *We've got this. Just you and me.*

I can't help but think of my grandfather.

Of so many of my ancestors. Of all the times I watched hearing people clam up, turn away, ignore them.

I can't help but think of DeHaan's impact. Halfhill says she doesn't know if she would have really gotten that from another teacher—"that human element of being deaf . . . that human connection."

Can't help but think of UPMC, the medical system that sprawls out from the University of Pittsburgh. How many of DeHaan's students ended up working in the Pittsburgh region, changing the experiences of deaf people in hospitals and beyond?

Kenny himself hadn't even planned to



become a teacher—he studied business and moved to Pittsburgh to work at BNY Mellon. But he found himself unable to move up in the company or secure a job elsewhere (when he took indications of deafness off his resume, he started getting interviews, but never anything more). At the same time, he had started teaching, and found his passion there. It worked out in the end, but the situation shouldn't have happened.

Now I wonder about those other students, those not studying medicine. Are they still in the region? When a deaf applicant crosses their path, do they think *Deafness no big deal*? Maybe: *Let's give them a chance*. Maybe even: *This person's unique perspective and skills could be a great contribution to our team*. Imagine that. Imagine enthusiasm.

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To be certain, more is needed than people who are simply unafraid of deaf people—we need massive, systemic changes across the board. Still, in a world dominated by hearing people, having more people who know ASL—and even more people who may have forgotten the language but have an appreciation for its critical importance, as well as the most basic respect for deaf people—is no small thing. This is an effect

that ripples, an effect that can grow.

Today, DeHaan is director of the Master's in Sign Language Education at Gallaudet University, teaching other deaf people to become ASL teachers. DeHaan loves teaching. He connects with people, shares with people, encourages people. He watches them grow. It's powerful and satisfying work, and it helps him share information about deaf culture. His work at the University of Pittsburgh, it felt important. He holds his index finger up, this is him. He uses his other hand to signify his impact: it begins like a fist and then the fingers spread outward from the index finger; it comes from him, and it reaches out. "If I can change 20 of my students, change their perspective . . . if we could just make more people like that . . ."

So much is needed. Eventually, he thought: If I could teach other teachers, this impact could multiply. Let's say five teachers. He holds his hand tall, his fingers spread apart, each finger a teacher. His other hand, this shows the influence. He teaches five teachers; they go out into the world, and then, from each of those fingers, influence grows and spreads. One, two, three, four, five. Influence, influence, influence, influence, influence. Such a wider impact. A bigger dream.

## Kenneth DeHaan Responds to “The Language He Dreams In”

Language is central to everything; it is not prescriptive. It is organic, ever-growing, and shifting like the ebb and flow of life. Writer Katie Booth does a beautiful job of capturing the essence of language, which is not merely a set of symbols conveying a thought, but a way of life, culture, values, morals, and most importantly, human connection. The person to your left and right, whether they are family, friend, or stranger, all yearn for human connection regardless of their religion, national origin, race, color, or sex. Differently-abled bodies, Deaf people in this particular story, also yearn for the same human connection which makes us whole, and language is central to this. Katie's story shines light on this by peeling away the veiled misconceptions, revealing our humanity under it all. So, the next time you bump into someone

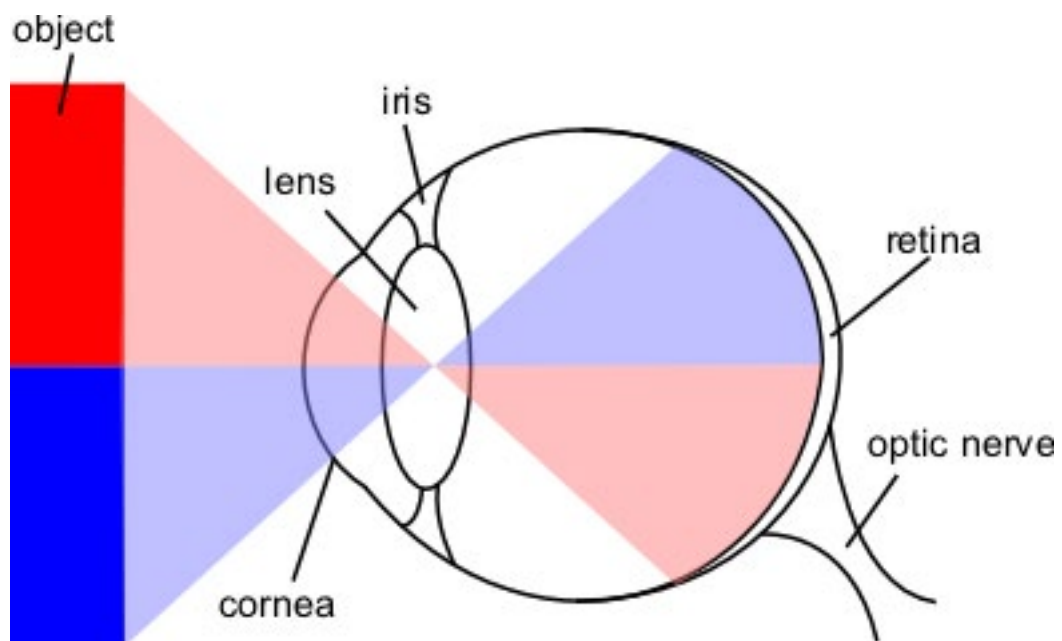
that doesn't speak your language or is differently-abled, a human connection doesn't require knowing a set of mutually shared symbols or jargon to share a thought. Give it a try: Wave "hello!" and experience the "shelf in front of the heart. The dominant hand, sitting atop it, begins flat and then swells back up to a circle"; let your heart and the heart of those you encounter fill "with hope, with happiness, with wholeness." This is the collective effort that moves the world in the right direction towards total inclusivity. Human connection is, indeed, the language I dream in.

# The Eyes Have It

Avis Zawadi

Sheila Carter-Jones

**Y**ou can check out different parts of the eye by looking at your own eye in the mirror or by looking at (but not touching) a friend's eye. Some of the eye's parts are easy to see, so most friends will say OK. Most friends won't say OK if you ask to see their liver!



## About the Part of the Eye That Concerns Fuchs' Endothelial Dystrophy

The **cornea**, a transparent dome, sits in front of the iris, or the colored part of the eye. The cornea helps the eye focus as light makes its way through. It is a very important part of the eye, but you can hardly see it because it's made of clear tissue. Like clear glass, the cornea gives your eye a window through which to view the world.

### *Seeing Over the Heads of the Audience*

She is being led into the room.  
Not by hand within a hand as if  
strolling along. Not by hand hooked  
into the arm of another with eyes  
that guide in the dark.

In the dim light she is like a shadow  
with eyes walking behind and making  
necessary adjustments to sense  
movement of the body ahead.

Is she really obscured by her disability?  
—the way she reaches for the chair, puts  
her body in and leans back to become  
one unfettered by ongoing degeneration  
of the cornea.

### *First Encounter*

I am rushing across the sky of North Avenue  
to catch up to her. My body is streaking to  
know who this woman is. Where she comes  
from. Where she is headed. And why is she  
walking alone in her air of independence that  
intrigues? The sunglasses, like goggles, block  
the same air that dries her eyes and obscures  
her vision. They also keep light out, which  
affects the pupils and mechanisms of the eyes.

In the falling dusk beginning to blacken the gray  
cement sidewalk, I see a thin shadowy figure.  
I start to beep the horn. Pull over, roll the window  
down and lean into a first encounter.

I ask if I can give her a ride. She gets in my car  
despite saying, No, I just live a few blocks up and  
a right at the light. A block down then a left onto  
my street. At this point of contact I don't know  
about her eyes.

I don't yet know the sunglasses she is wearing in  
the dark shield her eyes from a hypersensitivity  
to light as other cars zoom past, headlights shining  
and falling like stars as they pass by.

After more than several months, I learn of Fuchs' endothelial dystrophy (FED). It is a rare type of eye disorder that affects the cornea, the dome-shaped outer layer of the eye that helps you see. Because Mrs. Avis has had this disorder since birth, her vision has been slowly decreasing over time. There are indications that FED may be genetic. If someone in your family has it, your risk for developing the disorder is greater. However, its inheritance pattern is still ambiguous. Almost everything is unclear when it comes to Fuchs' endothelial dystrophy.

When she was a child growing up in the Bronx, New York, Mrs. Avis didn't wear glasses, but as she matured, the disorder became worse, diminished vision more noticeable. In fact, the disorder usually hits during one's thirties or forties, but it may not be readily noticeable because the symptoms are minimal during the first stage. One may not notice any significant symptoms until they're in their fifties, or the second stage.

By the time Mrs. Avis decided to stay and live in Pittsburgh, however, she was wearing glasses. As a doctor of psychology, she first came to Pittsburgh because of a patient whom she was helping to get through a residency. Since then, she was in and out of Pittsburgh until she ended up staying because, she says, *Pittsburgh is my kind of town with the museums and academics. It has a certain kind of charm.* It's no wonder that she calls Pittsburgh a "town" after having been born in the Bronx.

Fuchs' endothelial dystrophy, unlike other types of dystrophy, affects both of your eyes. However, vision in one eye may be worse than in the other. In Mrs. Avis's case, she has five for five—meaning that there are five things occurring in one eye and five other things occurring in the other eye. But, she says, *Not all things coincide.*

## Second Stage Experiences

### 1. *Cloudy, Not Blurry*

It sounds like a weather forecast. But it is not. It is how vision is described in the second stage of Fuchs', and Mrs. Avis is having a very hard time reading her mail through the haze. In fact, the mail is piling up. She has a special hand-held magnifying glass given to her by the University of Pittsburgh Medical Center (UPMC) occupational therapy department. She says she treasures it and it is worth everything. With it she can read who the mail is from. She feels that she would be totally blind without it as her vision is measured at 80-90 percent blind. Even so, boxes and boxes of mail have piled up. *It's horrible! Just horrible*, she tells me.

In order to tackle some of the mail, she has promised herself that she will try to struggle to get through three pieces of mail a day. This means she has to use the special magnifying glass as well as a reading machine that is similar to a small television. *You put the paper on the tray beneath and it makes the letters larger*, she says, with a voice that triumphs as if she has turned magician and "Voilà!" pulls a rabbit from a hat. Other times, a friend's significant other comes over to read some of the mail out loud.

Mrs. Avis' disability is an acquired one. Fuchs' endothelial dystrophy became worse and more noticeable as she matured. The vision loss caused by diminished vision first led to less reading and, now, no reading. Before Mrs. Avis' vision deteriorated, she enjoyed reading science and psychology journals, as well as information on ecology. For pleasure, she loved reading novels by one of her favorite authors, Danielle Steel. Now, that's not one of the pleasures she can enjoy—curling up with a good book and perhaps turning a few pages before falling asleep.

### 2. *Gray Day Turns Super Sunny*

It's the magnifying glass that comes in quite handy for Mrs. Avis on days like this. It's ironic that a magnifying glass is needed to read the print on medication bottles that contain the medicine needed to take for her vision . . .

And she says she can't even see  
the food she puts into her mouth,  
but she can taste squash soup and  
the scallions she eats as a side dish.

On a vision journey she met a Muslim.  
It wasn't the woman's religion that

made an impression, but her kindness.  
It was a delicious blessing.

Isn't it funny the combinations life  
serves us to learn how to live together?  
How to make us see more human  
even with 20/20 vision?

### 3. *Blessed Day*

A woman Mrs. Avis met while sitting outside took her to the store. Helped her shop by reading labels and taking her to different sections of the grocery store. That day, Mrs. Avis was able to get green pepper, Swiss chard, and, of course, a bag of onions—because she caramelizes them and freezes some for later. Mrs. Avis says she never would have been able to get exactly what she wanted if it hadn't been for the woman walking her around. That's the nature of a blessing. To support you. Not *do for you*. Mrs. Avis is determined to be as independent as possible, although on occasion she must ask people to pick up an item or two for her when they are going to the store.

This eye disorder may go unnoticed for years before vision worsens. The only way to help FED is through treatment. In the case of vision loss, you may need surgery. Mrs. Avis has had eight surgeries. The surgeries entailed the transplanting of a cornea, which has to be from a living person. And it cannot be refrigerated, so time is of the essence.

The second stage causes more noticeable symptoms because fluid buildup, or swelling, doesn't improve during the day. As Fuchs' progresses, later on, the symptoms can be so severe that they result in an inability to drive at night and, eventually, even during the day.

### 4. *A Very, Very, Very Bad Day Today*

Transportation is an ongoing challenge for Mrs. Avis. During the COVID-19 lockdown, she had to get to Massachusetts to the Boston Foundation for Sight. However, they would only accept her if someone was with her. She was hoping to get a disc in the eye that is similar to a contact lens. No one went with her. Yet she made arrangements anyway. Booked a reservation on Amtrak. Called and scheduled a cab weeks in advance, and off she went to stay with a friend in New York. When I asked her if she was afraid, she said, *No! I have no choice. I can't sit in the middle of the floor.*

Transportation is especially difficult in winter at the bus stop. Mrs. Avis says, *Figuratively,*

*I crawl to the bus stop. She says it's just as hard for her to get off the bus because she has to be aware of snow and puddles. She could easily slip and fall or get hit by a car.*

The most monumental and tragic thing is that she had to give up driving. *That was so hard to bear. Oh God, it was so hard to give it up*, she says. Her red Kia is now parked in a friend's garage. The latest news about the car is that a raccoon or some other small animal got into the car and ate three or four of the major cables. They chewed through them completely, causing three to four thousand dollars' worth of damage. She is continuing to try and sell the car, but because of this incident, the price has come down from \$13,000 to \$9,000. And, she adds, it must be in cash.

As a personal preference, she doesn't take ACCESS, a by-appointment transit service for people with disabilities and older adults. She is not willing to take an Uber or Lyft. And never a jitney for fear of Jack the Ripper's cousin, she jokes.

## 5. Outlook

Loneliness is a major effect of Mrs. Avis' Fuchs' endothelial dystrophy. She repeatedly mentions that it is hard to be three-fourths or more blind and alone. It's the feeling of being alone that hurts. When her husband was alive, she hosted two parties a year. One was on Valentine's Day because she's very romantic. To participate in this potluck party, you had to wear red, even if it was in a place where it couldn't be seen. Each person had to share a love story of any kind and say who the love was directed toward. The second party was called First Fire Party. It was called this because the party celebrated the first lighting of a fire in the working fireplace. The logs would be lit, and when the fire was blazing, guests would throw a handful of colorful crystals into the fire. It became, as Mrs. Avis recalls, *a magnificent fire, so colorful and beautiful*.

The diminished eyesight caused by Fuchs' endothelial dystrophy has limited her traveling as well. She used to spend time traveling to different places for different reasons. In winter, she and her husband did Nordic skiing in Vermont, Utah, and in Canada, north of Montreal, but Vermont was her favorite. In spring, summer and fall they biked on campuses of major universities like Harvard and Princeton. They belonged to the League of American Bicyclists (LAB), a national bike club that is broken into geographic sections. She and her husband were part of the Great Eastern Area Riders (GEAR). In short, Mrs. Avis was quite active before the stage of Fuchs' endothelial dystrophy she currently has. Now, Mrs. Avis says, *No husband. No fireplace. I have an entirely different life*.



## 6. *Not Overlooked*

*To have some support, she says, is a wonderful thing. This includes a man who brings her fruit—wonderful pieces from a farm that uses no insecticides. A man comes every Tuesday and a woman comes every Friday to walk her around to the park. Even with this support, she still feels lonely, adding, I have no family on planet Earth. That’s why I’m so lonely. So alone. It’s very hard. No aunts, uncles, or cousins. I would like a companion, a partner. Nothing special. Just a friend. Life for me is not like life for you.*

After nearly every conversation, Mrs. Avis says, *See you later alligator.*

I say, *After while crocodile.*

Mrs. Avis, you’re the bravest!

## Avis Zawadi Responds to “The Eyes Have It”

I'm so very impressed with Dr. Sheila Carter-Jones' description of my ocular tragedy. Dr. Carter-Jones has compartmentalized the different aspects of this ocular tragedy in a way that is so very starkly accurate. My avocation is traveling; I have traveled the world and do not know anyone who has traveled as much as I have. But I've had to give up traveling, which has significantly redefined my very existence. After traveling to another continent at will, needing to plan ahead just to go down the road to the grocery store is a stark contrast to my previous life. Every single motion takes a significantly longer time than ever imaginable. Concomitantly, I am a decidedly non-virtual person, making my lack of contact with other human beings especially painful and a contributing factor in my profound feelings of loneliness. My search

for companionship continues to be one of my major endeavors at this point: to share the remaining portion of this life's journey with another person. HELP!

# Ableist Bingo

Ava C. Cipri and  
Heather Tomko

**D**o you live in Pittsburgh? Are you visiting our city? If you're disabled and spending any time here, we invite you to play Ableist Bingo!

What's Ableist Bingo? It's like any other bingo, but with a side of ableism and microaggressions, as influenced by Fatimah Asghar, a Pakistani Muslim-American nonbinary poet, educator, filmmaker, and performer. Asghar's "[Microaggression Bingo](#)" is one of many poems exploring identity and personal struggles as a marginalized speaker through innovative forms in her collection *If They Come for Us* (One World, 2018).

This outside-the-norm, not-belonging otherness culled in an experimental fashion upends normalcy; it afforded us an

opportunity to craft our own versions. When the inherent cultural constructs do not fit, we must create another way, another window or medium. Following Asghar's lead, we've filled the bingo squares with experiences that happen to us routinely as disabled people navigating Pittsburgh's topography.

So, whether you're enjoying a coffee in Market Square, visiting one of our city's amazing museums, catching a performance at the Benedum or Heinz Hall, or communing with nature in Schenley Park—pay attention! Mark your bingo square (physically or virtually, your "call") if any of these things happen to you.

Don't forget to mark the Safe Space! For us, no space in Pittsburgh really feels

completely “safe” and free of ableism. But we’re hopeful for a time in the future when accessibility is the priority that drives design in Pittsburgh, creating inclusive spaces. Until then, our Safe Spaces are the places where, for us, the good outweighs the bad. Oakland has some of our favorite safe spaces, which happen to be green.

Schenley Plaza, where you can pick up a coffee and snack, bring your book and headphones, and spend a few hours reading peacefully at one of their outdoor tables under a shaded tent. Or Phipps Conservatory and Botanical Gardens, an

ever-evolving 1893 Victorian greenhouse offering best-in-show flourishing flora every season—a full sensory experience, offering classes and programs leading the way in sustainability, where you might also grab a bite at the café or stop by the gift shop.

If you “win,” well, the prize is up to you. You can choose to let the ableism go if you don’t feel up to confrontation, or you can decide to let the bingo chips fall where they may after a particularly harrowing bingo win. There’s no right or wrong way to play the game . . . and certainly no winners, either.

# Abelist Bingo

Ava C. Cipri

B	I	N	G	O
Another Pittsburgh journalist uses “tone deaf” to describe Trump’s rhetoric	Poetry workshop critique: “This couplet doesn’t have a leg to stand on.”	Unwelcome prescriptions: “But have you tried yoga/going paleo/manifestation?”	Comorbidities are a bitch	Waiting for the 71A Negley: “Temporary or permanent?” (pointing to my cane)
Failed compliment: “You amaze me, how you keep going, live.”	Internalized ableism wins today.	Another abled actor plays another disabled actor in another blockbuster	A colleague: “I hate walking in the snow. Tell me how I can teach in the same building as my office, too.”	Don’t speak louder into my right ear when I say I can’t hear in my right ear.
I’m exhausted with faking being fine	“Just eat phosphorous rich food,” says an intern after my 6-hour phosphorous infusion.	SAFE SPACE	“It’s not PTSD if you weren’t in the military.”	Instagrammer accused of <i>romanticizing</i> disability for using mobility aids while wearing leather & fishnet.
An envious writer says: <i>Marginalization is in.</i>	My EDS hypermobility as a dancer = win. A decade later = rib subluxation from turning in bed.	I’m passing in the Benedum audience until accompanied by my mobility aid: cane or rollator.	Qualified for Susquehanna service dog. Internalized ableism—no dog. Back on the 5-year waitlist.	Passing on Zoom, again
Immune-compromised: Harassed by a Rite Aid customer for wearing a mask.	“But I’m VACCINATED”—the response to my mask-wearing request while viewing Bloomfield apartments.	It could always be worse, so I’m told.	Mistaken as the patient at Presby’s ER when my partner is in the hospital bed.	Zero spoons & zero fucks left

## My Safe Space

*Ava C. Cipri*

I return to the cliff's edge. Bird's-eye view from the treetop canopy with palm trees nearing 60 feet tall. Below me are snaking streams and gushing waterfalls drowning out exotic birds and the laughter of children. I'm breaking a sweat, thankful I brought extra water; it's more humid than I remembered—the sun magnifying as if through a lens.

A breeze picks up before I descend into the tropical forest. I pass several grottos along kaffir lime and banana trees. After crossing three bridges, I smell orange jasmine and know I've arrived. It's my third visit to this healer's hut since I crossed Thailand's border last month. I drop my heavy backpack of provisions, and sit under bamboo and wait. While drinking hibiscus iced tea, I scan the medicinal drying racks.

I've turned away from the West to find a center in the East. To heal. Although no one ever comes, I keep returning because I feel my body grow stronger, here.

What I first think is a rush of pollen is actually snow. Flakes so thick they stick against the south-facing 8,000 square-foot single glass pane overlooking Panther Hollow. I unlock my Rollator and head down until I arrive at the lotus pond splashing with koi. It's December, and what felt like minutes was an hour, so I decide to take the elevator back up to the canopy level of carpentaria palms before exiting the conservatory.

One of the greenest buildings on Earth, Phipps Conservatory is one of my "Safe Spaces" in the city. Even before my

increasingly limited mobility, I sought refuge in the Victorian greenhouse. I still find solace there as a place to write, re-energize, and dream.

The level of accessibility for someone who uses a Rollator is impressive; I am able to enter almost every space. I also appreciate the vast amount of seating, from benches to waist-high walls (as in the Serpentine Room), for resting and regrouping.

What is most unfortunate is something that has created a divide in our city . . . the bike lanes. Prior to the inundation of bike lanes, Phipps was more accessible in terms of parking. It lost dozens of spaces, forcing the majority of parking to a little island and allotting a few handicap spaces with a drop-off point. In the busy traffic, it feels like a game of Frogger moving from the island across Schenley Drive to the drop-off point, then across the bike lane to safety.

# Abelist Bingo

Heather Tomko

B	I	N	G	O
“Sure, we’re accessible! There’s just one step to get in.”	Mistakenly reading the comments on a <i>Post-Gazette</i> article about a disability advocate suing Uber for lack of access.	A look of shock upon hearing that I went to CMU & have been working for over 10 years.	“Aww, how cute! Are they twins?” Every time I’m out with my sister, who is also disabled.	“Sometimes I forget you’re in a wheelchair!”
Waiting over an hour for a bus after Light Up Night because they’re all too full to fit my wheelchair.	“The pandemic is <i>only</i> dangerous for disabled people & the elderly” because, clearly, our lives are expendable.	Being stared at in public when I’m just walking down the street, living my life.	Your friends are asked, “Are you her mother? Sister? Just a friend?? Wow, that’s so nice of you!”	An Uber reminds me that, even though their HQ is here, wheelchair-accessible cars aren’t.
“Hey speedy! Slow down or I’m going to have to give you a ticket!”	Having to backtrack when walking to the Point because of the inexplicably missing curb cut near Gateway Center.	FREE SPACE	Waiting forever for the only bathroom big enough for my wheelchair & caregiver in the Pitt Union.	“I don’t know how you do it every day. If I were you, I don’t think I could.”
Buying tickets to a concert at Heinz Field, only to find that, again, there are no accessible seats on the floor.	“I went to college with someone in a wheelchair! Do you know John _____?”	Hearing the mayor say, “If it’s not for all of us, it’s not for us,” with no mention of disabled Pittsburghers at all.	Being talked to like I’m a child when I’m a 32-year-old woman.	“Have you tried glass straws? Silicone? You don’t really need plastic straws.”
Being told, “It’s not disabled, it’s <i>differently abled</i> ,” by a nondisabled stranger on the Internet.	Waiting to cross Fifth Avenue—a bus blocking the crosswalk.	“If you’re worried about COVID, you should just STAY HOME so the rest of us can live our lives.”	Searching for an accessible parking spot that doesn’t let my ramp off into a pole, flower pot, or grass patch.	Strangers talking to the people I’m with rather than directly to me—“Oh, she’s so cute, what’s her name?”



## My Safe Space

*Heather Tomko*

**I**t can sometimes be hard to avoid the seemingly innocuous ableism that's ever-present in our lives. So, when I want to be free, I go somewhere where I can escape other people's thoughts and comments—Schenley Plaza in Oakland.

While I'm certainly never alone in Schenley Plaza, it feels a bit like an oasis in the middle of Oakland, a green space among so many academic buildings and businesses. It covers an entire block, with sidewalks around the perimeter, a big patch of grass taking up over half the space, a tented area, food and drink kiosks, and The Porch restaurant. The sidewalk paths are all tree-lined, and have tables and chairs set up throughout. Benches are surrounded by bushes and flowers. There's a sense of being

in nature while in the middle of busy Oakland.

When I'm at Schenley, I feel like I can blend into the crowd. It's constantly bustling, filled with college students hanging out between classes, Oakland employees enjoying their lunch outside, kids (and dogs!) running around in the grass, and tourists stopping by after a visit to one of the nearby museums. There's always something going on—a WYEP concert in the grass, a Pitt-sponsored event going on under the tent, or students sunbathing/studying with their towels and books. I don't feel like I'm on display because there's always so much activity.

The entire space is so easy to navigate,

too. The sidewalks are nice and smooth, which means that I don't feel like I'm being jostled as I drive over them in my power chair. The tables are all just the right height and easy for me to ride right up to. It's just simple—I don't need to worry about accessibility at all.

I can pick up my triple, extra dry, nonfat cappuccino from nearby Starbucks or Redhawk, and pick up a snack from one of the food kiosks at the Plaza—the shrimp and

chive dumplings are my go-to. I can pull up a book on my iPad on one of the many tables dotted throughout the walkways and lose myself for a few hours in between turned pages and sips of cappuccino.

And if I do get a rude comment or an unwanted stare? I can pop in my noise-cancelling earbuds, blast some Taylor Swift or *Hamilton*, and pretend like I didn't hear anything from the outside world at all.

# Unsafe for Sensitive Groups

## Selene dePackh and Alana Gibbs in Conversation

### *The Mashup*

*Alana:*\*

Our parents instilled in us at a very young age to be kind to everyone  
always do your best  
stand up for yourself and for those who can't

I'm from Pittsburgh  
actually Bridgeville

*Selene:*

I moved to Pittsburgh in 1993  
arrived early on a spring morning  
the sun-sparkled tips of PPG tower were rising  
out of a faintly rose-tinted fog at near eye-level

It's more beautiful here than people from other places think

When my first marriage ended that summer  
I knew where I was headed  
I first came to Pittsburgh  
not knowing anyone

Once I accepted my situation and was more rational about it  
I could begin to navigate a plan  
I began to pull it together  
I am no longer dealing with foolishness  
going to live my best life

My parents raised us to speak up and fight for what was right  
to do the right thing even when no one is looking

Mostly I'm invisible these days

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*\* Throughout this mashup of the conversation between Alana Gibbs and Selene dePackh, the passages on the left side of the page are in Alana's voice, and those on the right side are Selene's.*

My disability is most times invisible

I was hyper-aware of needing to perform disability  
I love masks  
I have to wear them anyway for the  
mast cell disorder [environmental sensitivities]  
*. . . the dangers of allowing U.S. Steel to continue to operate  
what amounts to a doomsday machine that cannot be turned off . . .*  
[Ashleigh Deemer, the Western PA Director for PennEnvironment]

It was long said that black people don't get multiple sclerosis  
Quite a bit of the research didn't include Black men, let alone women  
Find your tribe  
they are most definitely out there

What did it mean for you to find your tribe?

I didn't realize how much I needed a tribe  
or how hard it would be to find them  
like I had been reunited with my family  
It made my heart so happy

Everyone was in the same boat with me  
not being able to read each other's faces  
Autistic Masking  
Wearing a physical mask is a lot easier  
When I've been in autistic-managed environments  
I find myself breathing easier, relaxing  
Lights are kept low

I watched the 2016 election in near silence  
in a room full of autistics  
We had the sound turned off  
and grieved our shock together without speaking

*The Biden administration says it will consider tougher limits  
on a deadly air pollutant  
that disproportionately affects low-income and minority communities. . . .  
Recent scientific studies have also linked fine soot pollution  
with higher rates of death from COVID-19.  
Black and brown communities tend to be especially exposed. . . .*  
[The New York Times, June 10, 2021]

*Guard Your Energy—*

Since MS, though, I am getting better at the NO  
Listening to your body is #1

I was told I didn't experience what I'd experienced  
The doctor just said he couldn't help me  
I've been gaslit more than helped for the most part

Gaslight  
I was unfamiliar with the term at the time  
Since then, it has come up often  
Such a slap in the face  
when you know that something isn't right

My therapist confronted me when I said I felt empathy  
I was either allowed to be completely human  
or—I was autistic  
deluding myself that I could feel

I only began to grasp the extent  
when I found my way to my peers  
and heard my story told over and over by  
so many marginalized people  
disbelieved before they'd even begun to tell their stories

Guard your energy and your heart  
Sometimes I do better than others

having to speak up so much in order not to get stepped on gets tiring

I have fallen asleep in my clothes with the lights on

Having a disability during COVID definitely kicked things up a notch  
When the pandemic struck it was like a punch in the gut

Not only were my business and livelihood in peril  
so were my mental and physical health  
Doctors were asking people to stay away  
I remember thinking that we were in some weird sci-fi movie

All my main characters are marginalized in some way

giving the reader the reassurance  
“this isn’t the real world”  
when I invite them into my stories

I have not nor will I ever watch the George Floyd video  
The news is not for me  
We came together and helped each other during quarantine  
then allowed the city to be ripped apart  
I felt like my soul was being shredded  
Being quarantined showed  
how quickly and drastically things can change  
how fragile my body is

I don’t know what that will mean for me down the line  
I’m apprehensive  
like the way I feel about Pittsburgh  
not an easy place to get around  
likely to get overwhelmed by  
pollution  
but at the same time it is full of magic  
the marvelously sinister industrial hulks

One of my guilty pleasures  
is looking at graffiti  
I know it’s wrong  
but the detail and beauty  
. . . amazing  
Pittsburgh has some really cool graffiti

Pittsburgh is a beautiful place  
It’s a shame more people can’t see that

## The Conversation

*Selene dePackh  
and Alana Gibbs*

**Selene dePackh (SdeP):** Hi Alana, to start, would you tell me a little about yourself?

**Alana Gibbs (AG):** I'm from Pittsburgh, actually Bridgeville, and I have my own business. I have MS, and I'm a disability advocate. Being a manicurist has allowed me to do a bunch of cool things that I didn't realize were possible. I have met some truly amazing people, been featured in trade magazines, been an educator for nail companies including Nail Alliance (Gelish) and Swarovski Crystal, was part of the Morgan Taylor manicure team for nine seasons at New York Fashion Week, have been able to help raise money for several charities, traveled, but most importantly, I have been able to connect with and assist people in a way that a traditional 9-5 job wouldn't allow. I can honestly say I LOVE

MY JOB. I've tried to work in other jobs—like retail and customer service—and found they just weren't for me.

I still have my original parents and one sister. Our parents instilled in us at a very young age to be kind to everyone, always do your best, stand up for yourself and for those who can't. These core values are what continue to inspire my sister and me to do the things we do. We both have careers based on helping people. Being connected to people is important to me. I also have two girlfriends who seem like they've been in my life forever that I also consider my sisters. I will be married for 19 years in September [2021], and have one son and two fur babies.

When I was growing up, I wanted to be a ballerina with the Alvin Ailey Dance Troupe, a fashion designer, and a psychologist. I

took dance classes for years. Unfortunately, my knees couldn't take it, so that dream was dashed. The summer I was 12 and entering junior high, my mom got my grandmother to teach me how to sew. This way, I could start making some of my own clothes. I learned quickly that cutting out patterns and measuring was not for me. That summer my mom also taught me how to do a manicure and pedicure from a *Color Me Beautiful* book. *That* I was definitely into. I packed up a kit in my peach caboodle and began giving pedicures and manicures to my family and friends. So my plan was now to go to nail school the summer I graduated high school, get my license and do nails while I was in college studying psychology. Took a psychology and sociology class in high school and hated it. Nails was still on the table, but just as a side job not a career. Well, we know how that turned out!

My favorite superhero is Wonder Woman. When my sister was born, my parents got me Wonder Woman Underoos and a "big sister" button. I think I connected with the fact that Wonder Woman doesn't just save the day, she tries to help people be better on their own accord. My favorite color is blue, any shade. My favorite animal is a pig. I have wanted one for years. Ninety-nine percent of the time I am wearing Converse sneakers. I pick the shoe then the outfit. I love to laugh. It's probably my favorite thing next to sleeping. I also enjoy watching movies, listening to all kinds of music, reading, being around fun people, and relaxing with my dogs.

When I am not working or on the move, I am most content being still. I can be found in a hoodie and leggings on the couch with candles burning, a weighted blanket over me, a dog curled up on my legs, drinking hot tea while reading a book or watching a

documentary or comedy. I am a very laidback kind of person.

**SdeP:** Weighted blankets are awesome!

**AG:** So, Selene, are you a Pittsburgh native?

**SdeP:** I was born and raised in Washington, DC, and lived in Maine for about eight years bridging my late twenties and early thirties. I moved to Pittsburgh in 1993. My ex and I had been planning to move to Morgantown, West Virginia, but I wanted to visit the old Art Institute. I had the usual prejudices about the city being drab and ugly. We arrived early on a spring morning, coming down Grandview Avenue—the sun-sparkled tips of PPG tower were rising out of a faintly rose-tinted fog at near eye level—it was magical. I thought, OMG, this is *Pittsburgh*? When my first marriage ended that summer, I knew where I was headed.

**AG:** One of my favorite things about Pittsburgh is the skyline at night coming through the Fort Pitt Tunnel. It's more beautiful here than people from other places think.

**SdeP:** One of the things I saw on your social media was your work with Unabridged Press and [A Valid Podcast](#). Can you tell me more about that?

**AG:** My sister Darah and I were asked by Jennifer Jordan of Unabridged Press if we'd be interested in telling our story by way of an [interview](#) for the 30th anniversary of the Americans With Disabilities Act. We told our diagnosis story and talked about how our illness affected our lives, our family, and our careers. We also talked about what the ADA meant to us. It was supposed to be an hour



or two of recording, but because of some technical difficulties we ended up recording for five hours. From that interview, Jennifer felt we would be good hosts for the second season of *A Valid Podcast*. I believe it was six episodes. We talked with Dawn and Daana of [Myelin and Melanin](#), Andrew Gurza of *Disability After Dark*, Judy Huemann, and Jennifer Keelan Chaffins. Judy is featured in the Oscar-nominated documentary *Crip Camp* and Jennifer Keelan Chaffins was involved in the famous Capitol Crawl as a child. My sister is a huge podcast fan and wants a podcast of her own. Our experience with *A Valid Podcast* gave us some perspective on podcasting and the type of show we'd want to do. Currently we are working on our own podcast. It is called *Self Care Sisters*.

**SdeP:** The recorded videos you've posted are really helpful to me because of my auditory processing. With video that I can pause, I pick up so much more information. I'd love to know more about *Self Care Sisters* and where to find the podcast when you get it started.

**AG:** Watch this space!

. . . tell me, Selene, what is your diagnosis story? What is your official diagnosis if you don't mind sharing, how old were you when you got diagnosed, did you have signs or symptoms prior to diagnosis, how did people (family, friends, coworkers) treat you during the "figure it out" phase, how did they treat you after, what would you say to your disability if you could?

**SdeP:** Getting a diagnosis has been a nightmare. Parts of the picture have been \*officially\* confirmed, but I've been gaslit more than helped for the most part. My life

has been marked by a number of serious medical errors that have left permanent damage. I've always had strange health problems, but only recently have found an answer that takes into account all the various aspects. I'm now diagnosed with autism (dx in my early fifties), neuropathy (early thirties), mast cell disorder (early sixties), arthritis (late fifties), hypermobility (childhood) with suspected Ehlers Danlos Syndrome (currently), and Postural Orthostatic Tachycardia Syndrome (adolescence). This group makes up a genetic cluster of disorders that are only now being recognized as a single entity, thanks in large part to a few people who have it and have done amazing research. Unfortunately, a lot of doctors don't like uppity patients who go looking into their own problems. Could be that's one of the reasons autistics have a life expectancy of 54. I'm way out of warranty.



My most recent experience with attempting to get a diagnosis and treatment was about five years ago, when I went to an osteopath for help—my hip had subluxed

(partial dislocation) for the first time. I came in with a slight limp and stiffness in the upper leg. I was told I hadn't experienced what I'd experienced, that there was no damage to the joint, and was given stretching exercises. When they didn't work, I researched on my own, and found the [Oh Twist](#) page via online autistic support groups. I drew up a document with all the signs supporting an EDS diagnosis, and was treated with condescension and given more aggressive exercises. I did the exercises faithfully, and my hip got worse. The pain got crazy, and I started needing a cane. People made all the usual comments like "Haven't you got enough sympathy for that yet?" when I kept using more substantial assistive tech. Finally, I went back to the doctor—breaking down in tears, which infuriated me—and he said he'd order an X-ray to "humor me." When the X-ray report came back, it showed the joint worn down to bone-on-bone. All the cartilage was gone. EDS cartilage is fragile and easily destroyed. EDS patients should not do regular stretching because it damages their joints. The doctor just said he couldn't help me and more or less shooed me out of his office.

I'm skeptical as well about a lot of the "treatments" offered by doctors who will give an EDS diagnosis readily. There really isn't much to do about it that's been proven effective other than gentle isometric exercise and using common sense, but suffering people will do and pay just about anything for hope, and that can be exploited. I think my best resources are a couple of no-nonsense support groups I've found and a few friends I've made in them. We compare notes and share life-hacks and jokes that keep us sane. I don't think what I'd say to my physical disability is printable. Laughing at it or swearing is about the best I

can do. My crutches have a mini-bumper sticker that says, "Honk if parts fall off." One of my favorite things is an EDS Life Hacks Facebook group that has a "Memes Monday" post every week. It gives me a chuckle, no matter how bad I feel. I need to let this thing know I can still make fun of it.

**AG:** Laughing and swearing, in my opinion, are great ways to handle lots of situations. Also your bumper sticker sounds awesome!!

You said you felt gaslit. Several years ago, my mother and I watched the movie *Gaslight* from 1944 with Ingrid Bergman, Joseph Cotton, and Angela Lansbury. I was unfamiliar with the term at the time. Since then, it has come up often. Such a slap in the face, especially when you know that something isn't right with your body. How did finally getting a "truer" diagnosis feel and did you ever address this with your doctors? Did you let them know how their nonchalant behavior affected you? When I read that part of your story, I just wanted to hug you and then punch your doctors in the nose LOL.

**SdeP:** Gaslighting by medical professionals has been in the fabric of my life from the start. My mother was prescribed the hormone DES (diethylstilbestrol) when she was pregnant with me in 1956 because she'd miscarried several times. Besides ultimately being proven more likely to induce than prevent miscarriages, DES has been implicated in a whole raft of reproductive system troubles in the offspring who were exposed to it *in utero*—everything from infertility to cancer. One of the most common conditions in girls turned out to be endometriosis, which causes brutally painful menstruation. Unlike Thalidomide-caused birth defects from the same era, DES-induced problems were only visible

once the affected people's reproductive systems matured, and there was a lot of resistance by the medical profession to accepting it as the cause. It was prescribed from 1938 to 1971, ample time for the problems to surface and then to be swept under the rug.

When I complained about horrendous periods that wiped me out, I was given the whole "shut down the adolescent drama queen" treatment and put on tranquilizers. In my late twenties, I couldn't stand it anymore and fought to get a hysterectomy. Gynecologists resisted because I hadn't yet had children, but I finally found one willing to do the surgery. I ended up having the operation rescheduled for a couple of months after my original appointment because the doctor hadn't put his vacation on the calendar. During that time window, I began falling and having shooting pains in my legs. Once I was opened up, it turned out my uterus was adhered to my spine with endo lesions that had eaten through the sheaths on my femoral nerves. My womb was hardened with years' worth of scar tissue, and my ovaries were long-destroyed, full of lesions and cysts that would have made me infertile for at least a decade, so all the delays had been for nothing.

I continued to have pain and falls after the surgery and was sent to a prominent young Golden Boy neurologist. At the time, this doctor was being featured in the local media of my rural state as having unearthed a pocket of multiple sclerosis cases for which he was avidly searching out the cause. He had diagnosed several times more instances in the area than statistics would predict. (I'm being deliberately vague here, because he's still in practice, and I don't care to open myself to legal jeopardy.)

Of course, even though my pain levels

were higher than would be expected for MS and his arduous series of tests came up inconclusive, he decided over my objections that I was another of his anomalous cases. I didn't respond to the increasing strengths of central nervous system medications he prescribed, and every time I complained about side effects, he upped the dosage since they weren't helping yet, and the side effects that were starting to give me symptoms of CNS disease only proved to him that he was right.

Finally, my then in-laws paid out of pocket to have me examined at a nationally recognized medical institute, where the director of the neurology department declared that I simply had a sh!tload of scarring on my leg nerves from the exit of my pelvis into my spinal cord, and yeah, that kind of thing can make someone fall a lot, as well as causing them to feel like they're having cigarettes put out on their limbs. He wrote a letter to the Golden Boy to the effect that he might want to re-evaluate his diagnostic procedures, but I never heard anything more about it.

Then, about a decade ago, when I was desperately looking for answers after once again being unable to complete my undergrad degree, I sought an autism diagnosis from a therapist who was supposedly an expert in the field and would counsel me on how to better manage the challenges that came with my neurodivergence. I got the diagnosis, and it offered a reason beyond personal failure, laziness, and poor character for my struggles with employment and education. Then, after a couple of years, my therapist confronted me when I said I felt empathy. I was either allowed to be completely human, having the full measure of compassion, but devoid of character—or—I was autistic and was simply deluding myself

that I could feel what an actual, genuine human could. That one left some bruises. In a lot of ways, it had been easier to get over the damage to my body than having to work my way beyond that cruel prejudice and to understand what heartlessness goes into the treatment of autistic people.

I only began to grasp the extent of the medical gaslighting I'd experienced when I found my way to my peers online and heard my story told over and over by so many people, most of them women, many non-cis/het and neurodivergent, women of color, people for whom standard English wasn't their first language, people judged overweight and in need of braces and canes—so many marginalized people disbelieved before they'd even begun to tell their stories.

It's wonderful that you've found such a real-life group of supportive people who understand what it's like to deal with being disabled. What did it mean for you to find your tribe, others like the *Myelin and Melanin* podcasters who live with many of the same issues you do?

**AG:** I didn't realize how much I needed a tribe or how hard it would be to find them. When I first got diagnosed with MS, I knew nothing about it and didn't know anyone other than Montel Williams and Jack Osbourne who had it. My family and I had to do a lot of research simply to figure out what having MS was all about and what my life might possibly be like with it.

Quite a bit of the research didn't include Black men, let alone women. It was long said that Black people don't get multiple sclerosis. Clearly that is [incorrect](#) (LOL).

My sister is my biggest, loudest cheerleader and advocate—plus the girl loves to research. She bombarded me with articles,

Facebook groups to join, seminars to go to, and podcasts. That's how we found Dawn and Daana of *Myelin & Melanin*. Talking to those ladies truly felt like I had been reunited with my family. They could relate to what I was going through and give good solid advice because they had been through it. And they gave that advice freely and compassionately.

Even though I have an incredible support system who listens and tries to understand what I'm feeling and going through and would do absolutely anything for me, it's different when someone has actually had the same experiences as you. Being able to add those ladies to my tribe was amazing. It made my heart so happy. Our interaction also encouraged me to cast my net wider and share more of my experiences to hopefully help someone else who is looking for their tribe. The tribe is definitely important. It can help with accountability, answer questions you may not want to ask other people, be a sounding board, a shoulder to cry on, a much-needed hug, and a deeper understanding of oneself.

What do you think about Pittsburgh's disability community? Is it your tribe? Do you feel the disability community in Pittsburgh is welcoming?

**SdeP:** That's a complicated one. I'm only familiar with the local autistic community, and while the initial meetings were welcoming, I found that my need to "write my own script" got in the way of developing closer connections. I've never been able to stick to a platform without questioning it in light of my lived experience, and that's a trait better suited to a solitary writer than a member of a community trying to raise its collective voice and amplify a position in unison. Given what I know about myself and

the effort it takes me now to make any kind of IRL connections, I've mostly developed my network online. It's been a challenge figuring out the terrain of my own multiple disabilities, how they interconnect, sometimes echoing and other times diverging from other people's experiences.

**AG:** From my understanding of you, Selene, you seem like a real badass in your vintage-ish years. I like it! I've met quite a few people within the disability community whom I would also classify as badass. Most of them say they got that way after years of dealing with the world's ableist nonsense. Do you remember what flipped that switch for you? My switch was flipped when I turned 40. That year I decided that I was no longer going to deal with foolishness and I was going to live my best life regardless of what my body was doing. So far, I can report that I am having a great time.

**SdeP:** Mostly, I just found I ran out of energy to put up with it. "No spoons left, only knives," as we say in the disability world. When I first came to Pittsburgh, not knowing anyone, after closing out my father's probate and getting away from my abusive first marriage, I wrote a lot of poetry. One phrase I came up with still sticks in my mind about how I got through it—"The hard sanity of pure exhaustion." Some days, and with some people, I can let a lot go, and some days it's a whole lot better for most people to leave me alone.

You seem enviably relaxed and competent in the way you deal with everything you have on your plate. How do you handle the fluctuations of your disability, particularly in advocating for another disabled person whose disability presentation also can be changeable? What advice might you have for

someone who finds themselves newly disabled? What do you wish you knew when you first were dealing with your own disability?

**AG:** Through doing nails, I have met some amazing people and had some incredible experiences. It has also given me the flexibility to be able to take care of my family when they were in need. My sister is bipolar with PTSD. It was a struggle to get her the help she needed and be available for therapy sessions and such. Being my own boss and having an understanding staff and clientele made it possible for me to not miss anything.

My parents raised us to speak up and fight for what was right. Also to do the right thing even when no one is looking. So being my own advocate, while sometimes frustrating, came very easy. My experience with trying to get my sister help taught me a lot about how the health system worked. When I got diagnosed in 2016 with MS, I was very aware and comfortable with asking for things and also questioning what I didn't understand. And not letting my doctor's staff blow me off.

So, I wouldn't say that I am stubborn, maybe headstrong and driven to a fault. My sister would strongly disagree. She tells me I am stubborn a lot. Before my diagnosis, I was very comfortable with burning the candle at both ends. It's basically how I was raised. I worked best under pressure and on lots of caffeine. I didn't say "no" a lot unless it came to my son. My sleeping habits were horrible. I was very aware of the fact that I was not living my best life, as the kids say.

Then, in April of 2016, all of that changed. I had horrible eye pain that felt like I got hit with a softball, and my vision was going in my left eye. My thoughts: Oh

my allergies are acting up, I am pretty sure I got something in my eye, must have rubbed my eye too much. That went on for two and a half days. Knowing what I know now I will NEVER wait that long to seek medical attention ever again. Turns out I had optic neuritis.

An MRI and spinal tap later found out the culprit was MS. I knew nothing about it. As far as I knew, no one in my family had ever had it. And I still couldn't see out of my left eye. Being a manicurist, the fear of not seeing the color or detail of my work was mind-blowing. I didn't know yet to be worried about possibly not being able to use my hands or speak clearly to people let alone being classified as disabled.

The treatment for optic neuritis is steroids. For whatever reason, they didn't work for me, and my condition got worse. The longer the nerve stays inflamed, the greater the risk of permanent damage. Thank goodness I have a rockstar of a neurologist who is also an ophthalmologist. He gave me some amazing perspective about my condition.

I was due to leave for a work trip that paid very well. I needed the money from that trip because I was planning to go away on vacation soon. Even though I still could not see and was in pain, I was still planning on going on that trip.

My doctor had a treatment for me to try, [plasmapheresis](#). I could either stay in the hospital for 10 days or do it as an outpatient. With the outpatient option, there is a high risk of infection, and it is very hard on your heart.

My doctor said, "Do you want to go on your trip and possibly do damage to your body or do you want to be better and see again?" I chose to see. Checking into the

hospital for a 10-day stint was totally necessary, but it was hard. Not having control was new for me. I wasn't able to work, and I had to say "no" to things. All I could do for those 10 days was give my body its much needed rest. I now had to reflect on my life and figure out how it had to change. I was angry, sad, nervous, and guilty. I was feeling that my actions of not pausing in life or driving myself to the edge of exhaustion had put me there. It was a punch in the gut. I don't believe that anymore.

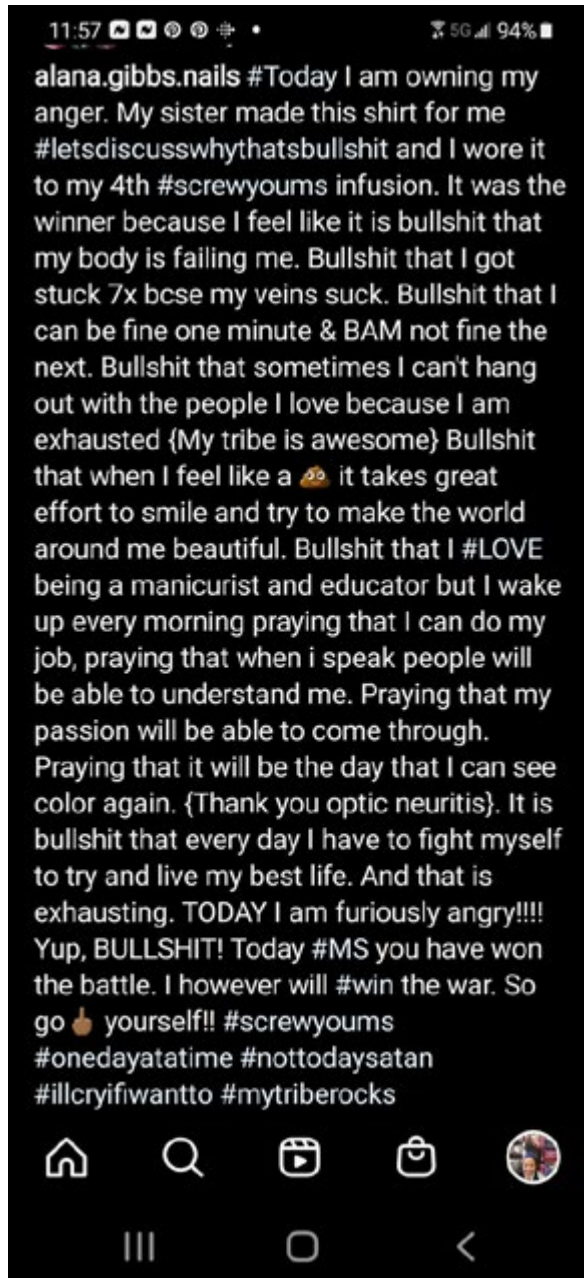
Once I accepted my situation and was more rational about it, I could begin to navigate a plan and figure out the "what next" in my life. MS has taught me that planning is essential. Even for how unpredictable this disease is, you have to have a plan. For instance, if X happens I/we are going to do Y. I started taking the advice I had been giving my clients for years: *Self-care is essential*. Slowly but surely, I began to pull it together. Sometimes I do better than others. That's where my tribe and support system come in. They definitely call me out when I am slipping and help me stay on track.

What I would tell someone who is newly diagnosed/disabled is that your self-care is just as important as the meds you're on. You are still you. Be easy with yourself. It's ok to feel exactly how you're feeling—and don't let anyone tell you otherwise. Yes, this situation truly stinks, but you're gonna be ok. If you don't vibe with your doctor or their staff, get a new doctor. It's ok to have a bad day. **You know your body better than any person, test, or machine; if something feels off to you, do not hesitate to tell someone, and don't take "no" for an answer.** Keep a journal of your symptoms and day-to-day feelings. Find your tribe; they are most



definitely out there. Don't take mess from anyone, especially toxic people or those random advice givers. Do your own research. Make yourself and your needs a priority. Listen to your body.

*The post below is from Instagram after my fourth infusion.*



home alone, and I cried for hours. I was angry and sad and hurt. The reason I was getting infusions was that my previous medicine, an injectable, was not working. My dad went with me to this appointment. Usually, it was my sister or mom. While I know without a doubt my dad loves me, he couldn't understand what I was going through or feeling at that time.

My disability was becoming very apparent to me at that moment, and it hurt like hell. In the beginning, I didn't consider or identify myself as disabled. MS was just something I had, like a cold. I think, for a little bit, I was in denial or possibly a bit delusional about my condition. It wasn't until I started having symptoms on a more regular basis that I recognized my disability and accepted it.

It took my feet feeling like they were being stabbed with pins, the feeling of something crawling on me, my fingers and arms tingling, the mind-numbing exhaustion that would slap me in the face midday, the fatigue I feel after taking a hot shower, the tingling sensation in my lips, the overwhelmingly horrible feeling I now get when my body is warm and my dogs lick me, the anxiety of speaking to people who don't know my situation and possibly not being able to get my words out. Worst of all, I think, was having my doctor say that "this medicine is preventative and not restorative" and not knowing if my sight would return completely. That was a huge hard pill to swallow: recognizing and accepting my disability for what it was.

To me, my disability is a chapter in the story that sometimes makes you laugh, sometimes makes you cry, sometimes makes you want to say this is the worst story I have ever read. And sometimes it makes

When I got home after my infusion, I was

you say, “Dang, that girl is kicking butt, what is she gonna do next?”

On a more positive note, doing my first Walk MS in 2017 helped me to be more accepting of my own disability. It also gave me a snapshot of what my tribe looked like and what they were able to do. Walking across that finish line and getting that medal was very emotional for me. I was thinking at the time, “Look at my people, I am one of you and we are unstoppable.” And I have to say the things I wish I knew when I first got diagnosed are the things above that I would advise someone else: It’s ok to feel whatever you’re feeling, and all of this is going to be ok.

What do people assume about you and your disability? How do you deal with know-it-all people and their toxic assumptions?

**SdeP:** When I was younger and needed to use assistive tech/accommodations (the endometriosis lesions at my spinal cord made walking a challenge), I was hyper-aware of needing to perform disability in a way that wouldn’t tick people off. They seemed to have no problem setting themselves up in judgement as to whether I was “deserving” of having the disability that I presented recognized.

Now that I’m in my crone stage, disability is more expected in the part, and I get less of that BS. I wear a “just try it, c’mon, you know you want to say it” face when the nasty, judgy ones start sizing me up. People can also be quite pleasant about accommodating me lately, perhaps because old ladies are supposed to be treated that way. Mostly I’m invisible these days, and having to speak up so much in order not to get stepped on gets tiring.

Do you find it exacerbates ableist skepticism when you “look perfectly fine”

sometimes and can barely function at other times?

**AG:** I absolutely hate when people say things like “You don’t look sick, you’re so strong, or brave, you’re such an inspiration.” All of that is crap! I do not want to be someone’s inspiration because I am sick and was able to shower myself today. I want to be an inspiration because I did something amazing. But on the flip side of that, because my disability is most times invisible, people don’t recognize my disability as one and just make assumptions. Also very frustrating.

For example, if I’m zoning out or having cognitive trouble and not talking, some people think I am shy or rude. Neither is true. Sometimes it takes everything I have to pay attention to a conversation. I’ve found that, like me, most people don’t know anything about MS unless they know someone personally.

I find myself educating people when I am in the mood. Sometimes I just don’t have it in me. Sometimes I don’t want to explain why my hands are shaking (“Oh too much caffeine today”) or why I keep dropping things; I don’t want to have someone else add the word they think I am struggling to get out. Honestly, it really does depend on how I feel as to whether I check them or not. That’s where ableism and MS get under my skin. Why do I need to explain? If I don’t feel like explaining, I let someone’s ignorance or assumption continue. It’s unfair. One of my concerns when I was newly diagnosed was disclosing to people that I was ill. It was concerning for several reasons. In a salon, your clients are everything. If they don’t come, you don’t make money. And if they think you’re unreliable, they aren’t coming.

I must admit I was fearful to tell some of



my clients. In my head, they were gonna think, “Oh, she’s sick or gonna be in the hospital so let me find a new manicurist.” That was my own hang-up and me judging others. My clients were amazing and super-supportive. Opening up and sharing what was going on with me allowed them to talk more freely about things that were going on with them too. We always had a good dialogue, but this just made it deeper, I think.

With clients of my coworkers, however, the situation was slightly different. For some of them, my illness was a topic of conversation, not concern. In those situations, I always spoke up regardless of how I felt. Disclosing is a lot like coming out of the closet. You’ll know when the time is right and with whom you want to share. And in my opinion, it’s not acceptable for people to “out” you without your permission.

We had a situation at the salon where a stylist did tell her client about my situation because the client was going through a similar situation and was looking for information and someone to talk to. That’s fine. It’s weird, this disability thing is a strange bird. Again, I would tell anyone in this situation to stick to your guns and do what’s best for you and your particular situation.

Selene, what do you want people to know most about your disability? Does it affect you professionally? How/in what ways do you advocate for yourself?

**SdeP:** I want people to know that the EDS cluster is more common than people realize, and that just because it often appears in those of us who are neurodivergent is no reason to dismiss it. The stigma that it’s a weird condition that mostly affects weird people seems like an almost instinctive

labeling response by some who connect it with the autistic hand-flapping, clumsy stereotype.

I sure as hell don’t want that precious sympathy that a lot of people apparently think is desirable enough to become disabled to get. I desperately miss the physical skills I used to enjoy— carpentry, gardening, faux finishing and restoring furniture—and I’d trade whatever sorry bits of sympathy I get for the chance to just be able to climb a flight of stairs while carrying something in both hands. Pity is vastly overrated as a motivator of disabled people’s behavior by those who think they bless us with it.

Although I consider autism to fall within the [Social Model of Disability \(SMD\)](#) more than as something that I have to do battle with, the damage directly attributable to my autism that was done by chronic bullying, domestic violence, and cruelly misguided therapy has left its mark. The SMD proposes that what makes someone disabled is not their medical condition, but the attitudes and structures of society. When I’ve been in autistic-managed environments, I find myself breathing easier, relaxing. Lights are kept low, with no fluorescents; there’s no electronic background jabber; people talk softly and take exciting conversations out of common spaces.

Sometimes autistics do miss that their behavior is disruptive when they forget others in the environment, but autistic-run social situations tend to be attentive to overall calm, and people who disturb it will be gently reminded of where they are. Stress is the cause of the overwhelming majority of negative autistic “behaviors.” That stress is usually caused by excessive sensory, social, and emotional demands common in neurotypical-controlled environments.

These days, I write, and, in spells of inspiration, I do graphic art/digital illustration to make myself heard. I consider myself blessed to have talents that I can use when my body is limited. I used to be more involved as an activist, but found I couldn't navigate the infighting. Creative works can draw in an audience and let them experience disability, which is the most intimate and effective form of advocacy I can do.

It seems like what you do could be kind of like that. Beauty as a fierce performative art is a powerful means of fighting back against being Othered. Do you view your work as a beautician harmonizing with your work as an activist?

**AG:** For many, many years, I have personally heard a lot of nonsense about being a manicurist, like, "Is doing nails your only job? Aren't manicurists supposed to be Asian? You'll never make as much money as a hairstylist." Not sure if people realized they were being offensive, but they absolutely were.

I love being a manicurist. It has allowed me to support myself and my family. I became a manicurist because I wanted to help people. It is a job that I would do for free. That's how I knew I was really into it (Luckily I don't have to do it for free). Through doing nails, I have been able to make a lot of connections with a lot of different people and have some awesome experiences.

One of my favorite experiences was doing the nails for the [Mon-Yough Community Services Center](#). My sister is a peer support person who also teaches wellness classes for many of the group homes in Pittsburgh. Mon-Yough was one of her sites. The people at the site were so excited about their

annual prom. There was going to be dinner, dancing, karaoke, games, and raffles.

My sister asked if I would come to the site and do nails for the prom. Some of the people had never had a manicure while others thought because of their disability they shouldn't have one. Both instances made me sad and needed changing immediately. One particular person, their hand kept shaking and they were smudging their polish. I simply fixed the polish and held her hand until it was dry. She thanked me for being so kind and patient with her, and making her feel pretty. She couldn't wait to get all dressed up and wanted to make sure I was attending the dance so I could see her complete look. Which, after that of course, I was going! EVERYONE deserves to feel beautiful and be treated with kindness, common decency, and respect.

This experience of being treated harshly at a salon is one I hear often from the abled and unfortunately more commonly from the disabled. At one of the sites, I taught hand care and basic hygiene. The majority of people at this site had mental health issues. They also told me tales of how they were mistreated or misunderstood at salons.

Every two weeks, I went to that site, and we talked and shared and laughed—and I pampered those ladies. They deserved to be listened to and heard. Every summer I, my sister, and some of my staff would volunteer at a camp for adults with cancer and their caregivers. It was called Camp Raising Spirits.

My staff and I would give foot and leg massages. One summer we massaged 100 feet. We listened, and sometimes we cried with the people, but there were always a lot of smiles and hugging. The point of the camp was to let the campers forget about

their cancer for those three days.

I think—kinda like Wonder Woman—being a manicurist and keeping to my core values have given me the power and courage to be a champion for myself and those in need. If I can do something to make someone else's life better even just for one day, I am going to do it. I am not afraid to talk to people or say what I need to say.

Like with doctors, for example, if I feel something new or wrong, I am reaching out. I don't care if that's not supposed to be one of my symptoms. I am telling you, and I am going to follow up with you about it. Email, phone calls, smoke signals . . . whatever it takes. Because I don't want years down the road for this symptom to actually be something where something could have been done but wasn't. Sometimes you have to be annoying and aggressive to get results. But it's *your* life and your body, so it's important.

**SdeP:** Wow. That work sounds like such powerful healing. At some point, I hope we can spend more time just focusing on that aspect of what you do. So many of us who have worked as disabled activists have dealt with burnout—do you have any suggestions on coping and staying effective?

**AG: *Guard Your Energy.*** A lot of times, it is exhausting to advocate for yourself or others. Making a million phone calls, being on hold, waiting for a call back, sending an email or two. It can be overwhelming. I take on other people's emotions and energy for 8-10 hours a day, and that's just at the salon.

When I get home from work or an event, I am wiped out and usually don't have the energy to do more than watch TV. Really, the TV is usually just on for background noise.

Quite a few times, I have fallen asleep in my clothes with the lights on. Now add the fun mind-numbing fatigue of MS. That's a party. In the past, when someone was in need, regardless of my own status, I'd find it hard to say "no." Since MS, though, I am getting better at the NO. Because of MS I have definitely become a [spoonie](#).

I am now picking my battles and delegating. Whether you are advocating for yourself or someone else, it's important to guard your energy and your heart. It can get frustrating and overwhelming at times. To decompress, I like to watch mindless TV and movies. *Bob's Burgers* is one of my favs. I blow bubbles to release stress and love a good candle. I also journal. You can always find bubbles, a notebook, and colored ink pens in my bag. I also read for fun, love rocking out to music of all kinds, and coloring. My sisters (one biological and one chosen) are my go-to people when I need to talk it out. Rest when you can and need to. Listening to your body is #1. All of these elements are part of my self-care routine. It's what keeps me sane and able to carry on. I strongly suggest to anyone and everyone to have a solid self-care routine. And as you and your situation change, so should your self-care.

What gives you energy and refuels you for your battles? What would you say is your greatest victory so far?

**SdeP:** I used to do a lot more computer graphics and loved the intense concentration, but I'm finding myself struggling with brain fog when I try to do things with software that once came easily. I hope I can get past that, and I'm trying to be cautiously more physically active to get my head clear. In the meantime, I've gone back

to playing with pen and ink, both for writing and drawing. It's simple, but it requires good concentration, and that feels like a healthy thing right now.

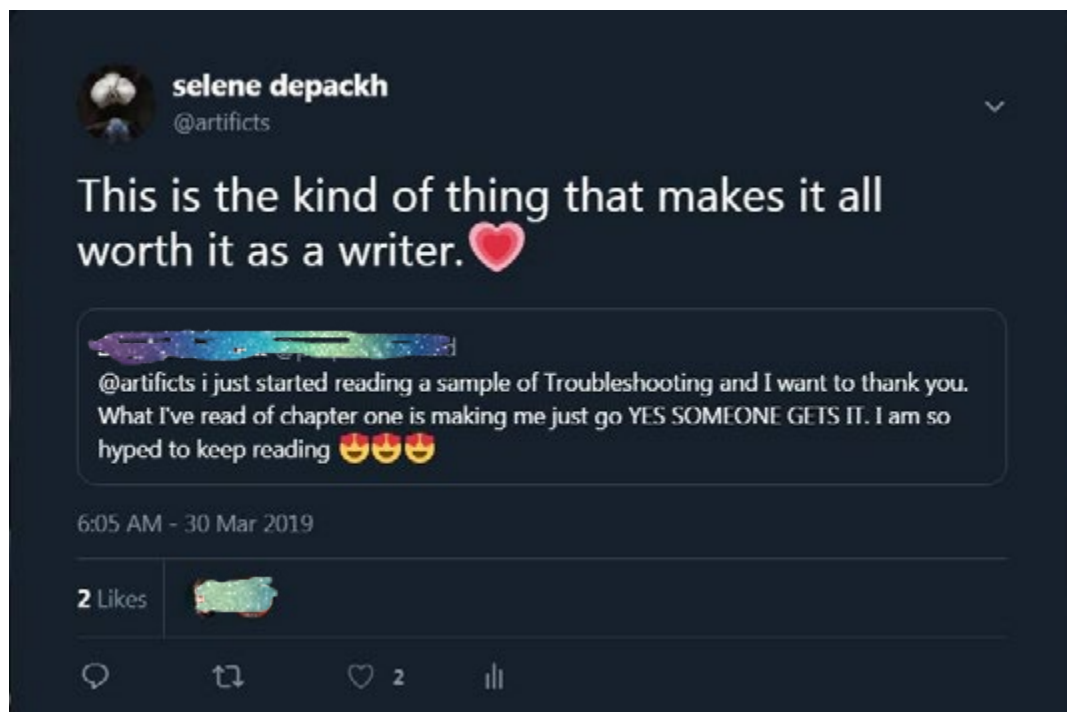
**AG:** I'm sorry to hear about the brain fog. It's something that comes with a lot of disabilities. What other creative outlets do you have?

**SdeP:** I'm also getting more serious about my fiction writing. I published my first novel with a disability-centered micropress in 2018. In retrospect, that wasn't the best choice, but it forced me to move on and up. I just had a novella that centers a pair of disabled older women accepted by *JournalStone*, an indie press I've admired for years. I'll be working with an amazing editor. It's almost enough to nick a small chink out of the fortress wall of my imposter syndrome.

**AG:** When did you start writing? What is your favorite subject matter to write about? And how many of your pieces have been published?

**SdeP:** I only started writing fiction seriously about a decade ago. I've found a foothold in the speculative fiction genres, from dystopian to slipstream to contemporary supernatural-inflected noir. All my main characters are marginalized in some way, and I write to bring them into dialogue with my reader. I find that giving the reader the reassurance of being able to say, "This isn't the real world," when I invite them into my stories allows them to let their guard down. Then, I can tell my uncomfortable truths in a kind of dream-language they haven't built up a resistance to hearing.

*Then there's the feeling I get when I see a posting like this one [on social media].*



I do still intermittently work in [digital mixed media](#). I terribly miss gardening, as the pun in my portfolio site title, *asp-in-the-garden*, might imply, but I'm finding it's too exhausting. I used to be a trim carpenter, and my spouse and I bought a great old house that I got about halfway through fixing up before I lost the physical strength to handle the work. That happened relatively suddenly when my hip went out, and then the medical treatments made it worse. I'm still trying to adjust to that new reality.

In addition to the half-dozen or so anthologies listed [here](#), I've had work in a couple of decent litmags, and there's the novel *Troubleshooting* that's been marooned by the publisher, a casualty of them being so small and having too many things on their plate.

**AG:** I really enjoy reading. I like to read books that have also been made into movies. I like to compare the two. Nine times out of ten the book is better. So far, the only time I liked the movie over the book was *The Fault in Our Stars*. Do you have a favorite book/author?

**SdeP:** It's hard to say a favorite. I love Angela Carter, Octavia Butler, James Baldwin—but also Borges, Nabokov, Chandler, Ballard—quite a few who aren't at all in the “enlightened/woke” category. I'd say I get my payback from that by learning their magic tricks and then using them for my own ends.

It's kind of like the way I feel about Pittsburgh, I suppose. It's not an easy place to get around if you don't walk very well and you're likely to get overwhelmed by loud noises, pollution, and people who have a very different idea of personal boundaries

than you do, but at the same time it is full of magic. I love Pittsburgh's history, the nexus of the founding of the country with all its military/colonial complications, the tragically forgotten labor movement heritage, the marvelously sinister industrial hulks that were here when I first came, now sadly torn down or sanitized.

**AG:** Pittsburgh is a beautiful place. It's a shame more people can't see that. One of my guilty pleasures—we'll call it—is looking at graffiti. I know it's wrong, but the detail and beauty in some of the pieces are amazing. Pittsburgh has some really cool graffiti. Do you have a favorite Pittsburgh spot or activity? Are there places in the city that you'd like to go, but that need to be more accessible?

**SdeP:** I wish I could just get on a bus and go to the universities like I used to. Even accessible transit buses leave you off with a quarter mile of hill to climb unless you can stand around and wait for a shuttle, and that's not happening. My spouse takes me to things when she can, but that's limited. The Carnegie is probably the most accessible of the places I treasure, but COVID-19 has made that impossible up until very recently. I'm not sure I could handle the bus now anyway. Being away from crowds has made me hyperaware of how much they stress me, even family gatherings that I used to be able to suck-it-up and get through.

How has the virus affected you? I'd think it would have been hard to keep your business going through it. How did the social turmoil of the past few years weigh on you, along with every other thing you've had to deal with?

**AG:** As we talked about earlier, I am a small business owner and self-employed. When the pandemic struck, it was like a punch in the gut. We were asked to shut down for two weeks. While two weeks is not ideal, it is doable. We, however, were closed for almost 3 months. April 1, 2020 is when panic hit for me. Not only were my business and livelihood in peril, so were my mental and physical health. Doctors were asking people to stay away unless it was an emergency.

Having MS put me on the compromised immune system list, and my son was 24 and thought he was immune to COVID-19. I felt scared, stressed, worried, irritated, sad, unsure, isolated, and an entire barrel of other not-so-pleasant emotions. Having all of that going on unfortunately caused an MS flare that I was trying to pretend wasn't happening. I remember thinking that we were in some weird sci-fi movie. Having a disability during COVID definitely kicked things up a notch.

My sister teaches wellness groups for several of the group homes in the area. She wasn't able to do it. That made me very sad because I have seen the benefit of what she does. Many of the folks looked forward to her coming and the normalcy she brought. I thought about the people who lived alone and couldn't have contact with anyone or go anywhere. Then the protests and riots began.

I have not nor will I ever watch the George Floyd video. I don't want to watch someone lose their life. What struck me about Pittsburgh and even the world was how we came together and helped each other during quarantine and then allowed the city to be ripped apart. I 100% believe in peaceful protest and expressing your opinions and beliefs. But a riot is something

I just can't get behind. After seeing how people were hurting each other and tearing down small businesses and the hate speech that was thrown everywhere, I felt like my soul was being shredded.

I've never really been a news watcher, but seeing all of that confirmed that the news is not for me. My sister and I were raised to be kind and respectful to all people. I truly don't understand the theory of hating someone because they are different from you. I pray often that as a whole we will get it together. Being quarantined showed me just how quickly and drastically things can change. It made me aware of how fragile my body is, and how my disease likes a lot of attention. Also that being around people who I love, even if we are just watching TV, is extremely important to me.

How did you survive the pandemic? How if at all did it affect your disability? Did being in quarantine help you discover anything new about yourself?

**SdeP:** Quarantine itself was lovely. I wish the world was that quiet all the time—the animals coming out in the streets, no human yelling and digital squawking, the sky clearing, birdsongs louder than traffic—that part was paradise for me. I didn't have to make excuses for avoiding social events. Nobody gave off waves of offense that I was being rude for not wanting to come join the raucous party that would ordinarily have left my brain feeling jammed up, rattling and ringing with jagged tin cans full of rusty nails and fishhooks.

It's like I'm that kid again who used to hide when guests came over, with my senses re-sensitized as if they were new, not bludgeoned into numbness by shrieking voices and unwelcome intimacies. It's



harder than ever to politely navigate those situations now that I've become accustomed to being free of them.

I'm not shy, not by any means, and there are many people I love with all my heart, but I do so wish that a lot of them could calm down. I also wish they didn't all need to be in one excessively perfumed, randomly food-filled place at the same time, hugging and yelling over each other with music and the television on—in order to feel properly affectionate. Not to mention that some of them, with whom I must stifle the urge to argue, have political leanings that have led them to avoid vaccines.

I was and still am afraid of catching the virus. The mast cell activation syndrome I have makes my immune system watchdog act like a caffeinated chihuahua instead of a mastiff. Every little thing in the environment sends it into a hyperactive frenzy, thinking it's under attack by some fatal disease. I feel like I have a bad flu more days than not. Unfortunately, when an MCAS (mast cell activation syndrome) immune system is actually attacked by a serious pathogen, it reacts so powerfully that it starts to break down the body it's supposed to protect. This cytokine storm is what kills many COVID patients.

I take an immunosuppressant to keep the MCAS under control, but I've just learned that for many people who take them, the vaccine doesn't cause antibodies to form because that reaction is thwarted by the medication. I don't know what that will mean for me down the line, and I'm apprehensive.

How are you with the vaccination issue? Does MS affect your body's response if you've gotten it, or your choice if you haven't?

**AG:** I am fully vaccinated. When people started talking about the vaccine, it was absolutely out of the question. I was not doing it. Then my brother-in-law got COVID and was extremely sick. This made me do some research on the vaccine.

Then I asked my neurologist about it. "Is it safe? What are the side effects and how will it affect my MS?" When the whispers about being able to travel when you were fully vaccinated started to circulate, that's what drove it home for me. I miss traveling.

So, for me, it was less about not having to wear a mask and more about seeing my friends from all over the country. I miss them terribly. Zoom wasn't cutting it. What I thought was interesting about the shot was how opinionated people were about it. Very similar to the whole mask debate. People aren't concerned if you get the flu shot. How is this any different?

**SdeP:** Actually, I love masks. I have to wear them anyway for the MCAS, and I bling them up. Now everyone was in the same boat with me, not being able to read each other's faces or demonstrate emotions in their accustomed way. There's actually something called Autistic Masking that's the way we have to act in order to be socially acceptable, and wearing a physical mask is a lot easier. One more thing I'll miss about the Year of the Quarantine.

I appreciate how open and accepting you've been with me when I talk about being as different as I am, and I'm profoundly grateful you've shared some of your most poignant thoughts and experiences with me. I think we could have a whole separate conversation just on the fine art of self-care and the science of spoon conservation. It's such a fraught subject, something that's

difficult for a lot of us to give ourselves permission to do.

I hope that when the book launch event for this project comes around, I can make an appointment with you for some absolutely killer nails to keep me feeling *Fierce*.

There are people who are more than worth my working across the challenges I carry around with me, and I've learned through this project that you're one of them. I hope you feel the same. **Thank you.**



# Linking Hands

## Richard McGann

**Cristina Hartmann**

One afternoon in December 2020, I sat at my kitchen table and weighed my options for my upcoming interview with Richard McGann. As DeafBlind people who communicate best through touch, we needed to meet in person. Not a simple proposition during a global pandemic that had made everything untouchable. It had been over four months since Richard and I had last talked, his big hands on my small ones, and now I had to figure out how to reach him.

Richard lives in Brookline, a 20-minute drive from my house in Lawrenceville, but neither one of us drives. A bus ride takes over an hour with multiple transfers. Paratransit services have limited availabilities and long waits. The rumors of Uber drivers going maskless made me wary of

using the ride-hailing app. All of the above options involved a high risk of COVID exposure, and Richard is over 60. So I did something I hate doing: I asked my boyfriend for a ride.

Richard and I usually chatted during the monthly DB get-togethers, which had been suspended during the pandemic. It was at one of those gatherings in February 2018 that I first met Richard.

That evening, I entered the Pittsburgh Association of the Deaf (PAD) in Uptown, new to the city and DeafBlindness. The smell of savory oxtail soup lingered in the air, and movement filled the room as hands shifted on top of each other. Word got out that there was a newcomer, and hands slipped under mine to ask where I was from and what had brought me to Pittsburgh.

Richard's friend guided me to a seat next to him, and he introduced himself with his trademark sweeping, almost flamboyant, movements. He was a lifelong Pittsburgher and a community advocate who had retired from the Western Pennsylvania School for Blind Children, where he taught DB children communication skills. "I didn't want to retire!" he said, his hands splaying outward. "I could've kept working!"

He handed me a business card that proclaimed him as "the DB Godfather." "You need something, you ask me!" he said.

Confused, I asked, "Like what?"

"Anything!" he said. "You have a problem, you ask me!"

There was a big problem to discuss when I tapped my way to Richard's house: the sudden suspension of SSP services in fall 2020.

It didn't take long for Richard to open the door after I rang the doorbell, and he pulled me in for a hug. He led me through a tidy house that he has lived in since 1988, first with his wife and now alone after his wife passed away in 2001. We sat down in his darkened kitchen, chairs pulled close so our hands could touch and we could talk about the SSP program that gave us access to the city.

Support service providers, more casually known as SSPs, go by multiple names, such as "co-navigators" or "interveners." Whatever the label is, the goal is the same: to enable a DB person to move through a society designed for the hearing-sighted. SSPs convey visual information using tactile communication so that a DB person can make their own choices. Richard calls them "our eyes and ears," a necessity in a world with few braille labels and even fewer people familiar with tactile communication.

Most DB people use SSPs to perform everyday activities like shopping, filling out paperwork, locating doctor offices in labyrinthine medical complexes, and attending social gatherings and community events.

In 2014, Pennsylvania established its first statewide SSP program that wasn't tethered to employment, opening up the services to more people—retirees, those unable to work, and those (like me) working outside of the VR (vocational rehabilitation) system. The program gave DB Pennsylvanians up to 10 hours per month with a trained SSP, 10 hours they didn't have to justify to a counselor or have to beg for.

Before the program's inception, many DB Pennsylvanians depended on friends and family to perform errands and attend social functions. Richard, who volunteered as an SSP before his sight declined to the point where he needed one himself, captured the anxiety and fear of never knowing when you could next go to the grocery store or the doctor: "Always, always worried." Richard shifted uncomfortably; both of us knew the uneasy feeling of being beholden to others. Richard expressed gratitude to friends and family who pitched in when needed. "I have to be patient," he added, referring to the times when others postponed their plans or canceled altogether. The odd feeling of uncomfortable gratitude was one I knew well.

On the day of the interview, my boyfriend asked if we could postpone the ride. Something had come up at work. I agreed because it would be churlish not to, putting aside my desire to go earlier. My schedule was no longer my own, and that was only one consequence of dependency. I rationed my needs and wants to fit others' schedules

and moods. I timed my requests for the elusive moment when my family or friends weren't stressed or busy, a moment so rare that I ended up postponing my requests or even forfeiting them altogether. Prescriptions went unfilled. My signature dish, spaghetti with Bolognese sauce, never got made because I didn't have all of the ingredients. Social events weren't even on the calendar—that would be asking too much. I could feel myself shrink a little each day.

We also had to worry about exploitation. I heard hand-murmurs about people to avoid throughout the Pittsburgh DB community—people who pretended to help but only harmed. A man grinned as he guided a DB woman, the joke being that he was wearing a vulgar t-shirt and the woman had no idea. A woman refused to allow a DB man to buy a product that she found objectionable. A volunteer stole a DB man's pingo (Pittsburgh-style bingo) winnings, which he allowed because she was his ride home. It was a bargain many had to make—subject oneself to the caprices of charity or stay home. And these were the privileged ones. Some didn't have the friends or family to make that bargain.

The pilot program changed that. It introduced a measure of accountability and reliability into DB people's lives and gave access to those without a support network. Or it did until September 16, 2020.

An email appeared in my inbox with the subject line in all caps: "Please Read Services Are Ending." The coordinator explained that the funding had not been renewed that year and services would end in two weeks. She apologized but couldn't give any answers. A flurry of emails followed. Many asked why this was happening and

worried about how they would get food during a pandemic. A man wrote: "Does [the agency] make fun of abandoned deafblind without food in the kitchens??"

Richard's fingers flicked into my hands, telegraphing his anger and fear. "Terrible!" was how he summed up the news, but he added that he was helping an agency secure emergency funding. We still felt shaken and dejected. It was more than the program's end that rattled us. It was the lack of communication—we were being cut off from our communities, and nobody was telling us why.

Richard has won several awards for his work as an advocate, so when I asked him what his proudest moment was, I expected something practical like a new program or funding for an old one. I was wrong. Richard's fingers rose into a steeple as he declared "setting up the WPADB!" his crowning achievement.

The Western Pennsylvania Association of the DeafBlind (WPADB) was Pittsburgh's first DB social club, operating from 1988 to 1994. In addition to gathering support from local deaf and blind organizations, Richard and his late wife Karen collected funds from donations and bake sales to charter a bus for the 20-odd DB members scattered throughout the Pittsburgh metropolitan area. They congregated in a basement to chow down, gossip, and make merry—hands draped over one another. The good times came to an end when venue issues forced the WPADB to shut down. It returned in 2012 as DB Gatherings. This time around, however, the DB had to arrange their own transportation.

Richard's recollections of schmoozing in the Lion's Club basement in Uptown reminded me of our need to connect with

one another. Social connection, the experience of feeling close and connected to others, is a universal human need. Transportation and communication barriers put DB people at a high risk of social isolation. “Big problem,” Richard said. “Many DB only stay at home. It’s not good for them.”

The pandemic has taught the general population something that we DB already know: Isolation can erode our bodies and minds. Once lockdown started, the media warned of higher rates of depression and health problems as we all detached from one another. Science confirms this: Studies report the ravages of social isolation on our bodies (heart disease and poor sleep) and our minds (depressive symptoms and increased anxiety).<sup>1</sup> A growing body of research shows similar symptoms among many DB.<sup>2</sup> Isolation might account for some behaviors Richard describes: “Some DB don’t want to learn Braille or tactile communication.” Lack of motivation, one of the hallmarks of depression, creates a vicious cycle of deepening isolation. But it does not have to be this way.

Richard has found many ways to connect with others. A Steelers loyalist and a monster jam rally fan, he follows scores and updates with his refreshable Braille device. Whenever possible, he goes to games and rallies with an SSP who describes the glorious touchdowns and spectacular truck crashes in tactile ASL. He also watches his

extensive DVD collection and movies in theaters via tactile interpreters, goes to church, and read books. When Richard joins in with the cheering crowds at sporting events and partakes in cultural activities like movies and books, he becomes a part of the greater social fabric.

I experienced the powerful feeling of human connection in June 2020 when I participated in a Black Lives Matter ASL video. As we walked to the East Liberty rally, my SSP described the scene: the tall buildings dwarfing a crowd of people wearing black and a woman giving an emotional speech about her dead son. My SSP’s hands twisted under mine as we walked alongside the other protestors, telling me how everyone moved in harmony. Her descriptions made the social justice movement tangible in a way no newspaper article could, and I felt the most connected to my community at that moment.

When most people talk about “livable” cities, they talk about bike lanes or affordable housing but rarely about social connection. Perhaps Richard’s more holistic view comes closer to what the term really means: “More access to television, shopping, books, and friends!” His index fingers hooked together in the ASL word for *friend*, a visual and tactile manifestation of one of our most basic needs—human connection.

As our interview ended, Richard and I waited outside in the cold for my ride home,

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1. Hwang, Tzung-Jeng, et al. “Loneliness and Social Isolation during the COVID-19 Pandemic.” *International Psychogeriatrics* 32.10 (2020): 1217-1220.

2. Bodsworth, Sarah M., et al. “Deafblindness and Mental Health: Psychological Distress and Unmet Need Among Adults with Dual Sensory Impairment.” *British Journal of Visual Impairment* 29.1 (2011): 6-26.

his large hand clasping mine. We didn't know when we would meet next or what lay in our future. The uncertainty remains today—the SSP program subsists on unreliable emergency funding, and a bill that

would guarantee funding languishes in the legislature.<sup>3</sup> When my boyfriend's car pulled up to the curb, Richard patted my shoulder and told me to keep in touch. With that, our hands parted.

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3. Multiple versions of a bill that would create a permanent SSP program in Pennsylvania have circulated the state legislature since 2018. Neither bill passed due to lack of attention and support. Representative Dan Miller plans to introduce a new bill for the 2021-22 session. In November 2021, DeafStone, a Pittsburgh-based nonprofit, received a yearlong state contract to provide SSP services to the DeafBlind. The contract funds only minimal coverage and training. Since this funding isn't a permanent part of the state budget and relies on contracts that might not be renewed, the situation remains fragile.

## Richard McGann Responds to “Linking Hands”

I have enjoyed what Cristina has written. She gives visual concepts, and this sows more creativity. In many ways, DeafBlind people are multicultural, no matter where we come from, as we grow up in the hearing world, blind world, deaf world, and dual-sensory world.

There are numbers of DeafBlind people coming from deaf culture, other DeafBlind coming from blind culture—as we mix them together, we see how sensitive some DeafBlind feel as they become concerned and overreact to what someone says to them. Some may believe it is drama but it's not. There are a number of DeafBlind People feeling that they are being judged. I encourage DeafBlind to be more open, not to be too serious, and not to be too concerned about what people think.

Still, I would like for the public to be

more open and show more eagerness to make DeafBlind people more comfortable, but remember that generations are different. The older generation is dying, and the younger generation is coming up. And I predict that another younger generation will overtake the young generation later—as with the Catholic church's Vatican I, Vatican II and, soon, Vatican III.

Similarly, many older DeafBlind and blind people don't like new Braille code, which was adopted in 2021 by BANA (the Braille Authority of North America) because older people don't always like new techniques, while the young generation is starting to adjust to the new changes in the code and later generations will be even more skilled and maybe will go on to create new updated codes.

As a Catholic, I do recall the old days

before Vatican II. Vatican II brought timely changes, but many older priests and nuns were upset and tried to tell us not to follow the new rules. Eventually, priests and nuns changed, and taught us and tried to encourage us to be more open to new ways.

We see the same idea in relation to racism. Yes, I confess, my father did use n-word in the past, but later came a new sensitivity to the word and a new understanding of the need for acceptance. New generations are bringing Black and white people together, like my second cousins having children who are biracial. For me, we are multiracial because in the Bible, it is said that, at first, everyone spoke only one

language. Our ancestors were curious to see what earth looked like from God's point of view, so they built their tower. God asked them what they were doing, and they said they were curious about what earth looked like to God and wanted to meet God up in the air. God crushed the tower, and then everyone was divided into groups that spoke different languages.

There are eight billion people around the world. There are 125 languages to speak. How is it possible that God can follow all kinds of languages like this? I think the only true language is body language: When you fold hands together and kneel down, God comes closer to you and listens.

# A Driving Force for Accessibility

Paul O'Hanlon

Jason Irwin

When he's not training Port Authority bus drivers to be more receptive to and responsible for the needs of passengers with mobility issues, you might find Paul O'Hanlon at home in front of his TV watching a favorite film by Alfred Hitchcock or Werner Herzog. From reading his resume, however, it's hard to imagine Paul relaxing. We spoke via Zoom, in mid-February 2021. At the time, the COVID-19 pandemic had claimed nearly 483,000 lives in the United States, and much of the world had been in lockdown since the previous spring. The pandemic and its rippling social and economic effects were no doubt worse for those with disabilities, the sick, and the elderly. Paul has lived with a slow-progressing neuromuscular disease in the MD (muscular dystrophy) family that

causes progressive weakness and loss of muscle mass.

Having a disability has not stopped Paul from living a full life. He'd resisted using a wheelchair for a long time, but once he made the decision, he realized he'd been accepting too much unnecessary struggle in his life. He also resisted a power chair, but now, if you're not careful, he'll talk your ear off about its advantages.

Paul originally enrolled at the University of Pittsburgh to study philosophy, but when he didn't see any "Help Wanted" signs for philosophers, this working-class kid switched to law. Paul's parents had separated when he was five or six. His father wasn't around much, and his mother worked as a switchboard operator for a local laundry service and later married a



mechanic who became a city police officer.

After graduating from the Pitt's School of Law in 1979, Paul worked as a poverty advocate. Then one day, Paul was downtown with a friend when he saw a Port Authority bus with a handicapped logo go by. He was determined to board the next bus, but his friend told him not to bother. "They won't even stop for you," he said. At the time, there weren't many routes that had buses equipped to take passengers in wheelchairs. This was a defining moment, and since then Paul O'Hanlon has been a driving force for accessibility in Allegheny County. As a disability rights attorney as well as a co-chair of the City of Pittsburgh-Allegheny County Task Force on Disabilities, he's worked tirelessly to improve the lives of the disabled.

Greater accessibility not only benefits the disabled, it benefits us all. "In our society, we act as if having a disability is something wrong," Paul explained. "But when it happens to an elderly person, we say it's something natural. We say that's just how it is." He talked about our conflicted relationship with aging, pointing out how, when we age, we acquire disabilities or, rather, lose abilities we once had. While we encourage young people with mobility issues to get a powered wheelchair, we tell the elderly to use a walker. "This attitude," Paul said, "creates unnecessary suffering." Maybe it's a result of our fear of getting old and dying—a defense mechanism to ward off the inevitable.

Though I don't use a wheelchair, I'm familiar with mobility issues. I was born with various birth defects and didn't find out until age 40 that I had something known as VATER Syndrome: a cluster of conditions in which three or more body parts are affected.

Among them, my left leg was shorter than my right, my left knee bent outward like an elbow; I had a dislocated hip and a clubfoot that looked like a chunk of coral. I had to wear a brace made from steel and leather with a cork lift, and my parents had to buy my shoes (a regular size for my right foot and a baby size for my left) at a special store in Buffalo, N.Y.—45 miles away from my home in Dunkirk. When I was 16, I made the decision to have my clubfoot amputated and my knee turned around so it would bend normally. I've worn a prosthetic leg ever since.

Still, I've been ignorant of the plight of others with disabilities. I had no knowledge of the struggles to gain accessibility and basic equality so many disabled faced. Because I didn't use a wheelchair and (due to my youth) had not yet faced discrimination, the significance of the ADA (Americans with Disabilities Act) didn't register with me. Signed into law in 1990 by then-President George H.W. Bush, the ADA is a civil rights law that guarantees to individuals with disabilities protections similar to those provided on the basis of race, color, sex, national origin, age, and religion. It prohibits discrimination against people with disabilities in all areas of public life, including employment, education, transportation, and in all public and private spaces that are open to the public.

It wasn't until my twenties that I realized just how inaccessible the world could be. My friend Joanie Burns, who had MD (muscular dystrophy), started petitioning local businesses in Dunkirk to make their buildings wheelchair accessible. The local library told her to call ahead and they'd bring the books she wanted out to her car. The art gallery and BJ's, our favorite bar, claimed they didn't

have the money to make improvements. The post office argued that a ramp would “spoil the historic look” of the building, even though, three miles away in the next town, a post office with the same design had had a wheelchair ramp in place for years. Sadly, Joanie died without ever seeing the results of her campaign.

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For most Americans, the daily commute to work can be described as drudgery—driving on congested streets and highways, or sitting on crowded buses or subway cars where it’s difficult to even turn your head. Yet, can the average able-bodied commuter imagine what that same experience would be like if they were blind or deaf, had cognitive or emotional disabilities, or if they were in a wheelchair?

After Paul O’Hanlon saw that bus with a handicapped logo go by, he was not only determined to board a bus but was also determined to help other disabled people board them. It took five years of constant advocacy, but he and people like the late Lucy Spruill, the City of Pittsburgh’s first ADA coordinator, helped the Port Authority of Allegheny County become the first major bus provider in the country to be ADA compliant. Prior to that, there was Magic Carpet Transportation Service, a consumer-operated nonprofit transit service established by Holly Dick and her husband, the late Paul Dick, in 1963; both of the founders identified as disabled. Magic Carpet ran until 1979, when ACCESS, a coordinated shared-ride paratransit service funded by a public-private partnership, was established. ACCESS provides door-to-door, reservation-only transportation service for thousands of Allegheny County residents with disabilities

who are unable to drive or use buses or taxis.

“Buses in Pittsburgh weren’t accessible to people who used wheelchairs until I was almost 40 years old,” Paul said. “When I started riding, I felt like I’d discovered a Pittsburgh neighborhood that I never knew existed.”

In the beginning, Paul mostly took the bus to and from work downtown. Nevertheless, it was a radical transformation, something unthinkable during his college years. He still remembers, with an almost child-like excitement, a bus trip he took 15 years ago from his home at the time in Squirrel Hill to the Greater Pittsburgh Community Food Bank in Duquesne.

“It was my first spontaneous attempt to use the bus to travel to a place I’d never been to before,” Paul said. There were concerns about access to the building itself, access to the bathroom, and whether the sidewalks would have curb-cuts. There were also concerns he might end up stranded, that the trip would turn into a nightmare. Travelers without disabilities rarely, if ever, worry about these things. In the end, Paul’s journey was a success.

“The overarching experience was that it was an adventure, an empowering experience,” Paul said. “I probably said something to myself like, ‘Shit, I can do this now!’”

So how does Pittsburgh rank compared to other metropolitan areas? “We’re more accessible than Philly, but lag behind Seattle,” Paul said. “In Florida, bus drivers will not move until every passenger is seated.” This is amazing, considering that some Pittsburgh bus drivers step on the gas before you have time to even tap your ConnectCard.

As a commuter myself, who depends on the bus to get to and from work each day, I

understand the difficulty in riding a bus. Even with designated seating, it is often a challenge finding a seat, especially when it's packed. In my experience, other commuters aren't always willing to surrender their seats unless you're elderly, blind, or in a wheelchair. Prosthetic legs aren't recognizable under your pants.

"Accessibility to public places should be part of the first steps to make Pittsburgh more equitable," Paul said in a 2020 *Pittsburgh Post-Gazette* op-ed on the ADA's 30th anniversary entitled "A Wake-up Call to Pittsburgh." Unfortunately, he admitted, when the city considers the ADA, it is usually an afterthought. He wrote that "as the pace of change in Pittsburgh has increased, attention to the ADA has become scarce."

I asked Paul if there was anything about the ADA he'd like to see changed. He said he'd like to see the ADA policed, or more specifically, he'd like state and local governments to act as if it's their job to enforce ADA rules and guidelines . . . because the ADA states that it is their job. Yet the burden to make public spaces accessible and hold businesses accountable often falls on the disabled themselves. "I just want to get in the door," Paul wrote. "I don't want to spend my life suing businesses."

"Pittsburgh," Rick Sebak claimed in his 1992 documentary *Downtown Pittsburgh*, "is a walking city." This is relative, of course, and depends on whether you are able to walk without difficulty. Recent expansion of sidewalk dining, due to COVID-19 restrictions on indoor dining, has presented new challenges for the blind and those who use wheelchairs. Then there are those businesses who think they are complying with ADA guidelines and have modified their restaurants and stores to be more "disability

friendly," only for disabled patrons to find that, in order to get to the "accessible" restrooms, they have to traverse a flight of stairs. This remains a challenge for me and is oftentimes a deterrent from patronizing a restaurant or store.

In the Oscar-nominated 2020 documentary *Crip Camp*, disability rights activist Judy Heumann said, "If I have to feel thankful for an accessible bathroom, when am I ever gonna be equal in the community?" Paul pointed out that in Italy, as well as most of Europe, everything is accessible, and we're talking buildings that might be five hundred years old or more. "They even keep the accessible bathrooms locked," he said, "so people without disabilities don't use them and mess them up."

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I asked Paul what he's most proud of, and he talked about the class-action suit he brought against the Pittsburgh Housing Authority over the lack of accessible public housing. At the time, less than five percent of public housing apartments were accessible to people with mobility impairments. Thanks to Paul's efforts, 300 units became accessible. He also spearheaded a "Visitability" program with Pittsburgh City Council: a two-step program that grants a \$2,500 tax credit to city residents who make at least one doorway and bathroom in their homes accessible.

"Finding accessible housing is hard in Pittsburgh," Paul lamented. "But even after you find it, you discover that everyone else is living in totally inaccessible homes, and so you're shut out of most family and social gatherings."

"Visitability" has been a growing trend nationwide for the past 10 years. According

to the Center for an Accessible Society, a social visit requires the ability for everyone who enters a home to be able to pass through doorways, to enter a bathroom, and to use a toilet. A house is visitable when it meets three basic requirements:

- *at least one no-step entrance*
- *doors and hallways wide enough to navigate through*
- *a bathroom on the first floor big enough for a wheelchair user to enter and close the door.*

Once the Pittsburgh City Council approved the tax credit, the city's Law department told Paul that they needed state authorization. After state authorization, Allegheny County Council passed a similar program. Any Allegheny County home made or built to be visitable is now eligible for a \$2,500 tax credit, and a home within the city is eligible for an additional \$2,500 credit for a total of \$5,000.

"Visitability," Paul concluded "does not need to make the entire home accessible but helps to break down barriers and promotes more social interaction." The tax credit, of course, does not force homeowners to make these changes, and with many older homes and apartment buildings in Pittsburgh, barriers still abound.

I live in a second-floor walk-up in Edgewood. The building, which houses four apartments, was built in 1932. Some of its features include hardwood floors, built-in bookshelves, and a decorative but no longer functional fireplace. There's an onsite washer and dryer, but they're in the basement. Yet my landlords have been very accommodating, designating a parking space in front of my building for me. Even so, Paul said that unfortunately he wouldn't

be able to accept a dinner invitation or be able to just stop by for a cup of coffee. Along with the fifteen stairs you'd have to climb to reach my apartment, there are even a few steps just to get in the vestibule. The steps aren't steep, but if you're in a wheelchair, or unsteady, it's nearly impossible.

This was made painfully clear to me back in January 2019. My mother had recently been diagnosed with terminal cancer and decided to move in with me and my wife Jenny. My mother was also adamant about not having any treatment. Instead, hospice would help make her comfortable. The problem was how to get my mother into our apartment. She was unable to lift herself from a sitting position, let alone walk. We called the local fire department and they sent three EMTs to meet us.

It was surreal. I felt as helpless standing there watching the EMTs lift my mother out of our car and strap her to a kind of a stretcher-dolly as if she were Hannibal Lecter. She looked so small, like a toy version of herself. After she was finally wheeled into our spare bedroom, I wondered if we'd have to call the EMTs if we wanted to take my mother somewhere? What if she wanted to go for a ride? As it happened, we wouldn't need the help of the EMTs again. My mother never left our apartment after that. She died just 18 days later.

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Along with the late Rachel Freund, who worked for the Mental Health Association of Allegheny County, Paul O'Hanlon has also fought for accessibility in voting for the disabled and those living in nursing and personal care facilities, as well as inmates in the county jail awaiting trial.

With COVID-19 and the surge in mail-in ballots in the last presidential election, you might think: Problem solved. This is not the case, as Paul was quick to point out. According to the census, people with disabilities make up the largest minority in the U.S. Take Pennsylvania for example: 150,000 of its residents live in nursing homes or personal care homes on any given day. That's more people than the population of Allentown, Pennsylvania's third largest city. "Every person in long-term care meets the definition of 'disability,' so I figure we can't have the voting significance we deserve if we allow 150,000 of us to have no real way to vote," Paul said. Allegheny County has more people in these facilities than any other county in the state.

"At the very least," Paul argued, "the state should require long-term care facilities to provide assistance in registering or updating registrations of residents, but it doesn't." Some facilities have adequate outside help from volunteers, but others do not. COVID has only made things consistently worse. Before the lockdown, volunteers went to hospitals and nursing facilities to help people register and to assist in voting. At the time of our interview, in the middle of the pandemic, this was no longer happening.

"We asked the state and long-term care facilities to proactively provide all residents with applications for mail-in ballots," Paul said. The state countered that, by making online registration available, it was doing enough. Care facilities said they had enough to do just dealing with the pandemic, and that providing their residents access for voting wasn't their job. To be fair, they did have their hands full, dealing with a new and unpredictable virus that, in February 2021, caused weekly death rates in the U.S.

topping 23,000. This left many residents of nursing homes, long-term care facilities, and hospitals without the ability to cast their vote.

Life in lockdown has made people rely more and more on computers, smartphones, and other electronic devices to help stay connected to loved ones, and the greater world. You'd think the use of Zoom and Facebook, as well as other virtual apps, would bring greater accessibility for those with mobility issues, the sick, the disabled, and the elderly.

I think of my mother, who, before her cancer diagnosis, spent most of her days and nights sitting in front of either her television or her laptop. These became her window into a world she saw less and less of in person. Her universe shrunk—as Paul said, referring to what happens to people when they get old—, as did her reach. "It's paradoxical. So much more of the world is available online. Participation has never been easier," Paul told me. Yet that participation isn't always easy, especially for the disabled.

In 2020, Allegheny County Council had a virtual meeting to discuss the use of "less than lethal force" by police on protesters in the aftermath of George Floyd's death. Since this meeting was online, people who normally were unable to attend due to age, sickness, or disability now had an opportunity not only to voice their opinions, but to hear and participate in debate with others. Things of course were not so simple. Officials shut down chat options, stifling debate, preventing citizens from voicing their concerns and communicating amongst themselves. This may have been intended as a way of moderating the general public and not designed to be one more barrier for the disabled, yet it only further illustrates Paul's

point, that accessibility is always an afterthought.

This is also troubling when we consider that almost half the people who die at the hands of the police are disabled. A report published by the Ruderman Family Foundation, an organization that fosters inclusion in society for people with disabilities, proposes that “while police interactions with minorities draw increasing scrutiny, disability and health considerations are still neglected in media coverage and law enforcement policy.”

Citing incidents from 2013–15, historian David Perry, along with disability expert Lawrence Carter-Long, said that increasingly police have become the designated responders to mental health calls. “People with psychiatric disabilities,” they state, “are presumed to be ‘dangerous to themselves and others’ in police interactions.”

The report wades directly into the racial debates over policing, noting that while coverage of police brutality cases has understandably “focused on race,” that lens can also obscure how disability factors into police interactions.

“I have found that my disability gives me one ability I don’t think I’d otherwise have,” Paul emailed, after our initial interview. “When I worked in Homewood as a young, white, disabled legal services lawyer, I could see that I was granted a kind of acceptance in the community that I don’t think I’d have had as an able-bodied white guy.” Paul says he’s learned that people who’ve experienced oppression can recognize others who’ve experienced it. I’d had a similar experience volunteering with various homeless organizations in Pittsburgh and New York. I felt accepted in a way I wouldn’t have been if I hadn’t been disabled.

Paul O’Hanlon may well have overcome a great deal in his life, and it’s obvious he’s brought about a lot of good, but he still faces many personal challenges. “The three of us,” he wrote in another email, referring to him, his wife Lori, and their son Sam, “have been living in a bubble over the past year, with almost no outside contact—primarily because of my vulnerability to severe COVID symptoms.” Starkly, he added, “We are at that age when we’re looking at the odds of my dying before her, and the possibility of monstrous ‘end of life’ medical bills.”

According to the CDC, as of September 2020, 61 million adults, across all identities, live with a disability and comprise the largest minority. One in three adults ages 18–44 have had an unmet health care need because of cost in the past year. The other thing we rarely think of is that all of us, at any time in our lives, through an accident or catastrophic illness, can become disabled.

Most of us don’t realize that disability impacts us all. In his novel *Blindness*, about a world-wide epidemic that causes everyone to lose their sight, José Saramago writes, “The difficult thing isn’t living with other people, it’s understanding them.”

While we cannot pass laws that require empathy and no amount of legislation will make a perfect world, we can at least become more aware of others and act locally to help bring about change that has reverberations globally.

By imagining a perfect world, we can start by working to ensure that the cities and towns we live in have homes and apartments that are visitable, that restaurants and stores have accessible entrances, aisles, and bathrooms. Our perfect world should have accessible public transportation and

schools, and a greater accessibility to health care and human services. While it is true that we have come a long way, we still have miles to go.

“The experiences and talents of people with disabilities are waiting to be tapped,”

Paul O’Hanlon wrote in his 2020 *Post-Gazette* op-ed, “as are the lessons from other, more accessible cities. Without leadership and committed action, the city will not meet its promise of ‘access for all.’”

## Paul O’Hanlon Responds to “A Driving Force for Accessibility”

I suspect it’s because I was born with a disability that I developed a distinction I call “being in the world.”

Being in the world begins when you step out your front door. Being in the world forces a moment-by-moment assessment of oneself and one’s place in the world. Being in the world is an opportunity for chance encounters, new friendships, exploration, discovery. Being in the world draws you to life. Being in the world supports your health and vitality, your well-being.

People with disabilities, people we call “shut-ins,” face a variety of barriers to their ability to be in the world. Less obviously, people who are poor, who are minorities, who are different—also face a variety of barriers to their ability to be in the world.

There’s a cost to being shut off from the

world. It’s a heavy cost—paid by the shut-in, by the person with the disability, by the world. Sometimes the world doesn’t know what it’s missing . . . I do.

I think my disability trained me from an early age to be attentive to barriers to being in the world. There’s an “unbearable lightness of being” in the world—no sooner do you think you’re there, but then the office party is moved to the second floor of the venue, and there’s no elevator, and you realize that you haven’t quite managed to be in the world.

Most of my life has been a kind of Zen practice of freeing people up to be in the world. It’s been the privilege of my life that I’ve had the opportunity to fight for things important to me.



## TRIGGER WARNING

### “Learning to Dream Again: Anne Alter’s Life with Schizophrenia”

Anne Alter’s story unpacks the experience of living with a mental illness in a sanist society, where people diagnosed with psychiatric disabilities are systemically silenced, neglected, and even abused. In her narrative, we learn about what it is like living with suicidal ideation and the experience of forced hospitalization, and recovering from patterns of abuse including sexual assault and predatory relationships—including a relationship with a mental health care provider outside of the family who made unwelcome references to their own incestuous impulses—as well as on themes of isolation, and emotional manipulation. Through the telling of Anne’s story, we are also introduced to Jennifer Matesa, the interviewer, who shares her own raw experiences of surviving emotional and sexual abuse. While both of these stories document the trials and trauma that can come with living a marginalized identity, they are really testaments to strength and resilience.

A list of resources that can provide support if you experience any distress or discomfort is available in the front matter of this book. **Click here to return to the resource page.**

It’s important to be aware of these resources as well as share them with others so we are all equipped and empowered with information that helps all of us stay safe.

# Learning to Dream Again

Jennifer Matesa

## Anne Alter's Life with Schizophrenia

S ometime in 2017, Pittsburgh native Anne Alter went to a meeting at an office building that is part of the University of Pittsburgh Medical Center's Western Psychiatric Hospital—known by clinicians who work there (of which I have been one) as “WPH” and by people who grew up in Pittsburgh (of which I am also one) as “Western Psych.” Anne, 55, is what the hospital's doctors and therapists would call, in clinical notation, “a patient well-known to WPH”: she has been receiving treatment from clinicians there since she was 15. From age 10, she had gone to St. Francis Hospital—which was WPH's legendary forerunner in caring for Pittsburgh's residents struggling with mental illness and substance-use problems—for panic episodes, obsessive and intrusive thoughts, compulsive and ritualistic behavior, and the

dramatic mood swings of bipolar disorder. More recently, which is to say for the span of her adulthood, she has seen WPH outpatient clinicians who specialize in the treatment of schizophrenia, a disabling mental illness that distorts people's thoughts and perceptions of reality. The epithet “schizo” is often used to refer to someone who has dissociative identity disorder (which used to be called “multiple personality disorder”), but that's not what schizophrenia is. Basically, folks with untreated schizophrenia can't tell what's real and what's not.

Anne says schizophrenia “was always there in the background of my early childhood years.” At 23, she began to experience delusions. For many folks who haven't had contact with anyone with schizophrenia, which is to say most people, when they hear

the word “delusions” they think “hallucinations,” but Anne doesn’t see things with her eyes or hear things with her ears that aren’t real. Rather, her delusions make her believe things that are not real: for example, she might believe that she is a specific person like Jesus Christ. She also has what she says is “the impression of voices in my head. I’m not hearing them with my ears.” Having worked at a psychiatric hospital, I’ve learned that all of us, more or less all the time, have voices in our minds that tell us to do stuff and sometimes these voices can disturb us with their intensity or the content of their messages (“You forgot to pay your credit card bill for the second month in a row, you’re such an idiot”), but these internal voices generally don’t persuade us to follow directives that may endanger our lives. When Anne’s illness is not controlled with antipsychotic medications, the voices convince her that she has to do certain things; if she decides to carry out their directives, she does things that land her in the hospital.

Some of Anne’s delusions have required her to be hospitalized for months. Because her mental illness is so serious, Anne can’t drive. She can’t work. She has had to give up many of her dreams and desires for her life. And she has learned to be rigorous about taking her medications and about practicing daily discernment, with the help of her care team, of whether the thoughts in her mind are grounded in reality or are a part of her illness.

The meeting she was attending at Western Psych on that particular day was an informational session about a potential program for people with schizophrenia who also have musical abilities. Anne has sung all her life, and she loves to perform even though, like many performers, she has

terrible stage-fright. Earlier in her life, she had planned to make her living as a performer: she earned her bachelor’s degree in theater arts from Earlham College in Richmond, Indiana. “I was completely out of my head in college, but I still loved the school and the education that I got,” she says. She would write 20 pages per day in her journal, and dance and roller-skate around campus. “I was seriously into dance in college,” she says. “Academically it was very hard because I was suicidally depressed alternating with mania, and I couldn’t concentrate.” As a high schooler at the Ellis School in Pittsburgh, she had gone to Western Psych for treatment of depression, but, she says, “I didn’t realize about the mania until I was in college.”

The schizophrenia and its terrifying delusions came a little later.

After the informational session, she approached the guy they said would be in charge of the musical program and asked whether she might sing him a song. Other people might be able to do this: just sing a song impromptu—*Hey, dude, listen to me! I got this*. But for someone with lifelong panic disorder plus schizophrenia, plus bipolar disorder, it can be a stretch to believe you can do anything you really want to do without it falling apart in your mind before you can make your body carry out your own wishes.

Or even to believe that the thought that you ought to sing for the guy is real.

The guy assented, and she sang, *a cappella*, the Jewish prayer for healing, “Mi Shebeirach,” a version which (according to the translation Anne prefers) goes, in part:

*Bless us with the power of Your healing.  
Bless us with the power of Your hope.  
May our hearts be filled with  
understanding*

*and strengthened by the power of Your love.*

Because of the fact that Anne's illnesses have sprung disastrous symptoms on her with little or no warning, because she loves to make music, *and* because she loves the Jewish community she has found at her Reform congregation, Temple Sinai, this particular song is important to her. Anne knew nothing about the guy she was singing for; she just hoped he would like the way she was singing, even if he didn't understand the meaning of the Hebrew words.

"I knew absolutely zip-zero-nada about Flávio when I sang for him that day," she says.

The guy, Flávio Chamis, is a conductor and composer known, among other things, for having worked as Leonard Bernstein's assistant conductor. A native of São Paulo, Brazil, and a longtime resident of Pittsburgh, where his wife holds the principal viola chair in the Pittsburgh Symphony, Chamis received his education in conducting and composition in Israel, Germany, and Austria. Apart from lecturing internationally about music, he has been a member of the Brazilian and Classical music committees of the Latin Grammys, and he writes his own award-winning music.

And the cherry on top: Chamis is also Jewish. So he recognized Anne's song that day.

Chamis ultimately put together a group of four musicians: two vocalists (of which Anne is one), a guitarist, and a bassist. They call themselves "Infinity." At the 35th annual Pittsburgh Schizophrenia Conference in 2018, Anne, with the guitarist David Baird, performed live for the participants; the following year, the entire group performed and participated in a panel discussion onstage in front of the clinicians attending

the conference. For the 2020 meeting, which took place virtually, Chamis produced a 30-minute [documentary video](#) about the group's work and its effects on their recovery from schizophrenia. It's called "recovery" because even though they are living with a mental illness that can never be cured (or, as Anne is, living with more than one illness), they each still have much to recover, and to recover from.

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Before her early twenties, when Anne began to experience the delusions of schizophrenia (the "big-ticket item" in her collection of mental illnesses, as she once wrote to Chamis), she had already been treated for bipolar disorder, OCD, and panic disorder. At age 10, she was treated at St. Francis, in a children's psychiatric ward, for three months. (Imagine spending three months of your fifth-grade year in the psych ward. Imagine going back to school—or trying to go back to school—after such a long stay in "the booby hatch," which is how Anne refers to the psychiatric hospital, any psychiatric hospital, in a series of social-media posts she has written during the COVID-19 pandemic called *The Booby Hatch Chronicles*.) At nine, she was taken to a private psychiatrist. She spent the next 13 years making her way through a series of private therapists' offices.

Then, at 21, she began to have delusions. The second decade of life is generally the time during which schizophrenia's delusions begin showing up. If folks with schizophrenia have co-occurring mental disorders, it can take quite a bit of skill to get the right combination of medications—plus an alliance with a therapist who actually knows how to treat folks who are struggling with

psychosis—relatively few therapists have that training. It wasn't clear to her treatment team at that point that the delusions were in fact signs of schizophrenia: people with bipolar disorder, for example, can also experience delusions during manic episodes, and bipolar is much more common than schizophrenia. Anne's psychiatrist gave her two antipsychotic medications and lithium, a mood stabilizer commonly used for bipolar disorder.

Mental illness can make people a target for others who would prey upon them, especially mental illness in young people who don't have much experience with the world. It's also well known that victims of violent crime generally are targeted by people who know them. After Anne graduated from college—"very ill and not sure where to go," she says—she began seeing a clinician who emotionally and sexually abused her. "He took me on an overnight trip, told me he feared my thoughts would hurt him, and told me that he had trouble thinking of me as just a daughter because he struggled with sexual feelings for his actual daughter," Anne says. He also used to simply hold her, and because she had been so lonely for so long and felt so misunderstood by society, she says, "I lived for this. I tolerated terrible things because I needed my connection to him so badly."

If you think this experience of Anne's is different from other women's experiences because she had mental illness, consider some of the stories of sexual harassment and abuse that have come out in the #MeToo movement. You don't have to be experiencing florid symptoms of mental illness to be tempted to put up with people harassing or assaulting you so you can get some human connection. In fact, Anne's recollections resonate with my own history, and I've

never had bipolar disorder, OCD, or schizophrenia. Anne and I are virtually the same age; at the same time that Anne was struggling with her feelings of wanting this abusive psychologist to hold her, I was in a relationship with a man who would have sex with me when I said I didn't want to. And because I didn't want to have sex, my body was not ready to have sex, and when he rammed his body inside mine, *it hurt*. I put up with it because yeah: I wanted, I *needed*, to be held. I was certainly depressed at this time, and I'm anxious basically all the time. So I and countless other women know this experience of nonconsensual encounters all too well. Such encounters become even more complicated with additional challenges of unstable perceptions of reality and attempts to trust a clinician whose job it is to help you stabilize those perceptions.

Then, at 33, while trying to understand and cope with symptoms that would turn out to be schizophrenia—on top of the three other illnesses she had been negotiating for 15 years—Anne was raped. During the trial, the criminal defense attorney made sure to say her version of events couldn't be trusted because she was "a schizophrenic." There's a difference between calling someone "a schizophrenic" and "a person with schizophrenia," and these days clinicians are trained to use "person-first language" to lessen the stigma of carrying diagnoses that are already inherently heavy enough, but certainly the lawyer knew what he was doing. This trial challenged Anne's mental health so much that she had to be hospitalized and couldn't continue to support the prosecution. She says that, as far as she knows, her attacker went free.

By age 29, Anne had been six years in a relationship with Herb, a compassionate, loving man 30 years her senior. She had

been earning a bit of money as an artist's model—it was a way of staying in touch with the performer inside her, and, she says, "Artist's modeling is very respectable." One night, she and Herb were waiting for a bus that never came, and someone mugged them at gunpoint. She was seeing a psychologist to try to address the trauma of the physical attacks and other kinds of violence she had experienced throughout her life.

At this time, Anne began traveling into the South Hills each day, taking two buses each way. She would call Herb from pay phones, asking, "Is someone following me?" She believed aliens were coming to get her. She believed she was Jesus. She believed she was one-half of conjoined twins separated at birth and was condemned to search in vain for her missing twin. She would wander around the suburbs all day. She was not eating, so her weight dropped under 100 pounds. When she came home, she would spend hours on the phone talking to nobody. She had also begun celebrating Shabbat at Temple Sinai, where she had found a community that treated her with tolerance, acceptance, and compassion, but, she says, all of a sudden during services she would have a convincing thought that the rabbi was her long-lost twin. It didn't matter that it would have been impossible from a genetic standpoint for any conjoined twin of Anne's to be a male; uncontrolled delusions don't respond to "reality testing." They're impervious to evidence.

Herb finally "302'd" her—in Pennsylvania, "302" is the section of the mental-health treatment law that allows for people to be committed involuntarily, and "302ing" someone is the colloquial way of saying you had them committed against their will. She was taken to Western Psych and put into a

locked ward for six weeks—"the Booby Hatch." Most of the staff, she tells me, treated her with respect, and she felt the psychiatrist at the hospital truly cared about her. Still, she says, she was in "physical agony" during that hospital stay. Many patients I have assessed upon discharge from inpatient care at "the psych ward" say the same. "The Booby Hatch" is not a pleasant place to spend a few days, let alone almost two months, as Anne did. Herb visited her every day. He helped her bathe. He brought her juice and crackers. He tucked her into bed every night. "He saved my life," she says.

Anne has been hospitalized a number of times, including—once when she was 32 after she stopped taking her antipsychotic medication—a two-month stint in the now-closed Mayview State Hospital. Anne tells me that she couldn't get physically warm during her entire stay at Mayview; she says she asked to be allowed to wear a head covering, and she was told she couldn't have one because if she looked "normal," she might run away (never mind that all the patients were dressed in street clothes). She was told that, if she wanted to be discharged, she would need to be more energetic. She was also told she drank too much water. "The nurse actually snatched the water glass out of my hand," Anne says. On one hand, she was told to do certain things; then, later, she says, "my psychiatrist would tell me cryptically that I wasn't being assertive enough. I tried to be compliant. I did everything he said."

Herb took two buses each day to visit her in the state hospital. He brought her food. He brought her company. And he brought her love. They had decided to get married a few times before, and Anne had always

called it off. Seeing his dedication to her during this hospitalization, she thought she could never find a more loving partner. “I planned my wedding from the hospital,” she recalls. “I bought three engagement rings from the gift shop, each looking exactly like a diamond engagement ring, and each costing five dollars. I bought three so I’d have spares in case I lost some.” She married Herb, and they were together for several more years until he passed away.

Over the years, Anne and her doctors have come up with a medication regimen that has stabilized her moods and kept her delusions at bay. For schizophrenia, she takes clozapine, an atypical antipsychotic medication that, like many antipsychotics, comes with risks of significant side effects, including metabolic problems such as diabetes. Anne has taken clozapine for 22 years and has gained a great deal of weight. “It’s heartbreaking to me how much weight I’ve gained,” she says. “I used to work as a print model and I loved doing that. I’ve had to deal with a lot of self-hatred because of my weight.” Anne’s Facebook profile picture shows a slim woman in her twenties dressed in a diaphanous black gown, wearing a pair of roller skates, performing an arabesque. Recently Anne did a photo shoot for a story in *Western Psych*’s in-house magazine about her participation in *Infinity*. “I was apprehensive about that,” she says. “Then I thought, *What the heck, I can be a plus-size model*. I put on my green velvet dress and my pearls. I looked good! I call it ‘choosing sanity over vanity.’ Which is what I’ve had to do.”

She doesn’t dare risk stopping her clozapine because, she says simply, it works. She also takes aripiprazole, commonly known as Abilify, another atypical

antipsychotic, which helps prevent delusions and stabilizes her bipolar disorder. “I don’t take any meds for OCD,” she says. “I just check things a lot.”

She sometimes hears voices telling her that terrible things are going to happen to her, or that people dislike or are laughing at her. “Sometimes it comes back,” she says. “Sometimes I’ll see a picture in the paper and think, ‘They’re imitating me.’ It’ll be like an old twinge, and then I’ll tell myself, *I don’t have to believe that*.” I asked her what skills she uses to help herself stay in touch with reality, and she immediately replies, “I take my medicine assiduously.”

She also keeps in touch with people in her life. “That helps me focus on what’s real,” she says. She sometimes zones out and loses the thread of conversations, but she practices mindfulness during daily walks, visiting the mailbox-sized libraries scattered throughout her neighborhood. This is one big way she has coped with the pandemic. She couldn’t go to temple, and because her father is so old, she had to socially distance rigorously. A great deal of scientific evidence exists to show that mindfulness—the act of noticing whatever is happening in the present moment—eases suffering for people with a variety of mental and physical illnesses. “I try to lift my mind out of everyday *tsuris*,” she says, using the Yiddish word for “troubles.” “I try to lift myself out of the daily grind and focus on nature and people and dogs I see outside. My illnesses have really destroyed my ability to read, but I look for books at the little libraries because even though I can’t read very well, it’s like, *Here’s a piece of my life that’s being changed because of this book*. I read cookbooks. I write gratitude lists—I call them ‘positive perceptions.’ I try to write down the positive way of

looking at situations in my life. My therapist helps me a lot, because I can be extremely hard on myself, and she talks me through stuff and helps me get out of that rut.”

Anne’s mental illnesses, when they’re under control, are largely invisible to other people. Her disability doesn’t require her to walk using a cane, or to talk with sign language, or to wear hearing devices. She has learned very well what she has to do to fit in. Among the skills she uses to cope with her mental illnesses are the acting skills she learned in college. “People are surprised when they find out I have mental illness because I present so well. I have to use all my acting skills,” Anne says. One thing I hear her saying here is that her acting skills help her make it easier for *other people* to be around *her*. What if it were the other way around: what if folks without mental illness had to learn skills that enabled them to interact with folks with mental illness? If young kids are not educated in the skill of empathy, they turn into cruel creatures who pick on others who don’t look like them—overweight kids who get chosen last for teams, socially awkward kids who get teased or poked with pencils, kids who have panic attacks or obsessive-compulsive behaviors (counting all the objects in their desks over and over; washing their hands even when they’re not dirty; repeating words out loud or moving their bodies in odd ways to make themselves feel safe) who nobody sits with at lunch. Eventually, cruel kids grow into adults who don’t know how to speak with someone who sometimes thinks she’s Jesus, and who avoid anyone whose speech or behavior are outside their ken. So it’s possible to see that people who don’t know how to talk to someone with mental illness are the ones who are lacking in social skills—not the ones with mental illness.

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Anne has a number of suggestions for improving life in Pittsburgh for people who have disabling mental illness. First on her list is improving public transportation. Twice, while taking an acting class, Anne was stranded at night because her Lyft or Uber apps would not work. Because folks with serious mental illness by and large do not drive, and because Anne was attacked while waiting for a bus that didn’t come, she believes that public transit should be funded better and expanded, especially at night. She also suggests, “Any organization in which mental health clients want to participate should address and make available rides to and from their programs.”

Her second suggestion is to create more affordable housing that is integrated throughout the city. Since her early thirties, she has had stable, safe housing, but in her late twenties she lived in a neighborhood where, she says, “I had to call the police every night because of gunshots nearby. I never felt safe, and there was no peace and quiet.” Folks in recovery from mental health difficulties—such as paranoid schizophrenia—benefit greatly from safety; or, rather, their recoveries are made much more difficult with surges of stress hormones and a sense of constant threat that may be too similar to the delusions they’re trying to hold at bay.

Third, Anne has a great many ideas for improvements to psychiatric hospitals. Anne would locate her “Better Booby Hatch” on a lot big enough to let patients have time outdoors on a daily basis. She’d have the architects design a gym and swimming pool so patients could get exercise. She’d pay her psychiatrists to spend “more time than a few minutes with clients on their daily rounds.”



She would establish a routine in which patients would have access to a therapist for an hour every day, “for ongoing care and support while being hospitalized.” She would give each patient a private room and private bathroom, and in each room, she would place an extra bed, so that, as she explains it, “immediate family members or close friends and partners can participate in care and advocacy for their loved ones.” She would have shuttle transportation for staff and families, “so that no one is excluded from care or visitation.” She would give each patient free telephone service in their rooms and make sure each patient is allowed half an hour per day to use their cell phones and laptops so they can remain connected to folks “outside.” She notes, “Since the current issue of these being forbidden has to do with the privacy of others, staff could supervise clients to make sure these are only used in the room at certain times.” She would design “a full-service cafeteria” where patients “would have a choice of healthy foods.” And she would pay attention to the hospital’s aesthetics: “The building would be beautiful, with open spaces, and full of natural light and outdoor vistas. There would be a lot of artwork, secured for safety, and furniture would be designed for aesthetics, not just functionality. There would be a large lobby where people can socialize, with beverages and snacks available.” She prefaces all these suggestions with the qualifier that they would constitute a facility “where the standard of living and care is so high that clients actually want to go there when they need to be in the hospital.”

Of course, many of these suggestions aren’t practicable for an urban hospital such as WPH that serves as a center of research and teaching. Psychiatric inpatients don’t

get an hour of therapy every day because, for one thing, that costs a lot of money; for another, this might encourage undue dependence on the mental-health system, and the whole idea is to help patients recover well enough to live outside the locked doors. There’s also the question of security, not just that of the patients (or “clients,” as Anne prefers to call them thus restoring some of their power) who may not necessarily be able to keep themselves safe, but also that of the staff and visitors. In 2012, a 30-year-old man entered the ground-floor lobby of WPH with two semiautomatic handguns and started shooting. He killed a 25-year-old therapist and wounded seven other people before police fatally shot him. In an effort to avoid a repeat of this atrocity, the first floor was reconfigured and all doors but one were blocked off. For years I was a regular visitor to the psychiatric library inside that building, and we used to be able to enter through a side door to get to the library; now, everyone except those with an employee badge passes through a single door into a set of huge metal detectors, and all bags are examined. The security apparatus itself takes up much of the ground floor, so a hotel-style lobby with snacks and artwork such as Anne envisions wouldn’t be possible, at least not in that building.

But in her reflections, I hear Anne dreaming. Which is not to say she’s engaging in “pie in the sky” imaginings; rather, I hear her exploring and expressing her deep, considered desires for her community to support people like her, who may at the drop of a hat have to commit themselves, or be committed, to a hospital stay of indefinite duration. Imagine you really need a break from some fantastically stressful times that have you unable to sleep at night or work well during the day, so you book a

flight to, say, Australia, and when you get to your high-rise hotel in Sydney you find out the food sucks and there's no place to work out, and on top of that the porter takes your wallet and all your devices and tells you the doors are locked, and you look at your bed and the pillow is thin and the twin mattress is covered in vinyl. This is what it might be like to move into a psychiatric hospital so you can relax, recover, and stop looking for the conjoined twin of your delusions. They're going to keep you safe, and they're going to keep themselves safe, and they're going to keep the rest of the world safe, all at great personal cost to *you*. It makes sense to me that Anne would dream of having a place to walk outside every day, a place to swim on rainy days, a shuttle to bring her elderly dad to and from the hospital, a therapist to talk to as much as she wants. If I were her, I would also want some little libraries posted throughout the halls and grounds. It makes sense to me that she would want some high-quality specialty food in the "full-service cafeteria." She's a vegan! I hear her saying she's not a crazy lady who sometimes thinks she's Jesus—she's an intelligent, well educated, hardworking, articulate woman who has reasonable desires that matter and that, if fulfilled, might actually make a difference in her recovery—and therefore in her community.

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Anne's last suggestion for improving life in Pittsburgh communities for people with mental illness is to endow those people with more visibility in the community. "This means more articles, news coverage, books, events, and general PR about the lives we live in the mental health system," she says.

"This will combat the stereotyping, discrimination and isolation most of us experience." It will, that is, if the coverage is informed, and if it seeks to undo the stigma and fear surrounding disabling mental illnesses such as schizophrenia. One example of the way the press is generally ill-informed about mental illness and participates in stereotypes is the number of stories written each year reinforcing the popular belief—one might even say the collective "delusion"—that gun violence and mass shootings are by and large committed by people with mental illness. Epidemiologic studies show that the vast majority of people with serious mental illnesses are never violent against other people. On the other hand, research shows mental illness is strongly linked with an increased risk of suicide—an extreme form of violence against oneself. And suicides account for more than half of American firearms-related deaths. Anne said one reason she loves Temple Sinai is that they're committed to the agenda of destigmatizing mental illness and pushing back against stereotypes. They've hosted a number of programs to help its members and the community at large understand mental illness, and Anne has participated in these, because she considers herself to be an advocate, not just a client.

And then there is her musical group, Infinity, which is also increasing awareness that people with serious mental illness can do things that ordinary folks may not think they are capable of doing—thereby showing that they themselves are not social outliers but ordinary people, with sorrows and joys, nightmares and dreams. Abilities. Desires. Lives. Anne's participation in Infinity has given her back a great deal of joy that her illnesses (and also some of the treatments)

have robbed of her. She has been stable for a number of years in her recovery, but she often still feels so much uncertainty. Is she really allowed to dream again? Will she ever be able to do things that she has wanted to do since she was young and imagined being onstage?

“I’m trying to accept the fact that I may not progress past a certain point,” Anne says. “It’s hard for me, because I haven’t had the kind of vocal training I should have had. I don’t read music. The mental illness interferes with both those things. I’d like to believe that I can someday be an actor and a singer. But I’m trying to make peace with the issues I’m facing and say, ‘If nothing else, I did progress to a certain point, even

with schizophrenia, bipolar disorder, obsessive-compulsive disorder and everything else.’ But it’s hard for me to accept that I still have a long way to go.

“There’s a paradox here because part of what I’m doing is to say, ‘This is what mental illness looks like and can accomplish. Look what people with mental illness can do.’ I’ve had a lot of loss over my lifetime, especially professionally. But things are happening now that make me feel like my work with Flávio is the right work at the right time. I tell everybody about my mental illness, and now I also tell them about what I *do*. It’s time for all these things to move forward—in my life and in society—and I feel glad to be a part of that.”

## **Anne Alter responds to “Learning to Dream Again”**

**W**hen I first drafted this response a couple months into working with Jen, I was still in the “honeymoon” stage of the project. I was still enamored of the idea of being featured in a book and being able to share my experiences with mental health issues and advocating for myself.

But it’s not so easy to bare your soul about many of the topics mentioned here. Jen suggested that I include some of my deeper feelings about the process.

Wow.

The process was hard as heck.

First, I had to take a leap of faith and trust Jen. She certainly earned my trust. She was respectful, patient, and careful in working with me. She was clear about what she wanted and envisioned for this project.

She was also a badass. She was relentlessly quick, focused, and thorough. A force of nature. Keeping up with her freed me to be honest, and forced me to be a better, clearer, more careful writer.

I learned from her about allowing spirit to animate writing. She put me back in touch with the writer I used to be, when I was unapologetic about being strong. On this project, I could let my truth speak through me, knowing that Jen would help me present my story in a way that people would understand.

Most of all, Jen presented my story with compassion, making it easier for me to sign off on this process that demanded such truth and introspection.

Also, this project has been an emotional roller coaster, comprised of pride, shame, excitement, trepidation, fear, trust, willingness, and defensiveness. Jen was absolutely right that my emotions would be opened up, and they were—like an overflowing bunch of popcorn kernels.

I would like to note that I have managed, despite everything, to do some meaningful work in the creative and performing arts. Over the years, I have been merging my mental health advocacy work with my creative and performing work. I did stand-up comedy at my Temple about my experience with mental illness. As Jen wrote, I have been singing with a group of musicians who have schizophrenia. I have also read accounts of my brain adventures to groups of people ranging from young doctors to Temple members. And during the pandemic, I have written essays on my Facebook timeline, entitled *Plague Diaries/Booby Hatch Chronicles*.

Over most of my life, I have fought back against my illness by working in many other capacities. From childhood onward, I have sporadically taught ice skating, horseback riding, and dance, and tutored speakers of Japanese in English. I was offered the chance to train for the Olympics in ice skating. I have acted for theater, video, and film; done modeling work for art, print, and performance art; and have been a technician for theater and film.

So I have gone from a rather detached, philosophical view of the process to a more immediate, emotional, and forceful way of looking at my words and the words about me. I am thankful: for Jen, for the project, and for the opportunity to be heard.

# Navigating the Roads of Power and Policy

Jessica Benham

Patti Murphy

## *Detours*

**F**irst-time Pennsylvania Democratic State Representative Jessica Benham is at the wheel as we introduce ourselves on a Sunday afternoon internet call. Her destination: Harrisburg. It is the first official three-hour road trip from Pittsburgh to the state capital she will be making before the start of practically every work week over the next two years. Five days before, in the November 2020 election, voters from Allegheny County's 36<sup>th</sup> House District confirmed "Rep. Jess" as their leader.

Time alone will tell how Pennsylvania—where the political pendulum swings in a purplish direction lately—will respond to having this feisty 30-year-old bisexual woman with a mobility impairment drive a share of the decision-making around state law and public policy. Rep. Jess is also autistic, an extrovert, and a University of

Pittsburgh PhD candidate, if an unlikely political candidate at a time of great either-or thinking among the electorate.

Luckily, Jessica is hard-wired for detours. Not just the literal ones she may encounter on jaunts to Harrisburg when roads are torn up. Or the unprecedented detours that keep changing our routines as the COVID-19 pandemic lingers. I am thinking more of the twists and turns that take those of us with disabilities out of our respective comfort zones on a regular basis.

Seldom is there a good shortcut through a construction zone, and there certainly is none through this pandemic. But, eventually, road work and pandemics (as far as we know) pass. Disability, whether it sets in at birth or later, remains for life. Which is why *Live/Ability* is a welcome and bright center-line for this narrative.

Livability runs deeper than mere accessibility. It implies permanence, a depth of caring that takes into consideration both needs—like safe entryways without steps or the daily presence of a 1:1 school aide for a child with intellectual or behavior challenges—and desires. The latter could be honoring a friend's preference for the phrase "autistic individual" over "person with autism," or the freedom to marry or work without sacrificing necessary resources. For Jessica, it also means people telling her they adore her sparkly cane as freely as they would compliment someone else on a new pair of eyeglasses. Or that the closed-captioning on the weekly "Rundowns with Rep. Jess" on social media identifies her beloved cat as Ravi, his real name, instead of Robbie, as it often does by mistake.

Accessibility, whether mandated by law or not, is often random or absent, particularly in older cities like ours that are replete with time-worn architecture and infrastructure too costly to adapt.

"Accommodations do not change the fundamental truth that the world is not built for people like me," Rep. Jess tells me. As for disability-friendliness, she says that Pennsylvania, a politically redder state, is "about equivalent" to bluer and flatter Minnesota, where she lived during college and graduate school.

At the same time, she notes that inaccessibility is endemic here.

"I feel more disabled in Pittsburgh. I am more disabled in Pittsburgh." There are obvious reasons—the steep terrain combined with an abundance of older buildings and potholes. Then there are reasons that may not get as much attention, like the region's consistently unhealthy air quality, which she notes causes disabling conditions

or exacerbates existing ones. And the treatment of jail inmates with intellectual or psychiatric disabilities including addictions. Rep. Jess actively supports measures that favor reducing the number of individuals with disabilities in prisons and eliminating disparities in education that force marginalized students into GED programs or alternative schools that do not meet their needs. Often, they are young people of color or identify as LGBTQ. Many have hidden or unspecified disabilities.

There is a worldview—some call it the charity model of disability—that it is up to the rest of society to protect those with disabilities from life's other adversities. This paradigm, of course, probably has little to do with geography or demographics. Still, I have from time to time sensed that Pittsburgh, with its tightknit neighborhoods, church groups, and ethnic communities, lends itself naturally to this way of thinking. I felt it big time during Spring 1986 after I became a victim in a series of purse snatchings in the Carrick section of the current House District 36, where I lived from my birth in 1961 through 1993. The crime occurred in broad daylight. A subsequent outpouring of well-meaning concern from relatives, friends, neighbors, and acquaintances who thought it best that I avoid going anywhere alone warmed my spirits. It also temporarily froze the quest for personal independence that meant virtually everything to me as a young adult with cerebral palsy.

One of the comforts of living in a major city known for its small-town charm is that many residents put a premium on taking care of the more vulnerable among us. On the flip side, this attitude can be more parochial than progressive. Sometimes it is too easy to get stuck in an automatic mode

of doing for others who are seemingly less able without first asking how to help them or if they need assistance at all.

I ask Rep. Jess whether this worldview meshes with her Pittsburgh experience. She immediately says *no*, adding, “People with disabilities are devalued, not protected.” Or their needs and differences are ignored. On the campaign trail, for instance, others more readily acknowledged her queerness than her disabilities. If ableism is indeed more prevalent in politics than homophobia, sometimes it is easier to acknowledge the challenge of being a young woman in a largely older male legislature. Disability, Rep. Jess says, is just not something we talk about.

Just putting a name to her disabilities happened for Jessica in a roundabout way. There were clues throughout her youth, hints taken from the near constant inner challenge of aligning her thoughts with her spoken words and allaying sensory cravings that would not simply go away.

At 19, while emerging from a broken relationship, Jessica talked with a psychologist who suggested autism as the reason her brain worked differently. Then, at 26, Jessica came to accept a similarly unsettling truth about her body. Her legs were not adequately supporting her, so she saw another doctor. The diagnosis: Ehlers-Danlos syndrome, a rare genetic disorder causing hyperflexible joints—or “floppy” ones, as Jessica likes to say. Many girls become women before discovering they are autistic, and there is a proven link between EDS and autism.

While living with disabilities has never bothered Jessica or made her feel ashamed, long-ago memories of prejudice from authority figures remain fresh in her mind.

At her elementary school in a neigh-

boring state, Jessica spent more time in the principal’s office than in the classroom because a teacher deemed her a bad kid.

The experience fuels her commitment to inclusive public schools and post-secondary vocational programs where there is a clear path to a future and no need to fear harsh labels or unwarranted school pushout. When Jessica and her family moved to Pittsburgh’s suburbs, leaders at their evangelical church equated disability with sin. How, she wondered, how could a child of God not personalize that?

Jessica’s parents decided to homeschool her after the primary grades, sheltering her with a determination she says had less to do with her unidentified disabilities than their unwavering belief in an inherently corrupt world. Somewhere inside, they probably harbored hard questions about their daughter’s habitual handwringing, licking, and chewing. And her struggles to find the right words to express—well . . . whatever—out loud. Maybe, like many parents in their position, they were fearful not so much of seeking but having to come to terms with a medical diagnosis that might apply to their child.

Meanwhile, Jessica found that sweet spot within where discipline meets differences that teenage girls find hard to accept in themselves. She finished high school early, joyous for the freedom to leave home to attend her mother’s alma mater halfway across the country. (Other faraway schools were not an option for this handful of a child.)

Jessica chose to be a student of subjects she did not inherently understand yet which resonate with who she is. After her bachelor’s degree in political science, she went on to complete master’s degrees in bioethics and communications. Her thesis for the



latter, *Proud to Be Autistic*, explores how individuals with disabilities choose to identify themselves versus the language used by others—including disability organizations and parents. The Pitt doctoral dissertation she is currently wrapping up examines photojournalistic portrayals of people with disabilities. Jessica's hot metal trap of a mind absorbs details like water on a sponge, making her right at home as a deputy whip, in charge of recording the attendance and votes of an assigned group of reps during legislative sessions. Colleagues entrusted her with this job within a job weeks before her swearing-in ceremony.

En route to Harrisburg on our November 2020 call, Rep. Jess forthrightly mentions the limited amount of time she has for our interviews, time that would grow tighter as calls for help with unemployment claims, vaccine appointments, and other pandemic-related matters stormed her office through the winter. I appreciate her honesty. How could she—or anyone, really—expect, let alone prepare, to begin their first term in public office in the middle of a global health crisis?

I bristle when Rep. Jess gives her blessing to my plans for doing mostly online research for this essay with a casual remark: "My life is public property."

Her words send a momentary rush of protectiveness through me. At twice Jessica's age, I had known more conventional politicians who pulled out of the game early on, I suspect, to free themselves of its unwritten rules of personal compromise and public scrutiny, or to recapture some sense of normalcy in their family lives. Yet from the start, Rep. Jess has struck me as her own person and a genuine steward for the underdog. Clearly, she can handle a lot, with little or no room on the calendar for

fretting over how the brutalities of politics or the biases of others might sway this fresh chapter in her career.

Like me, Jessica is not shy about her spiritual side, so I pondered writing this essay as though I were eavesdropping on her prayers. I also imagined doing some time-travel and crafting it as an endorsement for her re-election two years from now or my imaginary acceptance speech when Rep. Jess would someday pursue a higher office and ask me to be her running mate. (Imagine. Two women with disabilities on the same political ticket. Rep. Jess is one of less than a handful of elected officials in the United States known to be autistic.)

Then came the idea for a series of dialogues between Rep. Jess and fictional characters representing composites of her constituents. She would hear them out on matters she could do nothing about, like federal rules that punish couples existing on separate Social Security disability checks for marrying. In the next conversation, Rep. Jess might offer reassurance of her support for raising income eligibility limits in Pennsylvania's medical insurance program for workers with disabilities. There would be conversations about the economy, education, same-sex marriage, and the environment, the broader issues always rerouting to the disability experience. As Jessica said during a July 2020 forum coinciding with the thirtieth anniversary of the Americans with Disabilities Act and on so many occasions in so many words, "All policy has disability implications."

My main motive for pursuing any of the above writing tacks was to go places where the writer in me had not yet ventured. Pretty self-indulgent, yes? Rep. Jess and I, with my quirky cerebral palsy, had something major in common: the unchosen vocation of

managing the kinds of disabilities that, while maybe not absolutely qualifying as mild or profound, toggle between subtle and obvious in the eyes of others and perhaps, at times, in our own views. This characteristic lends itself well to passing, the practice of making yourself seem less disabled to blend in with the crowd or make the crowd more comfortable. We've both done our share of it—me by joining multiple extracurricular activities throughout my school years to compensate for things I could not do, like participate during gym class, or turn in neatly and promptly handwritten class assignments as my peers could. Jessica first engaged in passing as a young adult by learning to tone down the repetitive behaviors associated with her autism in public settings.

Despite our common ground, Rep. Jess and I are barely acquaintances and have never met in person. My original ideas for this piece were perhaps somewhat recklessly, bound for places a little too unknown. The instant thumbs-down Jess gave to the thought of even fictitious vignettes about her constituents appearing in print shows how deeply she respects their privacy. Taking a familiar journalistic approach to this project felt fairer to both of us. Fingers crossed, the story will go further in helping Pittsburgh and communities beyond to recognize the universal implications of disability and to embrace livability.

Back in 1990, when Jessica and the ADA were both babies, expectations for the new civil rights law leapt off the charts. It rattled me when people touted it as a silver bullet, the answer to the collective prayers of a unique segment of the population that, at nearly 20 percent of the whole, was larger than many may have realized. Or when, at the opposite extreme, folks pooh-poohed—

even smirked at—the prospect of gainful employment for anyone with disabilities who had no semblance of privilege to begin with, let alone the thought of someone like Jessica holding a prominent leadership role.

Early support for the ADA had a feel-good bipartisan ring as Democrats and Republicans, liberals and conservatives rallied for its passage. The new law shed slivers of light on the millions of Americans who—due to consequences of birth, accident, illness, or aging—were not able to process information, learn, communicate, walk, talk, see, hear, or do so much else that is seemingly effortless for the average person. It helped this minority group move out of the shadows and find new opportunities to lead fuller lives.

Thirty years later, a new generation echoes the longstanding cry that, too often, the ADA sends the people it is meant to serve on a detour to justice. It falls on these individuals, who are already navigating a less-than-accommodating world, to do most of the work involved in enforcing the law. Nobody polices its compliance, which is more rigid for public entities and new businesses than for much of the private sector. The ADA is, as Jessica wrote in 2020, “an incomplete set of protections enforceable only through lawsuit.”

In February 2021, she teamed up with Representative Dan Miller, whose district is also in the Pittsburgh area, to introduce legislation to create a Pennsylvania Department of Access and Inclusion to promote accountability and enforcement around the ADA and other disability rights laws at the state level. Their proposal calls for consolidation of existing resources and a new cabinet-level secretary in an oversight role. Modeled after a similar agency that Maryland established in 2004, the department

would be the second of its kind in the nation. At this time, the Benham/Miller bill needs additional co-sponsors from within the legislature before it can go up for vote.

Rep. Jess prefers to focus on “lifting up unheard voices throughout the commonwealth” rather than dwelling on inevitable barriers along the way. Disability advocacy became her full-time-plus job when she returned to Pittsburgh after her master’s studies and cofounded the Pittsburgh Center for Autism Advocacy, a grassroots program run by autistic-LGBTQ activists. There, she put her energy into ensuring that policy designed to protect the rights of autistic individuals truly did so. The center advocated for equitable Affordable Care Act provisions for Medicaid recipients and Medicaid waivers, making it possible for profoundly disabled individuals to live in the community. It drove the passage of Pennsylvania’s Paul’s Law, which prohibits discrimination against anyone with disabilities seeking an organ transplant or to be an organ donor. When the pandemic brought greater competition for grants in the nonprofit world and Jess lost the PCAA job, she just moved forward with the strong momentum she characteristically brings to her work.

It is worth noting that, before entering public office, Jessica also stood behind those dedicated to serving people with disabilities. She has been a staunch proponent of living wages for Pennsylvania’s direct care workers, hearkening back to her successful efforts to organize a union for student employees at the University of Pittsburgh student while pursuing the MA in bioethics she earned in 2019. Her professional life brims with opportunities to apply that degree.

Passion flares in Jessica’s voice when I bring up the anti-vaxxer movement, which has long contended that vaccinations cause autism in young children. Denying a proven preventive treatment for potentially life-threatening ailments to spare your child from an autism diagnosis, Rep. Jess says, sends the message it is better for a child to die than to live with certain disabilities.

Early in the pandemic, Jessica (not yet a state representative) started urging decisionmakers to prioritize distribution of COVID-19 vaccines for disabled individuals and the personal attendants who were with them 24/7. A December 2020 news story on the practice of rationing medical care for COVID-19 patients according to quality-adjusted life years (QALY) prompted Jessica to quickly take to social media to air her concern that patients with disabilities would receive inadequate care because, based on complex QALY formulas, their lives were deemed less valuable than that of the typical person needing care.

How is this for irony? The Institute on Medicine (now the National Academy of Medicine) in 1991 ranked disability as the number-one health problem in the United States, affecting both individuals and society at large. Fast-forward to 2020 when COVID-19 held the top spot. The coronavirus era has made pioneers of us all while highlighting the paradox that, in some respects, people with disabilities (along with their families and caregivers) are better equipped for this unexpected turn of history. Still, that does not make it easier for these forever-adapting individuals, who comprise a large portion of Rep. Jess’ constituency.

## *Intersections*

Most of House District 36 sits southeast of Downtown Pittsburgh on a hilly stretch of land winding ever so slightly into the suburbs from a handful of city neighborhoods that sprouted with the steel industry a century ago. My father grew up in the part we now call South Side Slopes. “God’s country,” he called it. Rep. Jess lives on the Slopes with Ravi, her cat.

On the district’s lower-lying western edge, highways hug a sparse business and residential area along the flood-prone Saw Mill Run creek that is one of numerous civic watersheds, figuratively speaking, that Rep. Jess has inherited. The threat of flooding during heavy rains looms in this part of town where change prevails as one millennium fades into another.

A solid white middle class community for as long as I can remember, District 36 is now home to more working poor (or unemployed) and more of a melting pot where longtime residents share the streets daily with black people, brown people, immigrants, and young adults who cannot afford to live elsewhere. Rep. Jess says a fair number of them ride bicycles or buses to work or school because owning a car is too expensive. Buses run frequently in the district, which is home to about 60,000 people, according to the 2020 census. Given current estimates that individuals with disabilities account for nearly one-quarter of the United States population, odds are that 12,000 to 15,000 of the people Rep. Jess serves have one or more disabilities. Probably more than half of individuals in that subset are unemployed, reflecting the broader pattern. The national employment rate for those with disabilities hovers

steadily at around 18 percent versus more than 60 percent those without.

District 36 residents have almost come to expect the area to make the news regularly for its drug problems and gun violence. Still, they seem to make the most of its parks, pools, food banks, volunteer street cleanups, and other positives. A few snazzy murals dot the streets as if to say, “We’re OK here.” In a more affluent pocket of the district, the upscale South Side Works spreads over multiple acres once covered with steel mills like the one where my dad worked. The retail-residential development shined a ray of hope for economic resurgence when it opened in the South Side Flats neighborhood 20 years ago. Though several key commercial tenants have since left, the complex rates a good ADA-accessibility score. And now, a major reconstruction occurring along the entire Carson Street corridor, filled with buildings that went up at least a century ago, holds promise for a post-pandemic economy and for people with disabilities. The project will add ramps, curb cuts, bump-outs, high-visibility crosswalks, and pedestrian countdown signals, making it easier for everyone to get around this bustling neighborhood.

Bustling is not quite the vibe I get while passing through other parts of District 36. The Brownsville Road business district, for example, feels emptier than when my mid-1980s foray into journalism took place in the Carrick office of a short-lived monthly community newspaper on the same block where Rep. Jess has her district office. Coupled with enough Pittsburgh-style rickety sidewalks, the sparseness alone gives one reason to think carefully about safety before venturing out, mobility issues notwithstanding. But there are also signs of

life, like the creation of a pretty public plaza at the clock tower where Mount Oliver Borough and the city meet, nicely renovated libraries and other accessible (if not always attractive) public spaces. Outside modest shopping centers, dollar stores, convenience stores, and fast-food restaurants, I catch glimpses of people with apparent disabilities more often than in my youth. Is this because there are more of these folks today? Because there are at least minimal ADA improvements, however fragmented, throughout the streets? Or that people have come to expect greater physical accessibility over the past few decades? Probably it is a combination of such factors.

I feel an uncanny karma thinking that Rep. Jess and I have traipsed the same streets, possibly too preoccupied with our work to worry about tripping and falling. Or the very opposite. Despite my limp and my spotty balance, I enjoy walking and am known to reject offers of rides in favor of a healthy stroll. Unlike me, Jessica is a driver. However, she occasionally calls for an Uber after long days at the state Capitol when her legs give out and her car is not on hand. She walks with a cane when the pep in her step is lacking. I suspect that using a cane, like driving, would be a tricky undertaking for me with my shaky hands and slow reflexes.

“Tricky” is an apt description for a scenario I experienced while trying to figure out the best ways for me to get around in pre-ADA Pittsburgh. Let me preface this by saying that, like other Live/Ability participants, I applaud Allegheny County’s local public transit and ACCESS paratransit systems for service to passengers with disabilities that in the post-ADA world ranks among the nation’s best. But back in the day, several Port Authority bus drivers

encouraged me to apply for the ACCESS program: a scrupulous application process and mobility test determined I was not disabled enough to qualify. And there went my motivation to reapply. Walking or riding the bus (and the T when I moved to southern suburbs) proved better solutions.

It is hard to know how much the ADA had to do with my less bureaucratic experience decades later when Port Authority Light Rail Transit station attendants said I ought to apply for a reduced-fare pass. Somewhere well into my 50s, I finally followed the suggestion, though I feared my income level might rule me out. Turns out a letter from my doctor was the sole requirement for the pass, a resource he thought made perfect sense for someone with mild disabilities who typically falls through the cracks when seeking government assistance.

District 36 residents no doubt have accomplished scores of similar personal administrative tasks with help from Rep. Jess and her staff. I picture them at her local office, live community gatherings or virtual meet-and-greets—folks who have spent a lifetime in the district, newcomers, military veterans, old, young, gay, straight, people of all shades and abilities. Scroll through the posts or peek at the videos on her Facebook page, and you get the sense she cares equally for the elderly and young parents of disabled children. She cares about Black Lives Matter and ADA anniversary events. Her constituents, much like autism and the disability experience itself, run on a spectrum—a beautiful color wheel mirroring humanity. It is not their diversity that strikes me most but their intersectionality—their interconnectedness as members of marginalized groups (or more than one minority group, like Jessica) making their way in a

city rooted in tradition. Rep. Jess is one of them. How lucky they are to have her fighting for what they need, day to day.

## *Bridges*

You may wonder why and how Jessica landed in public office. Well, chances are she asks herself that on occasion. It took plenty of coaxing from friends before Jessica decided to run against the self-described “old-school” Democrat who had represented House District 36 for 25 years.

As they cajoled, she laughed, wryly echoing her standard reply: “Yeah. OK. A bisexual disabled girl should totally run for office.”

As the joking subsided, it became clearer to Jessica that her knack for building bridges could drive change whose time had come. And so, she joined the race. The incumbent rep announced his retirement soon enough that he and Jessica never fully became political rivals. She got elected with more than 60 percent of the vote.

Despite the active community presence Rep. Jess maintained before her campaign through her autism and pro-labor activism, plus her roles as neighborhood block watch captain, judge of elections, and a deacon at her non-denominational church, I sense that she values mindful public service over keeping a high profile. More at ease helping than asking for help, she says friends typically look to her as the caretaker in their social circles. Privately and publicly, Jessica walks the talk. She grew up without a lot and shops at thrift stores. Extravagant spending does not feel right to her personally or as a lawmaker. She declined corporate PAC campaign contributions with a nod to those in her network who must crowdsource for wheelchairs and other necessities.

With widespread sheltering in place, campaigning took less physical effort and more creativity, a familiar mode of operation for people with disabilities. Instead of knocking on doors, Jessica conducted socially distant drop-offs where residents could pick up her literature. She held a virtual Star Wars-themed fundraiser. Her strategies of building intentional relationships, emphasizing volunteers recruited over dollars raised and referring to the campaign as “ours” not “mine,” will transfer nicely into life without pandemic restrictions. They are also reminiscent of the “person-first” approach the disability community finds so welcoming.

Rep. Jess is both realistic and idealistic in her commitment to making sure those with disabilities in this corner of Pennsylvania feel absolutely at home. It infuriates her that their needs are often overlooked in the bigger picture, a reality she believes the pandemic has magnified. She is grateful to be one of the helpers the forgotten ones can seek out yet has no illusions that time-honored bipartisanship around disability issues is a definitive problem solver.

“There are Republicans who listen to people with disabilities and certainly Democrats that don’t,” Rep. Jess says. “Disability justice cannot solely be found through electoral politics. You can’t address ableism by legislating it away.”

Meanwhile, she is doing whatever a two-year term will let her to bridge disparities between those who are able and unable to do certain things. If it were up to Jessica, livability might start with embracing individuality on both sides of that aisle. The problem is that we humans squirm at the notion of “specialness.” Admittedly, she says, the word has a weird supercrip-inspiration porn ring to it in the context of

disability. But truth be told, there is something special about every human being. That is why Jessica loves the notion of calling disability awareness days “acceptance” or “appreciation” days instead. There is nothing wrong with awareness, she says, but “Why stop there?”





## TRIGGER WARNING

“A Swirling, Lingering Storm:  
Corporal Kevin Craig Nixon”

“The Pain of Being Disabled: Loneliness”

“Despair: Living the Dream”

“Always Faithful”

“Kevin Nixon responds to ‘A Swirling, Lingering Storm’”

The honest and raw conversations between veterans Kevin Nixon and Emilio R. Rodriguez explore the devastating consequences of the stigma that many service members experience when they reach out for help. In these exchanges and poems, both Kevin and Emilio use their lived experiences to share with us the barriers to treatment that are erected and enforced by society’s stigmatizing beliefs surrounding the emotional toll of combat and, ultimately, how lack of support can be fatal. Through their discussion of stigma, PTSD, combat violence, isolation, and suicide, Kevin and Emilio urge us to become allies in the fight to acknowledge the very real struggles of service members. Their stories are also a rallying cry for veterans and allies alike to demand comprehensive and accessible lifesaving therapeutic resources. Kevin and Emilio’s stories voice the pain of loneliness, despair, and trauma, but the echoes of their words send a message of hope.

A list of resources that can provide support if you experience any distress or discomfort is available in the front matter of this book. **Click here to return to the resource page.**

It’s important to be aware of these resources as well as share them with others so we are all equipped and empowered with information that helps all of us stay safe.

# **A Swirling, Lingering Storm**

Corporal Kevin Craig Nixon

**Emilio R. Rodriguez**



As Desert Shield became a swirling, lingering storm for Corporal Kevin Nixon, the powerful rockets burst with a volcanic force that sent OIL SPEWING out of over three thousand wells in several fields littered throughout Kuwait. The previously beautiful and cloudless blue skies yielded to the ominous darkness of smoke, stench, and the fog of war. Chemical suits (MOPP level 5) were our wartime uniform. Frog missiles—that our government later admitted were projectiles loaded with sarin gas—were the only birds in the skies. The wind and desert sand pelted skin. The physical, emotional, and psychological torture of this environment made it almost impossible to escape without harm. Corporal Nixon told me, “Not knowing what was on the front line, I wanted to kill everyone. However, when we got shot at, we could not return fire. Clearly the rules of engagement are not the same for everyone.” He continued: “Before this war, I was a Marine from Washington, Pennsylvania. I was attached to an Air-Wing Unit in Beaufort, South Carolina, supporting 50 Cobra helicopters, after Parris Island. My first deployment from Pittsburgh MEPS (Military Entrance Processing Station) was in Pittsburgh, Pa.

“Days became nights, weeks, months, and then finally it happened: the storm had arrived and lasted a dramatic 72 hours. Seventy-two hours of no sleep, constant bombardment, fires, smoke, dust; it looked exactly like hell would look like. The fear of not being able to see and breathe was very prominent. The uncertainty of death and its companions—fear, despair, and anxiety—all set in with a panicked, morbid *Final Destination*. I was always thinking to myself, ‘Marines adapt and overcome.’ Still, this hell was difficult to circumvent. These eruptions of my extreme sleep discomfort while I was still in-country.”

Today, Kevin and I live in Pittsburgh. We know well the VA health system, where we’ve both cast our lot for recovering from our military experiences. But full recovery eludes people like us.

## The Pain of Being Disabled: Loneliness

*“Research suggests that loneliness poses serious threats to well-being as well as long-term physical health.”*

—[Psychology Today.com](https://www.psychologytoday.com)

Pain, according to Merriam Webster.com is “a localized or generalized unpleasant bodily sensation or complex of sensations that causes mild to severe physical discomfort and emotional distress and typically results from bodily disorder (such as injury or disease).” Pain can be experienced psychologically, physically, and emotionally. There is also the pain of loneliness, the pain of isolation, the pain of social anxiety, and the pain of not feeling human. Unlike many disabilities, pain is invisible to the naked eye and requires some level of diagnostic review before classification. The pain of invisible wounds is often compounded by the years of waiting, sometimes without disability payments, for someone to pinpoint its cause or even make a diagnosis. In the meantime, these veterans undergo years of psychological pain and trauma. Marines like Kevin Nixon become voiceless—social misfits who depend on a plethora of medical and psychological treatments. The pain of loneliness for veterans like Kevin and me is enmeshed in the physical, emotional, and psychological pain of being disabled.

The dictionary says that loneliness can be experienced as “a feeling of bleakness or desolation.” It’s more than that. Loneliness is sometimes the most painful of all pain. There’s the belief that no one will understand what you are going through. The hopelessness of no contact, and the isolation from physical and mental health support add to this bottomless feeling of despair, the desolate sense of abandonment. All too often, we are left to deal with the learned helplessness of suicidal impulses.

All pain eventually ends, and the human mind conforms to the bleakness of loneliness. The thoughts of despair set in and are enhanced by the psychoactive medications given to treat them. Over-the-counter sedatives heighten the powerful desolate features of these debilitating concoctions. Many of us are isolated to corners, for months, even years. These deployments are within one’s own soul: the turmoil, the self-searching, and the guilt. The societal categories we are then placed in, isolated even from other veterans at the VA hospitals (“behavioral health” they call it). PTSD patients at the Pittsburgh VA are given gold-colored bonnets so they can be identified when they wake from surgery. It’s not enough to be dealing with the biological toxins (we had/have no idea what we inhaled), the physical cancers that eat us from within; we also have to deal with the leprosy that comes with the labels, the anger of not being understood, isolated by medication or choice. Kevin said, “So further isolation from people is now necessary. For whose protection—theirs or mine? I’m struggling.” Many veterans feel that no one understands this level of pain, much less many of the nurse practitioners, interns, and fellows who treat us at this elite veterans facility.

For all too many veterans, the only solution to this level of pain seems to be suicide. This is how Kevin Nixon and I met. God placed us in this white, sterile padded-cornered room at the end of our ropes. Kevin on valet and I'm fast-roping through my crisis. Given that we had the same background, we began to communicate with each other a bit more as the days passed. As a former Marine, I appreciated having Kevin there. And although most of my combat experience is with the Army infantry, I chewed dirt as a young Marine. Since that day in 2019, Kevin and I have become constants in each other's life. A chance encounter has led us to honor our values as Marines and soldiers. Our service to each other does not stop on the battlefield. We have always been "men of honor" who value our most sacred creed: "No soldier/Marine left behind." So here is how we coexist: a promise to each other for each other. We both fight cancer, fibromyalgia, PTSD, heart disease, and other disabilities daily. But more so, we battle the deadliest condition: the real pain of loneliness.

Twenty-two veterans die by suicide daily.



*Dear Kevin,*

Your experiences were courageous:  
The deployments: L-O-N-G.  
Weeks, Months, Years  
Specializing in conflict,  
Destruction.  
Plowing through  
Those high-skilled-fields,  
You came home broken,  
Tired, loveless, waking up  
After “LIVING THE DREAM,”  
Emotionally stressed.  
From these prolonged experiences,  
Your injuries,  
The invisible ones,  
The ones you dare not talk about  
The ones you will eternally rest with,  
sit side by side WITHIN YOUR SUBCONSCIOUS.  
Psychologically Stressed.  
War,  
Your grading criterion—  
Soldier, Airman, Seaman, Coast Guard or Marine  
Levels gained by sweat, blood, and pain  
The up-down-up-down  
Marching,  
Singing cadence,  
loaded-up-18-clicks  
Humping in the rain.  
Physically Stressed.

## Despair: Living the Dream

Ask any returning soldier or Marine how he or she is doing. A common response is “Living the dream.” The fascination with dreaming of coming back to the “real world” often woke Kevin up in cold sweats. Anyone who has been deployed for prolonged periods understands this dream state. What are the realities of war? Are they even real? To Kevin, war was more like a dream state, where every day you’re one wakeup call away from going home, either by getting hurt, dying, or your end of tour. That big, fat, loaded-down freedom bird to the real world was not exactly for men like us. I recall a previous tour where the battalion was halfway home (not exactly—Kuwait) only to get recalled to do another 6

months after being there for 14-straight. No R&R. No leave. Somehow, even today, I remain trapped in this ancient biblical world.

To begin with, we were never minimum-type people. Every Marine always wanted to be that guy. You know: first in, last out. As time passed by, my desires to be “high speed” and “squared away” faded much like my religious aptitude. I walk around today in a semi-conscious state trying to stay alert enough to watch my own six. It’s crazy to believe that it took this long for me to begin to show signs of mental fatigue. I thought I was mentally tougher than this. Ironically, it’s not the death and gore that keep me up at night, but the many “what if” questions that go unanswered in my haze. My insomnia has now brought me closer to many of my fallen comrades, so much so that my dream life now interferes with my reality. The conversations with myself become a campfire in the middle of the desert like we used to have after a fierce night of fighting, those nights when we just sat around talking, waiting for the thumping in our chest to subside after the brutal assault we’d just put our hearts through. Reminiscing (that’s what I call it) is a mother@#\$%^&. It’s like war and the complexities that evolve from it continue to prosecute my soul. I was always under the impression that only God could judge me. I believe now that, as I lost my faith, God’s design shifted with me. It just took a few seconds, but how lasting those seconds have become. I’ve become. Consumed.

### *Hallucinate: The Faceless Burqa*

Today, I sit several feet away from the warmth of your breath.  
The last time I saw you, you were hundreds of yards away.  
Still, as I reflect, I remember you as vivid as yesterday.

We were outnumbered by thousands in that Valley of Death.  
Not surprising, your faceless burqa is the only one left.

Today, your burqa is the same as the one worn a decade ago.  
My body sweats and convulses as I step back to these similarities.  
Your hand and body gestures are just as divine today  
as they were then.

I recall the chaos of hate and pain delivering their final blow.  
Your bright-red lips poured out onto that third-world street.  
Your skin laid out the pale colors of lifelessness.

Today, I know you are not that woman.  
Am I living this dream?  
I wonder if you know what I am thinking.

Decades removed, we now sit face to face.  
I can't stomach looking in your direction.  
The fear and guilt are too intense.  
Anxious and sweating  
I wait for this episode to end.

Today, my staring makes you uneasy.  
What was going through your mind back then?  
Did you see the flash or was it the tube of guided metal  
Incoming toward you?

Today, your eyes pierce my memory through those burning flames.  
I close my eyes and hear the fire-cracked sounds of deafness,  
These forever scars of life.

I wish someday to reconcile our distance,  
To make an appeal for the fiery hell I sent your way.  
Today, I live the agony of that day,

Even though that someone was not you.  
Today, that Burqa remains Faceless,  
Silent in that place I once knew.

### *Flashback: A Shower in Iraq*

Sweaty beads of sand grit exuding from my wide-open-pores  
I sat on the bed inside my container housing unit,  
In front of the air conditioner enjoying this quiet storm,  
Reaching down to pull the sweat-filled Oakleys from my feet.

I removed the blood-soiled camouflage from my sand-trapped body.  
I grabbed my towel, shower bag, and shower shoes.  
Chewing on a granola bar,  
I exited the unit and locked the door.

I turned right down Audie Murphy towards  
The bunker walls and shower stalls.

The star-spangled rockets burst—  
A collateral affair of bodies spilling into the desert air.  
Water, blood, and sand swirled down the now congealing drain.



Electrical sparks dangled menacingly,  
Exposing the buildings' pain.

I lost a few more brothers that day.  
Even today, I can't wash away  
The sandy grit of Iraq.

### *Learned Helplessness: OUR Reality*

I could not tell  
The number of times  
But today, I sat  
Isolated and removed  
In the consciousness of my basement.

Images of life without me  
Continued their usual  
Fast forward flow.  
The musty air  
Invited a flash-back  
Ambiance,  
My reflection  
Measured against the life-span  
Of a concrete rose

Good and bad.  
A life spent hell-raising,  
The religious practices I chose  
Still questioning.  
I don't believe!  
No one would mourn  
No one would celebrate  
No one would care

I grabbed the cold metal clip  
Began loading the magazine  
To its full capacity.

One hallowed fragment  
Would suffice.

I inserted the full-metal-jacket  
Into the pristine, loyal  
Automatic.

My muscle memory  
Racked this round  
Into its final rested chamber

The smell of lubricant,  
The action of the recoiling slide  
Against my hands,  
I began to convulse.  
Determined,  
I placed the gun  
Into the familiar place  
Within my palm.

Urging myself to stay calm

Sweating  
Unstable  
My next hand motion  
Pressed the front sight  
Flush against my Temple

Swirling all my dreams  
Down the metaphorical drain:  
Life.

This, the most visualized  
Method, I thought  
“Straight thru the temple”  
Seemed impractical.

In my previous  
Marine life,  
Sudden death was assured  
By the impact of a perfect round  
On the pressure point between  
The top lip and nostrils,  
Centered!

At this point  
I placed the automatic into  
This familiar alignment.

My eyes became exasperated  
With their last visual moment,  
Closing for the last time.

I was confident  
I wanted to  
And was ready to die.

I began the controlled  
Trigger squeeze  
So familiar  
So accustomed  
So habituated.  
Without warning  
A scream  
Pierced the darkness  
Literally scaring the life back into me.

*Dad!*  
*Dad!*

I froze in position.

Like a good grunt  
I retracted the gun from my face.  
Tears mixed with sweat poured down.  
I tried to control my squeaky pitch.

I said to myself, Calm down bitch!

I placed the weapon on safe,  
Withdrew the magazine,  
Cleared this round.

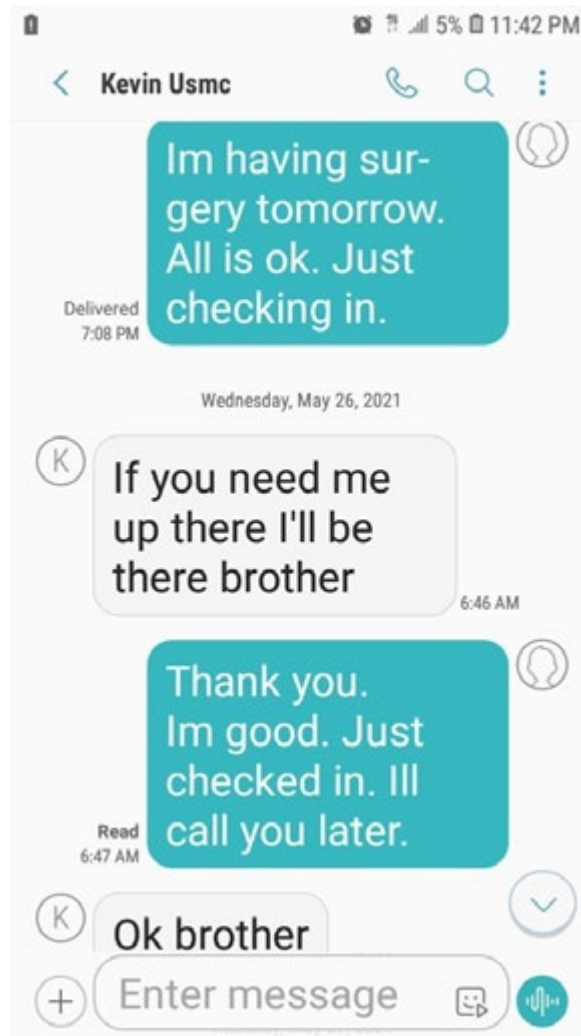
I squeezed my little girl until she  
Begged me to stop.  
*Dad!*  
*What's wrong with you?*

A bit apprehensive, surprised  
She took a step back.

She would have been  
The one who found me.  
Instead, she shocked  
Me back to life.

And still together. Kevin, myself, and other veterans stay connected thru loyalty, oaths, and the many creeds we all lived and died for. Surely you remember the buddy system, your battle buddy, your fire team. The trauma of loneliness is especially severe once societal labels are placed upon an individual. The stigma, the isolation and frustration become immobilizing. Anger, sadness, and depression chase us all. To a veteran with PTSD, it could mean his life. Please check in on a veteran today. Ask them how they are, engage in keeping them connected to this perceived reality we live in. Who knows? You could save the life of a hero veteran today. Twenty-two seconds of your time: Meet, greet, and engage for 22 seconds. Any veteran! Kevin said to me, "I prefer to be greeted by just a casual hello, rather than someone thanking me for my service. I swear, every time I hear *Thank you for your service*, I flash back to that . . . something I'm desperately trying to forget."

## Always Faithful



Today's treatments involve a fragmented concoction of psycho-sedation, a process that leaves you numb, uncomprehending, voiceless, cornered, and living in darkness. The pain of loneliness: 22 veterans die by suicide each day. Currently, suicide rates among middle-age and older veterans remain high. In 2014, approximately 65 percent of all veterans who died by suicide were age fifty or older ([www.va.gov](http://www.va.gov), 2017). My hope is that my words can invite a realistic conversation about creative solutions to dealing with suppression and trauma. The pain of loneliness affects us all.

## Kevin Nixon responds to “A Swirling, Lingerin Storm”

*Dear Emilio,*  
You were Enduring-  
Liberating-Freedom,  
Adjusting to your own battle cries,  
The sounds you still hear for real!  
Returning to your Home-Field,  
The pain of loss,  
Your Sacrifice,  
The stereotypes,  
The suicides—  
This crap is un-real.  
Twenty-two veterans die daily!!  
The facts are hard to conceal.  
How do you deal  
WITH THIS?  
The loss,  
The nightmares,  
The loneliness,  
The many what-ifs?  
Thank You for your service,  
your sacrifices and most of all  
Thank YOU for being a Patriot.

# Freaky Fire Guy

A Collaboration by Mark Steidl and Rick St. John

*There may be [. . .] sparks of divinity in millions—but they are not Souls till they acquire identities, till each one is personally itself.*

—**John Keats**, Letter to George and Georgiana Keats, April 15, 1819

*I wonder about the future and how you change with it. Now that is a mystery.*

—**Mark Steidl**, October 2006

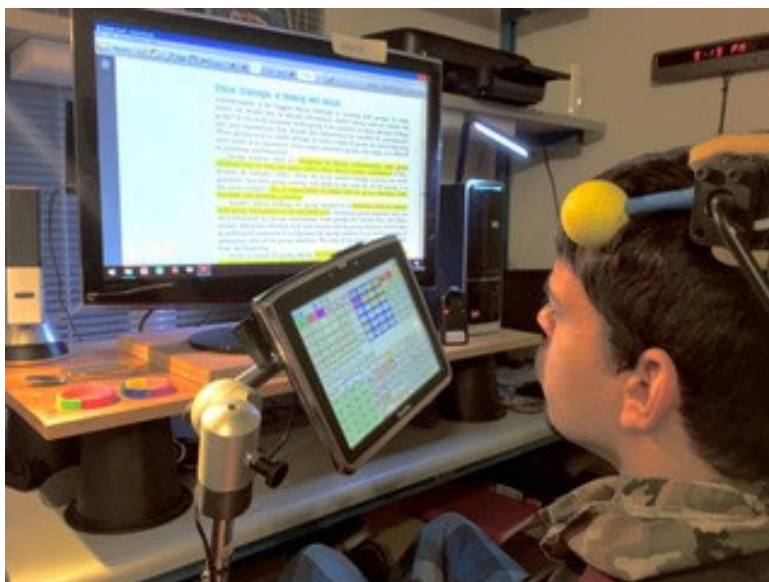
## 1. Prologue: Device-assisted communications from Mark

I have a disability. Don't worry.  
I have CP—don't worry about it. (age 10)

\*

Fine is fire.	Fine fire.	
Giant fine.	Giant fire.	
Hot fire.	The end.	(age 6)

## 2. At the first Live/Ability Zoom workshop: Rick's perspective [November 2020]



Bushy eyebrows . . . and a black goatee. A quirky, youngish man, leans forward, toward his screen. . . .

Is that rapt focus? Or discomfort? Something else?

He's in a wheelchair, in a harness of some kind.

A stark robotic voice intones:

*My name is Mark Steidl. I am 25. I have a Social Work degree from Community College of Allegheny County and I'm also a disabilities activist. I use a Dynavox communication device to talk. I use this equipment because I have cerebral palsy, which means that I have a damaged connection between my brain and my muscles. I am happy to be participating in this project.*

It feels pre-programmed, a little canned.

I steal glances at his image as the workshop carries on. Behind him: crowded shelves, computer cords, accessories. In central focus: Sassy yellow shirt; red bandanna at his chin. Mark's always-moving head—he almost lurches toward the screen. At the corner of his mouth, some kind of froth. I feel for him . . . and notice that his arms are both strapped down. But when something makes him laugh, he sparkles, beams.



Intro workshop over, everyone starts logging off the screen. I linger. From beyond Mark's frame, a woman reaches in (his mom?) and wipes away that bright, disturbing fleck of foam. Or is it flame?

**Mark's Childhood Quotes [2000–2011]** *When Mark began using a speech device at age five, his mother started jotting quotes from his communications on 5 x 8" index cards. These words were "gems" that felt precious to her. In some early quotes, she captured the phonetic or hurried spelling that appeared on his device screen. As background for this project, Rick transcribed the cards—interpreting handwriting, making minor clarifications, then selecting, reordering, and shaping the material into the roughly chronological literary form below.*



*I have CP . . .*

2 blus 1 eakols 3  
1 blus 1 eakols 2

We are home. Happy and family.

Put me on the lift.

You feeling your hart singing to you?

I am the king All the people come to me  
Come inside

Rool 1: Not touch anything  
Rool 2: knoc on door for help

I have a softly song  
Cal the sky to go to sleep

I want cold water in a little cup.

.....

## *Fine is fire.*

I need to go to the bathroom.  
I feel the push a little.

Computer after dinner.  
Wayr my “make picture” page, Mom?  
Bro gram it

Please sit by us pretty pleas if you do I always kiss you every day  
I mean I love you I care about you but I love Phil the most.

I can be anything I want to be Bus driver at [www.com](http://www.com)

I show you how to make a butter cake.  
You the addience.

Maura. Friend girlfriend.  
I love you valentine. Heart. Five.

You are quick as a violin.

---

## *Fine fire.*

“Boston”—by Mark  
Chapter 1: Nobody.  
One day King was angry! Change everything! Now! Change!  
Chapter 2: Parks? For wheelchair users  
Aquarium les wheelchairs in free because no access to top level.  
Boston —people friendly but not accessible mostly.

I need a tie. Straight down . . . I need a bigger tie.

Today I get married to K. Partners. Never apart.  
I have to get a ring. And breath kiss stuff.

I say Paul has a time out for 111 minutes and 11,111 seconds. No tv for a week.

There is a voice in your heart that says wright wrong mean nice.  
I apologize.

Issa is a woman blind black hair  
can't work because blind see bad sign talk  
on school street vacation in Ohio The end.

---

### *Giant fine.*

I want to be a aide after school because I want to help  
I have a friendship club and you have to take a membership to go in.  
I want to dance the flamenco with senorita.  
Paul I am layt. Call Beth. My watch sez 02:02 Dam  
Homework . . . but again again.  
I am getting really bored want to do something else.  
You can dance the ballerina while I play the piano.  
I went to a free library and I bought every book on the shelf.  
My bedroom rocks! It is white with a soft, green carpet.  
It is the best room!  
It can be wild so be ready to see my big crazy bedroom.  
That song was called I feel love  
When my arms flail, I don't know how to help my body.  
Be mine quick and fast

---

### *Giant fire.*

I am a writer. My article is called free life I want.  
That pump. I wish they would rip it out.  
On the other hand I like it.

New medicine? If I have to take it ok. But what are the issues.

“Sink or swim?” Let me swim!

Slow dancing? I could like ice skate.

Yes I’m sad. But not your business.

You see how we are? It’s like you’re invisible.

Don’t stand up for me.

I’m scared.

I practice until I get fancy then I am fantastic.

---

*Hot fire.*

I am normal. Whatever that means.

The first thing I need is a little deodorant.

Do you think I’m weird? Usually you love girls but I love boys.

I am strange. I don’t like me.

I am 11 and also 18.

My personality is mainly calm, but sometimes I do get upset when you don’t understand me.

No need to buy that rainbow flag.

I’m subtle. I don’t show. I even like sports.

My goal is to find out how everyone reads music.

I know they do but how—is it a code?

Can I take music lessons? I can pay.

---

*The End.*

I want cold water in a little cup.

**“Hello” scenarios, on campus [2013–2019]** *Representative communication challenges from Mark’s social interaction during his time at Community College of Allegheny County.*



She says “hi.” I smile. She’s come—surprisingly—across the room to meet me.

My eyes move to my screen. I wait for the cursor-square to reach, then flash around “hello,” and when it does, I lean into the large bright button-switch beside my head.

“Hello!” my speech-device’s boxy voice proclaims. I almost feel her startle at the sound, or cringe, but I’m concentrating on my screen. I’m lucky this time . . . the cursor’s almost crawled to blink on “happy”—as in “Happy to meet you!”. But—I know—it’s been too long—she’s already gone.

“Hi, Mark.”

It's Jim! He already knows it takes me time to operate my speech machine, so stands there, almost patiently. I'm waiting for the moving square to get to "Current Gigs" . . . which, once I bump the switch, can—with another wait—get me to the page of "Phrases for My Friends." But now some guy has grabbed him by the arm. They're jabbering. They move across the classroom, sharing photos on their phones.

So, yes, they're gone. My 47th crash & burn.

## Mark at a Disabilities Conference, Washington DC [2018]

Before the closing party, I was chilling with my friend Laura: “Sometimes,” I told her, “I wish I didn’t have quadriplegia because I would be able to dance like the sassy guy that I am.”

“Yeah, I know,” she said.

“But I’m ok with it—I’ve learned my life is just too fabulous to take for granted.”

She nudged her wheelchair closer to mine. “Ok, Mr. Fabulous, who’s gonna hit on more guys tonight—you or me?”



“Why *me*, of course.”

“You’re on, bro!” . . . and she laughed.

Ken, my favorite-ever aide, stepped up to roll me to my room, to change. “What am I going to do with you, mister?” he joked.

“This party’s only once a year,” I fired back. “And, you know, it’s hard to score with your parents around.”

.....

Well, the dance *was* wild! Hip hop, disco, Broadway, more. So many wheelchairs, jamming—just like playing bumper-cars.

Between the DJ’s sets, the noise died down. When I would spot a friend, I’d signal Ken to bring me over, next to them. I’d used my programed phrase: “It’s lovely to see you, may I please have a friendly kiss on the cheek?”

So, I talked with Ed . . . and Eric. Also, Tim rolled in—and here’s the funny part—I caught him making eyes at Ken. It was, for sure, one crazy time!

But when, I wonder now, will time be mine again?

**Mark's Lyrics for a Pandemic Performance Piece [2020]**



*LOST TIME*

*Life all a tizzy  
I was perfectly happy  
What else can I say*

*LIFE IN THE  
PRESENT*

*Soon, they tell me, soon  
Now with uncertainty and  
fury inside . . . I hide*

*All I ever hear  
is later, Steidl, later  
I sit right at home*



## LIFE IN THE FUTURE

*Soon, they tell me, soon  
wait for the world to resume  
the thing I most hate—Zoom*

### 3. We meet to discuss this project: Rick's Perspective [February 2021]

Mark's mom pulls their van in front of my apartment building, come to pick up the stack of index cards that I've transcribed.

It's a rare bright day in Pittsburgh. Sun glints off the chrome. Mark sits strapped in back, and I lean in to talk with him, the panel door slid wide. We're both masked, since social distance guidelines are in place. He's partly shadowed, still inside.

I know now to wait and give him time to speak; to ask him "yes" / "no" questions when I can.

I know his mom will stay reserved, but step in—if he gives a glance—to help flesh out his words.

"When we all get vaccines and once the weather warms, would you like to meet?" I ask. "Maybe at a gallery or park?"

I wait . . . as Mark writes back: "The Abbey." His mom explains: A café/pub and bistro place on Butler Street. "It's new . . . and hip and somewhat gay—he likes to show it off to friends."

We all agree. His mother volunteers to pick me up.

"I've been thinking," I tell Mark, "of calling our piece, *Fine Fire*. I like the quote of yours that goes *Fine is fire. Fine fire. A giant fire. The end.* Not sure I've got it right." I wait.

His voice comes back: "Freaky Fire Guy."

"OK," I answer, "*Freaky Fire Guy* it is." We laugh.





“So, when I see you next, can I call you ‘FFG’ for short?”

Mark says “Yes.” We laugh again.

His mom has errands left to do. The door slides shut. The van moves into traffic, with its sparkle and its haste.

*So, FFG it is, I tell myself.*

*For now, at least. And they head off—into the day that he’ll make his.*



## Afterword

Sheila Black

Back when I was in college studying poetry, a poet friend said to me, “A poem should teach you something.” I strenuously resisted this idea, arguing for “art for art’s sake,” by which I think I meant the right of the artist to explore anything. Yet over the years, my mind has changed. Now I see the teaching as a critical part of what poetry or any art *does*. I believe, with my poet friend, that a poem should map something for you, help you see or grasp a thing *better*. In the words of Pittsburgh poet Toi Derricotte, “The job of the artist is not to resolve or beautify, but to hold complexities, to see and make clear.”

As a disabled woman—and sometime poet—I’ve certainly experienced the silencing, erasure, and misinterpretation so many people with disabilities have gone through when it comes to our stories. We are to be

invisible; we are to pass for “normal” (whatever that means); we are to be flattered when someone tells us we are “heroes”—the latter of which (and I love that the disability community has taken to calling this “inspiration porn”) is actually strangely insulting because it implies that to be us is so challenging/terrible/awful that our very existence is an act of heroism. The book you hold in your hands is a wonderful counter-medicine to all this. Yet it is also something more: a nuanced and complex articulation of some of the values and practices of what I’d like to call *disability culture*. Most importantly, it suggests how the values and ideas that have informed disability experience can be an important force in revitalizing and rebuilding our sense of community.

What disability culture values or ideas am I talking about? The first is an honest

reckoning with vulnerability and interconnectedness. So many voices in this book speak honestly and forthrightly about their need for kindness, the help of others. Take for example Sheila Carter-Jones' profile of Avis Zawadi, a Pittsburgh resident who has Fuchs' endothelial dystrophy, which causes loss of vision. Carter-Jones writes, "A woman Mrs. Avis met while sitting outside took her to the store. Helped her shop by reading labels and taking her to different sections of the grocery store. That day, Mrs. Avis was able to get green pepper, Swiss chard, and, of course, a bag of onions. . . . Mrs. Avis says she never would have been able to get exactly what she wanted if it hadn't been for the woman walking her around. That's the nature of a blessing. To support you. Not *do for you*."

Unlike in mainstream discourse, such vulnerability is never to be confused with weakness or regarded with shame. On the contrary, an acknowledgement of shared vulnerability becomes a means of nurturing collective consciousness and strength. Jennifer Matesa's profile of Anne Alter, a Pittsburgh resident who has schizophrenia, underlines this: "People are surprised when they find out I have mental illness because I present so well. I have to use all my acting skills," Anne says. One thing I hear her saying here is that her acting skills help her make it easier for *other people* to be around *her*. What if it were the other way around: what if folks without mental illness had to learn skills that enabled them to interact with folks with mental illness?"

Matesa continues: "If young kids are not educated in the skill of empathy, they turn into cruel creatures who pick on others who don't look like them.... So it's possible to see that people who don't know how to talk to someone with mental illness are the ones

who are lacking in social skills—not the ones with mental illness." These remarks build on the notion of the social construction of disability put forth by disability theorists, which asserts that what we consider disability is less about the originating medical condition (deafness, low vision, mobility disorders, etc.) and more about the way that disability is constructed through the society's responses to the disability—the barriers, exclusions, and stigmas that make it difficult, if not impossible, for disabled people to fully function within society. Think, for example, of the way we often typecast people with non-normative mental states as unreachable or unapproachable or hard to take to. What, this book asks, would we see if we questioned some of the assumptions the ableist construction of disability has established?

In her profile of Pittsburgh DeafBlind advocate Richard McCann, DB writer Cristina Hartman reflects on some of the ways in which the disability community emphasizes human interconnectedness. Despite his many notable achievements, Richard describes his proudest moment as his work to form the Western Pennsylvania Association of the DeafBlind (WPADB), Pittsburgh's first DeafBlind social club. Here is how Cristina Hartmann translates her protactile conversation with Richard: "When most people talk about 'livable' cities, they talk about bike lanes or affordable housing but rarely about social connection. Perhaps Richard's more holistic view comes closer to what the term really means: 'More access to television, shopping, books, and friends!' His index fingers hooked together in the ASL word for *friend*, a visual and tactile manifestation of one of our most basic needs—human connection."

This theme of human connection is front

and center in a majority of the pieces collected here, from the poetry—namely “Sidria Sings: Sidria Williams” by Cameron Barnett and Emilio R. Rodriguez’s poems celebrating his friendship with his fellow war veteran Kevin Craig Nixon—to the essay profiles of a broad spectrum of disabled Pittsburgh citizens. The value we hear articulated again and again is that only in the truth and tangible outlines of our need for one another can we begin to forge communities that work, communities that are alive and vital in their collective caring.

Another disability culture value we encounter in *Pittsburgh Live/Ability* is the idea that to grasp truth we must begin by acknowledging that there are multiple sides to every story; truth arises out of multiple perspectives. The choice for writers and interviewees to collaborate on their piece, or to follow a piece by the writers (many of whom are also disabled) with commentary and reflection by the subjects of these pieces, adds a crucial layer to the work. As readers we are asked to consider more carefully how we hold the stories we are told and also how more multifaceted perspectives might grow our vision of community.

I can’t help feeling this insistent emphasis on being open to multiple ideas and understandings comes from this anthology’s deep immersion in disability culture, whose members understand that they represent a spectrum of *different* embodiments and experiences. Jim Ferris, one of the pioneers of the “Crip Poetry” movement, says that a key factor of disability poetry is that it proposes an understanding in which what is historically considered to be in the margins is placed at the center. He writes in his essay, “Crip Poetry or How I Learned to Love the Limp,” “Emily Dickinson’s description of poetry is wholly centered in the body; crip

poetry is centered in the body as well, but it is centered in bodies which are themselves off-center, apart from the norm, off where it is easier to see, to perceive, where there is even more to feel.”

Back in 2011, I was lucky enough to serve as a co-editor of *Beauty is a Verb: The New Poetry of Disability*, an anthology which included poems and essays by disabled poets. At the time, the anthology was somewhat groundbreaking because it spoke to people with disabilities and also gave an abled audience insights or a map through which to modify their (often very limited) understanding of disability culture and poetics. My co-editors and I began that project with a very simple idea: we wanted to explore how the experience of non-normative embodiment—the experience of having a visible disability—might shape poetic process and aesthetics. Most of all, we wanted to take a non-tragic view of disability that positioned it as an identity that was productive and could lead (and had led) to creative innovation and discovery.

*Pittsburgh Live/Ability: Encounters in Poetry and Prose* performs a similarly critical mapping. Through the pieces collected here, we gain a three-dimensional picture of what disability and being disabled feels like for these subjects in the City of Pittsburgh in the second decade of the twenty-first century. We learn about the activism in the community; we learn what the community has and hasn’t done. We learn how relationships between people can change the landscape as with Pennsylvania State Representative Jessica Benham’s work to establish a state bureau devoted to disability access or Paul O’Hanlon’s lifelong project of advocacy for accessible housing and transportation.

Yet the book reaches well beyond the

obviously political issues around disability to document a multitude of private moments—friendships, delights, love stories, the jokes and strategies disabled people use to make their way through their city—the City of Bridges. One of the delights of reading *Live/Ability* is meeting so many complicated, quirky, brilliant people who open their lives to us. From Ava C. Cipri and Heather Tomko’s “Ableist Bingo,”—a game!—as well as their respective essays on their city’s “safe spaces” to “Freaky Fire Guy,” the fabulous hybrid collaboration between poet Rick St. John and CP writer Mark Steidl, this book is full of personality. By going

intensely local and focusing on what is right in their own backyards, the creators of this anthology have accomplished something fresh and revolutionary—a way of growing an indelible local literature—a map which, to harken back to Toi Derricotte’s words, allows us “to hold complexities and see clear.” I am so proud and moved that this effort came out the disability community. To return to the poet friend I started with—what does it mean to have literature teach us something? *Pittsburgh Live/Ability: Encounters in Poetry and Prose* provides a compelling answer.

## Participants



Photo by Josh Franzos

**Cameron Barnett** is the author of *The Drowning Boy's Guide to Water* (Autumn House Press), which was a finalist for an NAACP Image Award. He earned his MFA from the University of Pittsburgh and teaches middle school English. He is the recipient of the 2019 Carol R. Brown Creative Achievement Award for Emerging Artist. Cameron's work explores the complexity of race and the body for a Black man in today's America, more of which can be found at [cameronbarnett.net](http://cameronbarnett.net).



**Sidria Annette Williams**, 29, describes herself as “a talented woman.” She’s an active member of New Bethel Baptist Church, works in the mailing department at a vocational training center in Pittsburgh, and graduated from Taylor Allderdice High School. Sidria grew up on the North Side and still lives north of the three rivers in a group home that’s part of the Emmaus Community of Pittsburgh.



**Katie Booth's** work has appeared in *The Believer*, *Catapult*, *Harper's Magazine*, *Kaleidoscope*, *McSweeney's Quarterly Concern*, *WHYY's The Pulse*, and *Vela*. It has been highlighted on *Longform* and *Longreads*, and her essay “The Sign for This” was selected as a notable essay in *The Best American Essays 2016*. She has received support from the Edward Albee Foundation, the Blue Mountain Center, and the Massachusetts Historical Society, and was a 2017–18 John W. Kluge Fellow at the Library of Congress. She grew up in a mixed hearing/deaf family. Her first book, *The Invention of Miracles: Language, Power, and Alexander Graham Bell's Quest to End Deafness*, was published by Simon & Schuster in 2021.



**Kenneth DeHaan** is a passionate Deaf bilingual person who started his career in the financial sector (wealth management) at the Bank of New York Mellon. Navigating his way through an abled-centric society, he saw the cracks and flaws in our structure and discovered another hidden passion along the way, teaching. He found his passion in teaching and educating others. His professorship began at the University of Pittsburgh. Today, he is a professor at Gallaudet University. Kenneth brings a blend of unique perspectives through the lens of education and business at his place of practice. This unique skill set is amplified through his doctoral studies in Higher Education Management. Kenneth has taught a variety of courses related to language, education, and culture for various organizations, schools, and colleges. His methods are informed by research and pedagogical practices. Of the variety of courses Kenneth has taught, his passion lies within social justice and advocacy.



Photo by Gabriel Colombo

**Sheila L. Carter-Jones** taught in the Pittsburgh Public Schools and in Chatham University's and the University of Pittsburgh's Education departments. She earned her BA from Carnegie Mellon University, and both a MEd and PhD from the University of Pittsburgh. In her creative writing career, Sheila is a fellow of Cave Canem and the Callaloo Creative Writing workshops. Her poetry has been published in several journals, anthologies, and magazines. Sheila's full-length book, *Three Birds Deep*, was selected by Elizabeth Alexander as the 2012 winner of the Naomi Long Madgett Poetry Book Award, and her chapbook *Crooked Star Dream Book* was named runner-up for the 2013 New York Center for Book Arts Chapbook Contest. She is currently working on a new manuscript of poems.

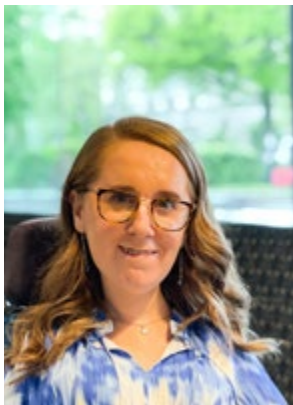


**Dr. Avis Zawadi**, a city girl from the Bronx now living in what she calls "The Wilds of Pittsburgh," has been interested in behavior and response to stimuli since childhood, so it was not at all surprising that she professionally pursued psychology and psychoanalysis as a lifelong endeavor.





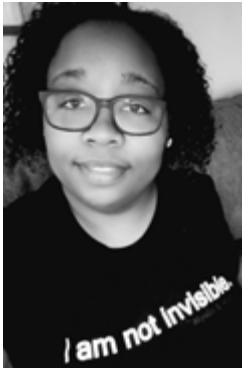
**Ava C. Cipri** is a nonbinary queer writer, educator, and activist in Pittsburgh. She is a co-founder and poetry editor of [The Deaf Poets Society: An Online Journal of Disability Literature & Art](#). A Pushcart, Best New Poets, and Best of the Net nominee, Cipri has work published or forthcoming in *Boulevard*, *Cimarron*, and *Stirring's Manticore: Hybrid Writing from Hybrid Identities*, among others. Ava has two chapbooks: *Leaving the Burdened Ground* (Stranded Oak Press, 2018) and *Queen of Swords* (DGP, 2018). She holds an MFA from Syracuse University and takes Carlow University's [Madwomen in the Attic workshops](#), where she runs in the company of other Mads. Ava resides at [www.avaccipri.com](http://www.avaccipri.com) and tweets at [@AvaCCipri](https://twitter.com/AvaCCipri).



**Heather Tomko** is a native Pittsburgher, lifelong resident, and graduate of two of the city's universities—Carnegie Mellon University and the University of Pittsburgh. As a woman with spinal muscular atrophy, a neuromuscular disease, she is passionate about disability advocacy and access. She is the outreach coordinator at the University of Pittsburgh's National Rehabilitation Research and Training (RRT) Center on Family Support, and blogs at [The Heather Report](#). She was the winner of the 2018 Dick Thornburgh Disability Service Award, the 2019 ACHIEVA Award of Excellence for Community Awareness, and was Ms. Wheelchair USA 2018.



**Selene dePackh** is a queer, neurodivergent crone who forefronts marginalized characters in her work. She worked as an illustrator before turning to writing. Kirkus describes her first novel, [Troubleshooting](#), as “a gripping, lyrical, and ambitious dystopian novel,” and describes its narrator as “a character of immense depth and originality. There are few protagonists in sci-fi—or literature in general—that present an autistic perspective with such specificity and pathos.” Her short dystopian SF and weird/horror stories have appeared recently in *Nightscript 6*, *Oculus Sinister*, *SYNTH 2*, and *Recognize Fascism* (Pushcart nomination for her story by the publisher), among others. Her novella *Golden Road* was published by JournalStone in 2022.



**Alana Gibbs** was born and raised in the suburbs of Pittsburgh. She is a licensed manicurist of 21 years and the owner of Hair 2 Sole Beauty Studio in Bridgeville. Being a manicurist has allowed Alana to do many things. One of her favorites has been participating in New York Fashion Week for 13 seasons. Alana is a wife, mom of three (one son and two fur babies), a Converse shoe connoisseur, and amateur podcaster. Like her favorite superhero, Wonder Woman, Alana tries to make the world a better place. Spreading the importance of self-care is her current mission.



**Cristina Hartmann** is a Brazilian-American writer living in Lawrenceville. Born profoundly deaf and now DeafBlind, she writes in ways that explore identity and relationships through disability and immigrant experiences. She received the June 2020 Deaf Artist Residency Award at the Anderson Center in Redwing, Minnesota, and her work has appeared in *McSweeney's*, *Peatsmoke*, and *Vox*. She loves scarves, cheap port, and first-person narratives.



**Paul Richard McGann, Jr.**, is a DeafBlind Pittsburgher who grew up in Mt. Washington and currently lives in Brookline. He attended the DePaul Institute for the Deaf (now called the DePaul School for Hearing and Speech). He was the first Deaf student to attend the Community College of Allegheny College (Boyce campus), then went on to attend the Helen Keller National Center for DeafBlind Youths and Adults. For 37 years, McGann worked at the Western Pennsylvania School for Blind Children, serving as a DeafBlind intervenor, a supply manager, and a brailist; he also taught DeafBlind interpretation for 17 years at the Community College of Allegheny County. McGann has been a longtime advocate and organizer for DeafBlind and disabled people, having been a vice president for the American Association of the DeafBlind (AADB), and the founder of the first and only DeafBlind club to be chartered with the International Lions Club. Since 1991, he has been an advocate for the [City-County Task Force on Disabilities](#), and since 2002, he has been a member of the Behavioral Health Task Force for Persons who are Deaf, Deaf-Blind or Hard of Hearing in Allegheny County.



**Jason Irwin** is the author of three collections of poetry: *The History of Our Vagrancies* (Main Street Rag, 2020), *A Blister of Stars* (Low Ghost, 2016), and *Watering the Dead* (Pavement Saw Press, 2008), and of the chapbook *Some Days It's a Love Story* (Slipstream Press, 2005). He's also had nonfiction published in various journals. He lives in Pittsburgh.



**Paul O'Hanlon** is a retired lawyer who worked for a disability rights law firm from 2001–2014; before that, he was the Senior Housing Attorney and Housing Unit Chief with the Neighborhood Legal Services Association in Pittsburgh. He has been involved in a number of advocacy issues in Allegheny County, particularly around housing, accessible public transportation, and voter engagement. In the early 1990s, following the passage of the Americans with Disabilities Act, he convened the Accessible Transportation Work Group, which worked with Port Authority to implement the accessibility requirements of the ADA. In 2002, O'Hanlon filed *Washington v. Housing Authority of the City of Pittsburgh*, a class action on behalf of residents; the case settled, with the HACP building 300 fully accessible units and committing to 10 percent Authority-wide accessible units (double the federal minimum). In 2003, he spearheaded efforts to incentivize visitable housing design through tax credits in Pittsburgh and Allegheny County.



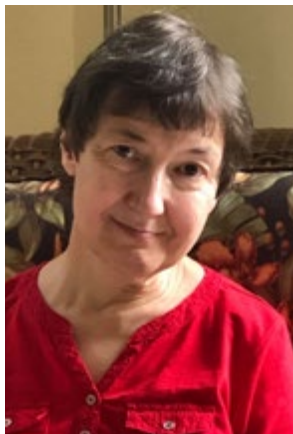
Photo by Pamina Ewing

**Jennifer Matesa**, LCSW, MSW, MFA, is a therapist in private practice. Previously, she was a therapist at Western Psychiatric Hospital's Bellefield Intensive Outpatient Program, where she taught dialectical behavior therapy to clients with depression, anxiety, bipolar disorder, and personality disorder. She is the author of four books of nonfiction, two of them about mental health issues. In 2013, she was awarded a fellowship at the U.S. Substance Abuse and Mental Health Services Administration.



Photo UPMC Creative Services

**Anne Alter** has been a lifelong member of the "Mental Illness Club." While being "certifiably nuts," she has been a teacher; an actor for theatre, video, and film; a public speaker; a singer; a dancer; an athlete; a model for fine art and performance art; a writer; a college graduate; and a technician for theatre and film. Having fought for her rights within the mental health system from the age of nine, she has become an advocate for the rights of people with mental illness to live openly and without stigma. In some ways, her illness has proven to be a gift, and she is pleased that life events have brought her to to this project.



**Patti Murphy** has written on disability issues for more than 25 years. She is a communication specialist for Tobii Dynavox, producer of augmentative and alternative communication (AAC) technologies and solutions for individuals with complex communication and access needs. Her work has appeared in the former *Pittsburgh Press*, *ADVANCE for Speech-Language Pathologists*, *Closing the Gap*, and *Exceptional Parent*, as well as in the *Pittsburgh Post-Gazette*, where in the late 1990s she wrote a column on disability-related topics. She is the author of a chapter on AAC for the anthology *Cutting Edge Therapies for Autism*. Patti enjoys writing short humorous essays, practicing yoga, dancing, and all things musical. She lives with her husband in Bethel Park.



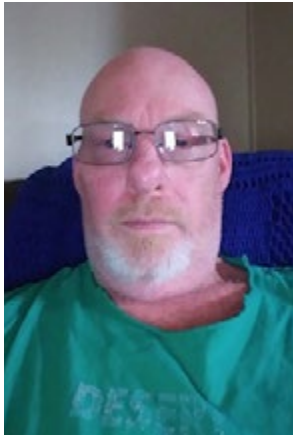
**Jessica Benham** is a Pennsylvania State Representative for the 36th District. She has an MA in Bioethics from the University of Pittsburgh and an MA in Communication from Minnesota State University, Mankato. She is currently completing her doctorate in Communication at the University of Pittsburgh, studying disability protest movements.



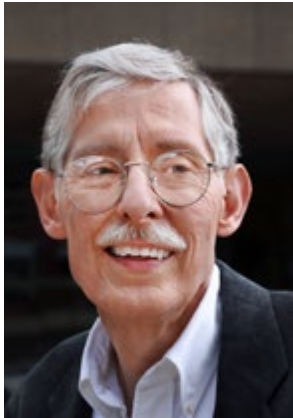
Illustration by Sam Thong

**Emilio R. Rodriguez** is a combat veteran from the U.S. Virgin Islands who grew up in Pittsburgh's McKees Rocks. He has received a 90% disability rating from the Department of Veterans Affairs. A graduate of the University of Pittsburgh, Emilio now pursues his passion for writing, using this platform to discuss experiences in Iraq and Afghanistan in hopes of opening a dialogue that would use creative writing as a vessel for unlocking its therapeutic power for other veterans. His deployed years as a Marine and U.S. Army Infantry team leader have enabled a desire in him to help other veterans, all the while creating his own tangible therapeutic space.

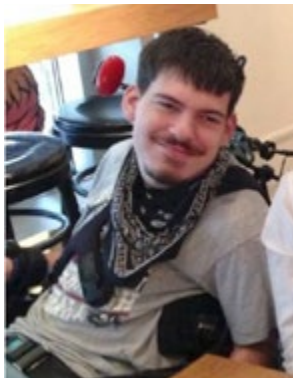




**Kevin Nixon**, after graduating high school, enlisted into the Marine Corps on his following birthday. Kevin spent a year overseas in Okinawa, Japan, and then was transferred to MWSS-273 in Beaufort, S.C. He deployed to Desert Shield/Storm from there. Upon completion of his tour, he exited the Marine corps and entered civilian life. A truck driver for some twenty years, battling the combat stress and road fatigue made his health issues worse. He has not yet been evaluated for a pension through the Veterans Administration, although he exhibits many of the same illnesses as other veterans deployed in that region and battles cancer, PTSD, fibromyalgia, just to name a few of his disabilities and invisible wounds.



**Richard St. John** is the author of *The Pure Inconstancy of Grace* (Truman State University Press, 2005; first runner-up for the T. S. Eliot Prize for Poetry), *Each Perfected Name* (TSUP, 2015), *Book of Entangled Souls* (Broadstone Books, 2022), and *Shrine* (a long poem released as a chapbook in 2011). For more information, please visit his website: [www.richardstjohnpoet.com](http://www.richardstjohnpoet.com). Rick lives with low vision and related issues arising from retinopathy of prematurity. During the 1950s, the condition was associated with premature birth and oxygen levels used in incubators. He has, for instance, never been able to drive and has considerable difficulty with facial recall.



**Mark Steidl** is a disability rights advocate and 2020 graduate of the Community College of Allegheny County, where he majored in Social Work Foundations and served as a student government senator. Mark was diagnosed as an infant with cerebral palsy and uses a variety of technology to manage his condition. He serves on the youth caucus of the National Council on Independent Living, advocates in a variety of disability rights campaigns, and is a proud member of the LGBTQIA+ community. He works at Tobii Dynavox, a world leader in electronic communication devices.



**Sheila Black** is the author of numerous books for children and young adults, as well as of four full-length poetry collections, including *Iron, Ardent* (Educe Press, 2017). Black has also edited anthologies featuring literature by disabled authors, including *Beauty Is a Verb: The New Poetry of Disability* (Cinco Puntos, 2011) and *The Right Way to Be Crippled and Naked : The Fiction of Disability* (Cinco Puntos, 2017). In 2012, she was awarded the Witter Bynner Fellowship by the Library of Congress. Black is a founder of Zoeglossia, the nation's first organization dedicated to nurturing the work of poets with disabilities.



**Ellen McGrath Smith** teaches at the University of Pittsburgh and in Carlow University's Madwomen in the Attic program. Her poetry has appeared in *The Georgia Review*, *The New York Times*, *The American Poetry Review*, *Los Angeles Review*, and other journals and anthologies. Books include *Scatter, Feed* (Seven Kitchens, 2014) and *Nobody's Jackknife* (West End Press, 2015). Smith, who is hard of hearing, has taught in the Zoeglossia program for poets with disabilities, and has published work in *Beauty Is a Verb: The New Poetry of Disability* and *The Right Way to Be Crippled and Naked: The Fiction of Disability*. Her chapbook, *Lie Low, Goaded Lamb*, is forthcoming from the Seven Kitchens Press as part of its Keystone Series.

As you read *Pittsburgh Live/Ability: Encounters in Poetry and Prose*, we urge you to do so safely. Below is a list of resources that can provide support if you experience any distress or discomfort. It's important to be aware of these resources as well as share them with others so we are all equipped and empowered with information that helps all of us stay safe.

- **Suicide Prevention Lifeline: 1-800-273-TALK (8255)**

- **Suicide Prevention Lifeline: 988 (as of July 16, 2022)**

*For TTY Users use your preferred relay service or dial 711 then 1-800-273-8255.*

- **Allegheny County Peer Support Warmline Service: 1-866-661-WARM (9276)**

*Peer specialists are trained to actively listen to their peers, empathize with their concerns, and empower individuals to choose their path to wellness and recovery.*

- **PAAR (Pittsburgh Action Against Rape): 1-866-363-7273**

*Access text/chat via: [paar.net](http://paar.net).*

- **RAINN (Rape, Abuse, and Incest National Network): 1-800-656-HOPE (4673)**

*Access TTY: 1-800-799-4TTY (4889)*

- **Substance Abuse and Mental Health Services Administration's (SAMHSA) National Helpline: 1-800-662-HELP (4357)**

- **National Domestic Violence Hotline: 1-800-799-SAFE (7233)**

*TTY: 1-800-787-3224*

*Live chat: [thehotline.org](http://thehotline.org)*

- **National Alliance on Mental Illness (NAMI) HelpLine: 1-800-950-NAMI (6264)**

*Web chat: [www.nami.org/help](http://www.nami.org/help)*

- **Resources for veterans**

*NVF Lifeline for Vets: 1-888-777-4443*

*Stop Soldier Suicide: 844-317-1136*

*Veterans Crisis Line: (TTY)711+1-800-273-8255 #1; or text 838255.*

