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Disabled Lives and Pandemic Lives: Stories of Human Precarity

By Carol Rogers-Shaw

I've lived all my life in the Northeastern United States, and always looked to March as the end of winter and April as the beginning of spring. But in 2020, it was different. Throughout the cold months of January and February, we began hearing news stories about the devastation triggered by a new and mysterious disease. As the seriousness of the situation became increasingly clear, my husband and I wondered if, as a disabled woman, I needed to take any particular precautions. We decided I should call my doctor.

I am a 62-year-old, White, American woman. I was diagnosed at the age of 20 with Type 1 diabetes, which has resulted in numerous hospitalizations, frequent health crises, and life-threatening events. Type 1 diabetes was classified in 2008 as a disability under the Americans with Disabilities Act Amendments Act. I spent most of my career, from 1989 to 2014, as a public-school teacher of students ages 14 to 18 who had identified disabilities. In 2020, I completed a PhD in Lifelong Learning and Adult Education, during which I focused on the needs of learners with disabilities transitioning to higher education. Much of my life and career has been devoted to the experiences—my own and others'—of living with disability.

That call to my doctor is burned into my memory as our first real moment of fear, and it was hard not to panic after I hung up. We live in the Adirondack mountains where healthcare is less accessible than in other areas. The doctor told me to head somewhere with top-notch healthcare providers and to stock the house, so I didn't have to leave it for at least three months. I threw clothes and all my diabetes supplies into the car and raced to the Triangle in North Carolina, where my daughters live. As I drove, I made a mental list of what I needed, including food to meet my dietary restrictions, insulin and pump supplies, syringes and alcohol pads, sensors and meters, blood-testing strips and glucagon, and anti-nausea and anti-diarrhea medicine. I relied on years of experience planning for contingencies that might arise due to my disability. That weekend my daughters and I made my last trip to a store for over a year, and I began a fourteen-month quarantine.

The Covid-19 pandemic, which is still ongoing more than two years later, has taken a serious toll on everyone. In some instances, experiences are widely shared across communities and people regardless of other differences. In other instances, the differences, including where one lives, one's economic resources and employment, race, gender, age, and access to medical care and vaccines have meant that in a very real sense, there has not been one pandemic but many pandemics, or rather one pandemic experienced in many different ways.

What I feel most when I think about the isolation and making do during the pandemic is anger. Daily news reports tell us stories of service workers assaulted and even murdered when asking

customers to mask up; airlines reporting record numbers of mask-related incidents; school board members and teachers threatened and attacked over safety protocols; anti-vax protesters expressing a wide range of grievances.

The virus seems to have intensified a lot of people's anger, including those with disabilities. While the pandemic has created anger for a lot of people, many individuals with disability have a few more things to be angry about like "devastating ableist violence— eugenicist triage protocols, mass death in residential institutions and the normalization of disabled death" (Linton, 2021, para. 1).

While frightening, the pandemic has also been a time of uncanny familiarity for many people living with disability. That is, many things that are known to people living with disabilities—and perhaps especially to people whose disability, like mine, has a major medical dimension—came crashing into the consciousness and experiences of people in the mainstream. People without disabilities had no or limited experiences with how the needs of one's body can move our lives out of "the normal," can impose demands that involve limitations, risks, isolation, and uncertainty, and can provide opportunities and new ways of doing things previously taken for granted.

Watching the pandemic unfold and seeing people who did not know how to manage its challenges brought me back to my life with disability. Much of the fear and panic generated during the lockdown resulted from confronting the same issues that people with disabilities live with all the time. There were moments when I watched coverage of the pandemic or listened to people I knew talking about it when I wanted to shout, "Let me tell you something about my life, the one I live every day as disabled." There were times when news stories flashed across the screen and I felt the urge to scream, "Let me and others with disabilities tell you what we already know, you poor folks who are coming late to this game of human precarity."

I want to tell these stories, to show the ableists that those of us with disabilities are really the stronger ones and to laugh at their ignorance. Yet despite the temptations of indulging in this illicit pleasure, I also see that telling some of the stories of the pandemic through the eyes of a person with a disability provides an opportunity to build profound connections. We can recognize shared vulnerabilities and the unexpected creativity that we need to survive. The better part of me argues for the altruistic focus rather than the vengeful one (although I am not going to deny those feelings).

When I think back over my experiences during the pandemic, I realize that my thoughts, feelings, and actions have been deeply entwined in my being a person with a disability and a teacher of learners with disabilities. I hope to share my view of adjusting to a new reality brought on by the pandemic through my lens as a disabled person who has lived and even thrived with a

disability and has worked with children, youth, and families who have developed significant strengths and understandings of the realities that result from a disability diagnosis.

I also want to share how finding those strengths and gaining greater understanding does not mean life gets easier. Just as it is still very hard to live a disabled life, it remains a challenge to manage Covid-19 restrictions despite the introduction of vaccines and treatments. Throughout this piece, I hold on to the basic belief that telling stories honestly provides us as teachers, parents, and individuals with pathways to strength.

For the readership of the *Bank Street Occasional Papers*, what I hope is to provide stories that demonstrate both the emotional complexities and the many strengths that can develop as the result of living with a disability. Whether the reader is disabled, works with students with disabilities, has loved ones with disabilities, or has little direct relationship to disability, my goal is to present a way of turning the tables, of making it clear how a life with disabilities can uniquely equip us to live with precarity and to offer insights to others for whom a profound sense of precarity is a new experience.

I would also be less than honest if I did not say that this piece arises from the sense of horror I have had throughout the pandemic about conversations about “lives worth living” and “lives worth saving.” During the pandemic, doctors have been faced with deciding who was worthy of a ventilator or an experimental cure. Individuals with disabilities can easily be deemed unworthy (Ne’eman, 2020) due to societal views of disability. Ho (2020) argued that “cultural values validate the narrative of worthy versus unworthy bodies. But the entire discussion needs to be rewritten as marginalized creators and activists repeatedly point out that there are no unworthy bodies” (p. 115).

Individuals with disabilities are not worthy only because they might have a particular set of skills or funds of knowledge that others can learn from as they navigate situations like the pandemic. It is not about judging worthiness by putting pluses and minuses in columns on a table. It is about changing the view that comes up with that list of positives and negatives in the first place. If we can see that one human body is not worth more than another, we might head in the right direction. We might see that different does not mean bad.

In this paper I begin with a short overview of Disability Studies in Education (DSE) and what it brings to how we conceptualize disability, including its criticism of deficit-based discourses and practices, its embrace of a strengths-based perspective, and its insistence that much of the experience of disability is not inherent to the disability but to its social reception. I talk about the important role of storytelling in Disability Studies, and I make use of stories and analysis to examine the similarities between those living with disabilities and all of us living through the

Covid-19 epidemic. I end by calling for more empathetic and reciprocal relationships between individuals with and without disabilities.

Disability Studies in Education

Too often the mental picture that others create to describe individuals with disabilities is what it's all about. Disability Studies in Education (DSE) is a strengths-based view of disability. It strives to create a school space for all learners to be remembered for what they can do, not what they cannot do.

As a high school English teacher, I worked with seniors each fall on their college application essays. I always began with the story of a conversation I had with a college admissions officer. He described going through stacks and stacks of applications, trying to get a mental picture of the students in the files. He said that he and his colleagues tended to label the applicants by the two strengths that stood out in the pages of high school records, essays, and recommendation letters. He would remember a particular student as “the basketball-playing poet” or “the science fair-winning actor” or “the trilingual fashion designer” or “the jazz-playing gamer.” I would tell my students to think about the label they wanted the admissions committee to apply to them and tell that story.

One student approached me after class and asked if she should say that she was dyslexic; she felt the need to explain her low scores on standardized tests. I asked her if she thought of her learning disability as a strength. We talked for quite a while. What emerged is that over years of struggling with reading tasks, she had become an expert in study skills. She used color-coding, visualizations, word maps, mnemonics, and a variety of other techniques to compensate for her learning disability. So yes, she could describe it as a strength.

A few years later, not long after the Virginia Tech massacre, I had another conversation. The student was concerned that if the university she was applying to knew she had a bipolar diagnosis, they would view her as a potential school shooter. She understood her challenges, stuck to her treatment regimen, and led what she described as a very typical high school life. Yet she also knew that others viewed her disability in extremely negative terms. She avoided mentioning her disability during the application process, despite recognizing her own courage to face it every day. She knew that others would not see her strengths, and she might be labeled as potentially dangerous.

One of the most surprising comments I ever received in a teacher evaluation occurred toward the end of my high school teaching career. The assistant principal pointed out comments I made to my class that he thought were unique and thanked me for their message. He mentioned that when I was justifying teaching lessons the class was struggling with, I explained the necessity of

completing the work by saying, “When you are in college you will need to write analytical papers,” and “When you own your own business you will need to write effective marketing materials.” What surprised me was that he found it unusual that a teacher of disabled students would make remarks like these.

The Key Tenets of Disability Studies

Proponents of Disability Studies in Education take the position that disability is a social phenomenon, which reflects a social and cultural context (Taylor, 2016); it is not located solely in the individual with an impairment. They avoid a deficit-based lens and promote socially just education that provides true inclusion (Baglieri et al., 2011; Connor & Berman, 2019; Danforth & Gabel, 2016).

Legislation may have improved access by opening doors, but it has not changed viewpoints. There may be more opportunities for learners with disabilities, but access has not “disrupted the ways that schools continue to privilege students who can assimilate into normative expectations of ability or behavior” (Ferri, 2015, p. 16). DSE calls for moving away from the assumption of a “normal/disabled” binary. In educational settings, the myth of the “normal child” implies an “abnormal child.” It creates a measurement scale used to divide students into the categories of general education, more normal, or special education, more abnormal; it does not offer a broader understanding of the typical diversity of human beings (Baglieri et al., 2011).

The effects of the medical model of disability are still pervasive in education, and “current models of inclusion or integration have not shifted deficit-based views of disability” (Ferri, 2015, p. 15). This deficit viewpoint sees a disability as something to be fixed or cured. The goal is to strive to be as normal as possible given society’s definition of normality.

Connor and Berman (2019) argue that the idea of belonging, rather than of a normal/disabled binary, needs to be forefront in the minds of teachers. Berman, a parent of a child with disabilities, said belonging is about “finding happiness in daily life, ways to communicate, and to learn” (Connor & Berman, 2019, p. 924). Access and accommodation are not enough; learners with disabilities should be welcomed into a school environment.

As a teacher, I tended to apply special education accommodations to the entire class. If one student required a word bank (a list of key words or phrases to support pupils) for a test, everyone was given the word bank; if one student needed class notes, I provided lecture outlines to all students. I must admit that I did it more for convenience than based on an understanding of true inclusion. I recognized that the accommodations an Individual Education Plan mandated were likely to help all students, but I was still haphazardly implementing inclusion. I had not learned to focus on strengths.

And in the same way that Connor's (2020) article states, "I [did not] like to be told that I view a student with a deficit mindset," I thought I was a champion for learning disabled students. Unfortunately, I continued to use deficit labels. I thought I was being supportive when I described my students as "challenged" or having "special needs." It took me a while to realize just how condescending and diminishing those terms are. I did not follow my own advice to students when I told them to use strength descriptors in their college essays.

Rather than viewing the learner as a representation of the disability, as in the deficit-based thinking of special education, DSE embraces the many intersecting facets of an individual within a group of other multi-dimensional individuals. In his book, *The Power of Disability*, Etmanski (2020) describes individuals with disabilities as "authoritative sources on creativity, resilience, love, resistance, dealing with adversity, and living a good life" (p. xi). These are the strengths we need to focus on as we shift our mindset. The college admissions officer I mentioned earlier used a two-part descriptor of assets to encapsulate the essence of each student in his application folders. It's clear that naming a student a "resilient and creative warrior" rather than a "disruptive autistic student" moves us in the right direction.

The experiences of learners with disabilities in classrooms would improve if we acknowledged that "accessibility is understood as an act of love and a collective responsibility, not the responsibility of a few individuals" (Etmanski, 2020, p. 135). The experiences of all learners in an inclusive classroom are co-created, based on the meanings we give to each other's presence and to the expectations and material conditions of a given classroom. If we represent the presence of abnormality among what would otherwise be a kind of uniform normality, something that needs to be accommodated, then we imagine the presence of learners with disabilities to be charity or an inconvenience. Reciprocity is not possible under such circumstances.

Such perspectives evade the reality that the experience of disability takes on specific meanings in specific contexts. For example, what it means to be deaf is quite different in signing than in non-signing communities. Being in a wheelchair in environments that assume the presence of accessible design has a different meaning than being in an environment without such designs. As Boldt and Valente (2016) write:

[D]ifferences, rather than being the property of the individual, emerge in the group and consequently require a collective response (Herrou & Korff-Sausse, 1999). In other words, the recognition, experience and meaning of a disability can only be understood through how they exist in comparison to, and interact with, other ways of being. Exclusions are likewise a function and responsibility of the group. (pp. 321-322)

It took me a while to acknowledge that terms such as "handicapped," "differently abled," "person with a disability," or "disabled person" are political and may be understood as indicative

of something that is lacking (Davis, 1995, p. xiii). These labels illustrate the attitudes, beliefs, and values of the institutions of society (Goodley, 2011, p. 5). National culture, economics, history, religious affiliations, laws, and social and educational structures all contribute to the hegemonic view of disability that determines the extent of discrimination faced by people with disabilities.

That is why Danforth and Gabel (2016) describe DSE scholars as critical watchdogs who must constantly question pedagogical practices and assumptions regarding disability, especially focusing on the responsibilities of schools and educators. Access and accommodation are not enough; there is a moral obligation for learners with disabilities to be welcomed to a schooling environment where they clearly belong. Danforth and Gabel (2016) argue for a change in the definition of accommodation from a legally required but minimal alteration of content delivery, instructional materials, and assessment that perpetuates ableism. In their new understanding of accommodation, rather than attempting to fix the learner, the community itself is altered.

The lack of successful inclusion of students with disabilities in classrooms from PreK to higher education (Connor & Berman, 2019; Slee, 2019) indicates the need for educators to reflect on their beliefs and their practices, and to move away from using a deficit-based frame of reference when they look at their students with disabilities. Importantly, DSE uses narrative in research to privilege the voices of disabled learners and their families (Connor & Berman, 2019; Valente & Danforth, 2016), just as I am attempting to present the lived experiences of disabled individuals through my storytelling. How we use words and what stories we tell reflects our views on disability.

The Value of Storytelling

Central to Disability Studies in Education is the principle and power of storytelling. As Valente and Danforth (2016) argue, storytelling is “a medium for provoking dialogue about inclusive classrooms and school communities. It offers readers stories of classroom life that provide insights into understanding the complexities that make up the lives of children with disabilities, their families, and teachers.” Valente and Danforth go on to argue that too many of the stories told about children with disabilities in schools are “disconnected from the lived experiences of those [they intend] to describe” and are “informed by a deficit perspective” (p. 4).

I would add that too often, in the justified desire to avoid deficit framing of the lives and experiences of those of us with disabilities, we avoid talking about things about disability that feel tragic or traumatic. Not wanting to be ableist, many struggle to find ways of talking about the grief, loss, and trauma that people with disabilities and their loved ones can feel in relation to the disability.

It is a tricky space. On the one hand, I do not want to contribute to ableist assumptions about lives that are “whole” or “more valuable” versus lives that are somehow compromised or “damaged” or “tragic.” At the same time, it is critically important to acknowledge that disability is very often experienced as loss. I believe this is because of its positioning in an ableist society that sets up constant assaults on the daily lives of people with disabilities. But there are other reasons as well, such as the need to accept limitations, which is something that all humans face at one time or another. Regardless of its cause, we must have a space for honestly engaging in the emotional complexities of life with disability.

I feel strongly that there is a need to talk about the difficult or tragic or traumatic experiences that shape or change our lives. In the early years of my own diagnosis, I did not always have the words I needed or the will to be open and candid, but the emotions and the need to talk were there. I think it is important that these stories tell our truth and I know that remaining authentic is not easy. Because stories of disability cut close to the pain we carry, the storytelling process is complex.

When I write about disability, I try very hard to be sincere and express exactly what I think and how I feel, despite these thoughts and feelings being very different from others’ thoughts and feelings on disability. I hope that if I can tell an honest story, I can increase understanding of what living with a disability is like and maybe increase empathy too. Living in lockdown due to the pandemic heightened my sense that empathy is needed today, and I realized that the pandemic experiences we shared might provide a foundation to build that empathy if we can see the parallels between living with a disability and living in a pandemic.

Storytelling as an instructional tool is powerful because it is engaging and evocative; stories unleash the imagination and transport us away from the harshness of life or help us to understand that the difficulties we face are not ours alone (Clark & Rossiter, 2008). They can help us to understand the roots of our rage, when and where our rage is misdirected, and to come to terms with and even transform our limitations, a capacity that has been much needed and often missing during the pandemic. Stories can help us acknowledge our grief even as we know that to feel that grief might betray our political will.

When we tell a story, we take an experience and figure out what it means by putting it into a narrative form that makes sense (Clark & Rossiter, 2008). For example, we might respond “to an illness by constructing a narrative of restoration and hope, as opposed to a narrative of victimization, struggle, or loss. The choice of narrative—the sense we make of an experience—determines how we respond to and manage that experience” (Clark & Rossiter, 2008, p. 62). I want my stories to focus on that meaning and present a whole view of disability, although not a universal one.

For me, storytelling is a part of life where we “dream in narrative, daydream in narrative, remember, anticipate, hope, despair, believe, doubt, plan, revise, criticise, construct, gossip, learn, hate and love by narrative” (Hardy, 1968, p. 5). I wonder what happens to individuals with disabilities when most of the narratives told about them “focus on the good deeds perpetrated by the nondisabled person while all the while relegating the disabled person to little more than a prop, depicting them as hopeless, helpless and without agency” (King, 2016, para. 9). Like King, I sometimes speculate about “How would it feel to be treated like a prop to make someone feel better about themselves without any consideration for [disabled persons’] feelings?” (King, 2016, para. 9).

Everyone’s disability stories are different, but some threads weave their way through many of these narratives. And I recognize some of those same motifs in pandemic stories.

Krueger (2021) and others describe people telling stories about the vaccine (Pfizer or Moderna) they have received (Krueger 2021; Health & Wellness Staff, 2021). She says that these stories have joined “some people in the playful rivalry questioning their privilege, asking themselves why they care [about which vaccine they received] and how their posturing might look to others in the world who have no vaccine at all” (Krueger 2021, para. 6). Her observation illustrates our need to be a part of the cultural narrative as the “construction of a narrative is not purely a personal process; it is also social in nature” (Clark & Rossiter, 2008, p. 63). We all have shared our lockdown stories—the challenges and triumphs, the fear and determination, the sadness and celebration. Stories bring us together and help us heal from shared trauma; the vaccine stories are a way for people to share positivity and hope after months of anxiety and depression, even as we acknowledge our place in the wider world (Krueger, 2021).

Individuals with disabilities have learned the importance of telling their stories; “autistic, blind, deaf, wheelchairs users—we are all part of this big community of people who are struggling to have our stories told. And not just told, but told in an authentic way” (Etmanski, 2020, p. 85).¹ By sharing their stories, individuals with disabilities can diminish feelings of invisibility.

¹ A number of websites share the narratives of individuals with disabilities and document the significance of hearing and respecting their stories. *Suffering the Silence* is dedicated to telling the stories of individuals with chronic illnesses and disabilities. The co-founders point out that despite over 133 million people in the United States alone experiencing chronic illness, the associated stigma is hard to manage. The websites offer them a platform to speak their reality (Cashel et al., n. d., para. 4).

The *Disability Visibility Project* (Wong, 2016) is another site that shares the stories of individuals with disabilities. The site directs individuals to share their stories orally through StoryCorps, and it publishes work created by disabled writers, championing “disability culture and history [and] ... [supporting] and amplify[ing] the work of other disabled people and organizations in the community” (Wong, 2016, para. 1).

DSE also seeks to undercut “inspiration porn” stories. Young criticizes these “overcoming” stories:

The purpose of these images is to inspire you [the non-disabled person], to motivate you, so that we can look at them [the disabled person] and think, "Well, however bad my life is, it could be worse. I could be that person." ... I've lost count of the number of times that I've been approached by strangers wanting to tell me that they think I'm brave or inspirational ... They were just kind of congratulating me for managing to get up in the morning and remember my own name. And it is objectifying.... And life as a disabled person is actually somewhat difficult. We do overcome some things. But the things that we're overcoming are not the things that you think they are. They are not things to do with our bodies.... I want to live in a world where we don't have such low expectations of disabled people ... I want to live in a world where we value genuine achievement for disabled people. (Young, 2014, 3:09)

It is critical that disability stories do not merely describe people with disabilities as “heroic overachievers or long-suffering saints” (Research and Training Center on Independent Living, 2020, para. 3), but instead recognize that we all must overcome obstacles daily. Stereotypical “supercrip” stories (Martin, 2017; Silva & Howe, 2012, Schalk, 2016) paint an inaccurate picture of real lives. Many disabled individuals cringe when they are described as inspirational because they have felt the sting of pity and resent being called inspirational in a condescending manner that does not recognize their lived reality. There are valuable stories of disabled lives that do inspire, yet we need to examine them carefully to ensure they're not inaccurate or perpetuating stereotypes.

Narratives of Disability and Stories of the Pandemic

There are many similarities between dealing with disability and managing life during a pandemic. Among the several points of overlap, I focus on three meaningful points of connection between my life with disability, the lives of my disabled students, and life during the pandemic. These three storylines have stood out for me over and over again since the onset of the pandemic:

Disability Rights, Education, Activism, and Mentoring is a national organization for college students with disabilities. It publishes the [*DREAM/NCCSD Weekly News: Timely News about Disability and Higher Education*](#). There are also a significant number of blogs and articles by individuals with disabilities (Carlson, 2014; Churchill, 2014; Farrelly, 2017; Holly, 2020; Thompson, 2021; Weinstein & Bufalini, 2015). All of them point to the need for people to tell their stories and be heard.

- Living creatively in the face of limitations.
- Being in proximity yet separated, and never having a sense of true belonging.
- Learning to live with precarity, and the fear, grief, and longing that come with it.

I hope to prompt moments of recognition and empathy in readers and to move them to consider unexpected and creative alliances. I also hope that readers will be moved to reflect honestly with themselves and will be able to draw strength to confront the difficulties we have faced and continue to face.

Living Creatively in the Face of Limitations

Many years ago, I started a freshman English class with twelve students, all boys. Eight of the students had Individual Education Plans (IEPs), with labels such as “specific learning disability,” “multiple disabilities,” “emotional disturbance,” “behavioral disorder,” and “language impairment.” The others had weak basic skills. Many of the students were viewed as troublemakers, the ones teachers hoped did not show up on their class lists.

The majority of the students were African American or Latino, reflecting the racialized nature of special education, where “disproportionality in schools is part of the historical legacy of racism within the United States” (Connor, 2017, p. 227). The “historical interlocking of race and ability differences, specifically in connection with the so-called high-incidence or subjective disabilities” (Artiles, 2011, p. 431) is clear in the labels that defined my students. The chance of their finding academic success was even more difficult for them as students who were minoritized.

I doubted my ability to teach these students effectively. I questioned whether I could create lesson plans that met their needs, and I was concerned that I could not clearly identify my own bias and work effectively against racism. I worried about finding a way to unlock an academic process that would allow them to gain something valuable from our year together and find a social space where they belonged, a place where they faced less discrimination. My thought on that first day was, “Oh well, here we go...”

I began by discussing the structure of the course, the types of assignments we would be doing, and the books we would be reading. I went over class rules and expectations as they slouched in their seats and stared out the windows. I didn’t know about Disability Studies in Education then. I didn’t know about strength-based teaching, but instinctively I realized that I needed to “shift from what is wrong with students to looking at why they behave in certain ways [allowing me] to

interact with them [in] more meaningful ways to problem-solve” (Connor, 2017, p. 230). I recognized the need for change.

They knew they were in this class because they struggled with reading and writing. They knew they had been labeled as problem students who could not manage their behavior. It was clear from the start that they were not anticipating success, and they certainly did not expect to enjoy the class. I thought it was going to be a long hard slog, and I am sure my students thought so too.

We were wrong. In my years of teaching there has never been another class where the students and I laughed so hard and where we shared so many honest stories. We were truly in it together, and by the last day in June, we had all changed. They could identify some strengths that would substitute for disability labels, and I became a better teacher.

Classroom management was tricky; they loved to fool around and I always had to be careful not to let their antics go too far. It required creativity to respond to my students and channel their energy in positive ways. The truth is, it was their creativity that built a unique class community.

I still chuckle at the memories of the pranks they played on me. One day I entered the classroom just before the bell, quickly took attendance, noticed Frank was absent, and then moved to the center of the room to discuss the class work. All of a sudden Frank jumped out of the closet in the back of the room and frightened me so badly I had to sit down and breathe deeply to recover. The rest of the students could barely contain their hilarity and that moment became a class legend. But I got even.

I frequently stopped at Dunkin Donuts on my way to work and bought a dozen donuts for that early morning class. I would leave the box out on my desk with a pile of napkins and if the students worked diligently, towards the end of class, I would pass around the snacks. Seeing the bright orange and white box on my desk was a great motivator. One day, about ten minutes before the bell was set to ring, I picked up the box. I opened it and shouted “April Fools!” The box was empty. The chorus of “That’s not fair!” and “I can’t believe you did that to us!” rang out loudly. Then I headed for that same closet in the back and pulled out a platter of a dozen donuts for the students. Another legend was born.

All that laughter was different from what my students often experienced. We laughed together; no one was mocked or mimicked. I do not know exactly how we came together. I know for sure it was not something specific I did. It was the way they built relationships despite or maybe because they were excluded from others in the school, being in the “special” classroom. And it was not about my inclusive teaching; they were the ones who invited me to be a part of their community.

There was a bank of computers along the back wall of the classroom. The students would each sit at a desk as I paraded back and forth along the row, making sure they did not stray from the assignments to random entertaining websites. One day they introduced me to RateMyTeachers.com. I dreaded the thought of what might be posted about me, but they assured me there was some good stuff there. And there was. They had already added some comments, but they were not satisfied with them. A couple of students grabbed a thesaurus, and they started hunting for superlatives that would make me sound amazing. It turned into quite a vocabulary exercise, with lots of laughing and debate about whether a word's connotations fit exactly what they wanted to say. It was eye-opening for me to see the strengths they attributed to me. They said I was exacting but fair, good-natured and kindhearted. They decided to add a few derogatory postings so it would not look too fake, and then my many weaknesses were laid bare. I was an annoying stickler for grammar rules. I assigned too much work. And I had terrible taste in music. Their creative writing reached a new level that day.

For weeks, they would make use of the words they had found in the thesaurus and apply them in class. One student would tell me that the homework reading was scintillating and another would compliment a friend on his discerning remarks or insightful commentary. I told them that their responses to the quiz questions were perceptive and their essays were remarkably perspicacious. Again, we laughed uproariously, but I could not help wishing that they knew what it was like to be labeled based on their strengths rather than according to their disabilities and others' perceptions of them.

Towards the end of the year, we started reading *The House on Mango Street* by Sandra Cisneros (1984), the story of a Mexican American girl growing up in a working-class neighborhood in Chicago. The chapter "Hairs" elicited a round of sibling mockery in this all-male class, as they told stories about their older sisters—the one who spent Saturday getting hair extensions, the one whose abuela braided her long locks whenever she visited, and the one who did not like the curly red hair she had inherited from her mother. When the discussion devolved into a commentary on who had the most attractive sister, I quickly turned the page and read aloud the chapter "Boys & Girls." They reached the unanimous decision that this class without girls was the best one they had that year, because as Cisneros noted, best friends understood each other's jokes without explanation. And we all understood that their academic challenges were not the only things that defined them.

It turned serious when we read "My Name" and they complained about teachers who did not care enough to learn the correct pronunciation of their names and other students who used their names like a slur. That led to a lot of stories about feeling left out and disrespected. I saw the frustration many of my students felt when, no matter how hard they worked, they did not get the results they wanted.

These students diligently completed assignments, even when it took them a lot longer than their classmates; they studied longer hours, often for lower scores than their peers; they tried to follow their support staff recommendations for organizing binders, color coding information, using visual reminders; and they went home feeling like failures when they received lower grades than classmates who claimed that they had not even studied.

They told me everyone thought they were stupid and wondered if they would graduate. They were used to being excluded; they were always in the “special” classes. College did not seem like a possibility for them. High school was just about surviving. I tried to encourage them with supportive statements about working hard and finding success one step at a time, but that now seems rather trite.

I just could not react quickly enough when they expressed a lack of self-confidence and belief in themselves. I understood that day-to-day struggle. I knew something about the enormous amount of resilience and perseverance needed to keep on going after continually suffering setbacks. Yet they kept on going, just as I keep on going despite the numerous hospitalizations and health crises caused by my diabetes. I recognized that piece of disability life, that perseverance.

At the beginning of their senior year, two of the students asked me to write their college letters of recommendation. I thought back to the discussions we had had **in class and the platitudes I had spouted at that time because I did not know what else to say. Still, I knew that the community we built did have a lasting effect and contributed to the success of these students standing before me as future college freshmen. It was easy to compose their recommendation letters.**

I don't want to sound pollyannaish and offer banalities that assume hard work and self-belief will simply and unfailingly lead to desired success. I know that attending college can be exceedingly challenging for some students with disabilities without the necessary support, and students who are minorities in those environments face additional difficulties with racism and classism. The numbers of disabled learners are increasing on college campuses (McIntire, 2015), and getting in is only the first obstacle to overcome; graduation rates still lag behind non-disabled students (Fleming et al., 2017). But it does happen.

Not long ago I received a Facebook message from Alma, a former student I hadn't heard from in over ten years. When she first entered my classroom, she was an emergent bilingual student, having recently moved to the United States from Honduras. In her message, Alma talked about how discouraged she had been in high school, but that she had felt inspired because she thought I believed in her. Today, she has a master's degree in public health and a second master's in chaplaincy. She reported being happily married to a physician she met in graduate school. That's a long way from her sophomore English class of minoritized learners identified with various

disabilities. It was heartwarming to hear that I may have inspired her, but I also know that she faced many more barriers after she left my classroom.

Coming to Terms with a Disability

I know about slogging through life, feeling that I just need to make it through another day. In my senior year of college, I was diagnosed with Type I diabetes. In the early years, I saw it as a disease more than a disability. For me, becoming a person with a disability was a gradual process; I went to a doctor, he diagnosed a chronic illness, prescribed a treatment plan, and I went on living. I had always been a perfectionist, and suddenly, with this diagnosis, I was far from perfect. My body no longer worked the way other bodies worked. It was not “normal.”

I do not know when I started to recognize that I had a disability; there were several factors that contributed to the shift in my thinking. One was the relentless nature of diabetes. There isn't a cure. I know it will never go away and that feels to me more like a disability than a disease. My sense of a loss of control is part of the overwhelming pervasiveness of my disability. I cannot go out and leave my disability at home. I cannot forget I have diabetes. Every day, I wake up and check my glucose level. I record the time and the meter reading up to fifteen or twenty times a day. I write down everything I eat and how many carbohydrates I consume. It is the relentlessness that is hard to handle.

How other people have treated me has also led to my shift in thinking. There were times at work when I was singled out and treated differently than my colleagues. I was often required to submit official doctors' notes for time off for medical tests when other teachers did not have to follow the same rules. My principal doubted my need for personal days related to my disability. He thought I was “faking it” and falsely using my diabetes to secure a day off. This angered me and I became more conscious of protesting against the injustice experienced by disabled individuals and acknowledged I was one of them. I started going to the school nurse's office to document in writing the fluctuations in my blood glucose levels. I had to create an official paper trail in my fight against my principal's lack of understanding and empathy.

Then there was the moment when I was filling out an official form and reached the section on disability and saw diabetes listed as an example. I checked the box. From then on, I became very conscious of those boxes, and the legal labels that applied to me. I felt a strong sense of being different. But I also came to see myself as a part of a community, the community of those with disabilities. As a high school English teacher, my training was in language and literature, and my knowledge of disability developed through co-teaching, reading, and professional development rather than through formal academic study. When I began my doctoral program, I did more substantial research on disability, and I started to see myself reflected in the research articles I read.

I came across *Nothing About Us Without Us: Disability Oppression and Empowerment* by James Charlton (1998). The book discussed the work of disability rights activists who advocated for the participation of disabled individuals in creating policy that affected them. I knew my experiences could not lead to my understanding of all disability experiences, but I made more conscious decisions to tell my stories, to be part of “Us.”

Creative Hacks and Plan Bs

Individuals with disabilities often talk about the need to develop creative “hacks” when their disabilities are not accommodated or to have a Plan B when their access is denied (Clarke, 2020; Field et al., 1998; Thompson, 2021). People with disabilities frequently must devise makeshift devices to overcome obstacles. In her TED talk, disability rights activist Stella Young (2014) said,

I learn from other disabled people all the time. I’m learning not that I am luckier than them, though. I am learning that it’s a genius idea to use a pair of barbecue tongs to pick up things that you dropped ... I’m learning that nifty trick where you can charge your mobile phone battery from your chair battery. Genius. We are learning from each other’s strength and endurance.... (6:30)

Creative solutions to disability may be the result of focused thinking or come about spontaneously. Colin, a high schooler with autism, had difficulty concentrating in his late morning English class. There were several rowdy students who were quick with jokes and did not hesitate to clown around. With each wisecrack and loud guffaw, Colin’s concentration diminished, and he could not successfully complete the assigned writing. To him, these jokesters were like the toddlers rambling across their parents’ Zoom screens in the background or the family dogs who started barking as soon as mom needed to present her work to the management team. Colin’s unfinished work started to pile up, and this increased his stress. Colin would leave the classroom frequently to walk the halls and try to refocus his attention, but the distractions were still there when he re-entered the classroom.

I had had Colin in class the year before, and I happened to have a prep period alone in my classroom at the same time as his English class. He started dropping in on his hallway jaunts, and it turned into a solution. He would attend the start of his English class on writing workshop days, and once he understood the writing task, he would leave and head for the computer at the back of my room. I would be sitting in the front planning and correcting while he typed up his work. When he finished, he would head back to his class. My classroom became his creative way to manage distraction, allowing him to concentrate and work around the limitations of his English class.

There is a lot in a disabled life about taking risks and daring to embrace creativity. On the one hand, individuals with disabilities may need to be risk averse, as my husband argued when he told me:

I think you sometimes push the envelope. And what would happen, right, if you did get really sick and you didn't have enough food and we're in the middle of the damned woods on a hike? What am I going to do? Run back? Okay, I could do that. But what are you going to do sitting there in the middle of the woods? It doesn't happen that often, but there are some times when I feel like you could be a little bit more conscious of how far you are pushing the envelope. (Rogers-Shaw, 2020, p. 41)

We have not done much hiking since that conversation. If we go for a long walk or a bike ride, I am always carrying so much stuff—my glucose monitor, the finger prick device, the test strips, raisins, fruit snacks, juice bottles, that it does not always seem worth the effort. And when I do have to reach for food to balance a dropping glucose level, I am conscious of how much I need to take, and how long I need to space out the snacks, and whether or not to keep walking as if I am okay or stop and wait until the level rises, and how to avoid getting my husband upset as I stuff raisins into my mouth, and how to answer his constant questions about whether I am okay or not.

I think some individuals with disabilities will tell you that sometimes they want to take a risk, and they do not want to feel the guilt that comes when they recognize they are a burden to those who support them. They want to act independently: “No one wants to look back at their lives and feel they missed an opportunity that could have been life-changing” (Weinstein & Bufalini, 2015, para. 13). There are disabled people who may advise you to act rather than put something off because they understand that life is fickle and fleeting; the present is the right time “to correct mistakes, tell someone how you feel, forgive a grudge, open yourself up to a new relationship, act on a long withheld, positive impulse and the million other things you may consider doing” (Weinstein & Bufalini, 2015, para. 13). Some of those who have lost loved ones during the pandemic might say the same thing; treasure what you have because it can quickly disappear.

Ingenuity and flexibility make a difference, and assist in finding joy and overcoming struggles. Just like teachers who are taught to have a Plan B for when the lesson goes awry, or parents who are working at home while simultaneously home-schooling, accessibility issues force individuals with disabilities to have a plan B in mind all the time (Clarke, 2020; Field et al, 1998; Thompson, 2021). And even with a plan B, they know there is a good chance they will have to improvise.

Experienced teachers become experts at revising lesson plans on the spot just as parents became more skilled during the lockdown at managing competing responsibilities. In the same way,

many individuals with disabilities become experts at adapting. They recognize that putting things into perspective and getting creative makes a difference (Holly, 2020): “Stressing out over the small things in life is not healthy. Negative aspects in a day can be disappointing, but we have to think about the bigger picture” (Farrelly, 2017, para. 5). This is where flexibility and creativity are important.

One day I assigned my class an analysis of a scene from *Romeo and Juliet*. It was an afternoon toward the end of May. The classroom was warm as the sun beat down on the large windows spanning one side of the room. We were all thinking about the last days of the school year. Students broke into small groups and started working on a variety of ways to reveal their thoughts: outlines, dialogues, poems, essays. They were typing madly on the keyboards of their laptops and murmuring quietly; it sounded almost like the white noise some of us use at night when we can’t fall asleep.

My mind drifted as I sat at my desk, and then something moved in my peripheral vision. I glanced up and saw my special education co-teacher plastered against the back corner between a table and the wall cabinet as three boys, two of whom had disability labels affixed to their school records, conducted a sword fight using rolls of bulletin board paper. They seemed to be whacking each other quite vigorously, but my co-teacher—despite the ghastly look on his face—signaled that things were under control.

My first thought was, “How are we going to explain this if the principal walks in?” I slowly rose from the desk and meandered around the room. By the time I made it to the far back corner, the students had dropped the rolls of brightly colored paper and were drawing on one large piece they had ripped from the blue roll and spread out on the table. When I approached them, they told me they had been “brainstorming.” They were trying to figure out exactly how Tybalt’s sword went under Romeo’s arm to stab Mercutio. Their creative use of blades devised from rolled paper had been useful, and they were on to diagramming the scene. I am sorry that my first reaction that day had been thinking of what I would say to the principal to avoid a reprimand and lecture about class control and dangerous behavior, rather than recognizing the ingenious use of bulletin board paper.

For many individuals with disabilities, fighting against limitations and coming to terms with them is part of daily life. The pandemic forced others to face the same kinds of limitations. And yes, we struggled with those limitations, we felt anger and disappointment, but we also needed to figure out how to adapt and get on with life. We cannot live in a space where we are always fighting. It is exhausting and unproductive. There is joy and a sense of accomplishment when we adapt and move forward.

Struggling with Limitations During the Pandemic

Since my diabetes diagnosis over forty years ago, I have tried to regain control, and maintain control, while acknowledging that “independence is not about doing everything for yourself but about having control over how help is provided” (Morris, 1998, p. 10). For me, as I’ve written, “the lack of control, and the fear of losing even more control, has been one of the hardest elements of disability to accept” (Rogers-Shaw, 2020, p. 61).

The irony of control for someone like me is that I spend most of my life trying to control things—particularly my blood glucose levels—and I feel any loss of control of my life acutely. I have the fear of being exposed as disabled and judged for something I cannot control, and I know my students have been judged because they struggle in ableist classrooms.

The pandemic has heightened a need for creativity to handle the limitations we face. I think a lot of people learned about loss of control during the pandemic. Sometimes I wonder if the mask wars are not so much about politics as they are about an underlying fear of losing control, of trying to assert freedom of choice in order to take back control in a situation where one has lost control.

A lot of the pandemic has also been about struggling day after day, hoping for a spark of creativity to find a solution to the challenges. The effects of race are not only visible in classrooms: like those with disabilities, racial minorities are disproportionately affected by the pandemic. The faces of people of color are much more prominent in news stories of health care aides and grocery store workers, in the delivery people who brought packages to my doorstep as I was privileged enough to stay inside, and in the number of mothers forced to drop out of the workforce due to a lack of childcare options. The Center for Disease Control and Prevention (CDC) reported “more COVID-19 cases, hospitalizations, and deaths in areas where racial and ethnic minority groups live, learn, work, play, and worship” (CDC, 2021, para. 4). The CDC argues that “we all have a part in ... promoting fair access to health. To do this, we have to work together to ensure that people have resources” (para. 6). I think we could often substitute the word “education” for “health.” Both educational inequity and health inequity diminish opportunity for marginalized populations.

Along with others, I feel the inescapability of the pandemic, just as I feel the omnipresence of my disability. Those without disabilities often view the disabled through the standpoint of illness where there is a diagnosis, a treatment, and a cure, but disability is not a linear process (Reaume, 2019), and cure is an inadequate, if not offensive perspective. Moving through life is much more irregular and happenstance than any linear model of “progress” can suggest.

What is crucial to realize is that when we face adversity, whether from a disability or a pandemic, we can benefit from putting up a fight even if we lose. It is vital “to take pride in the fact that you made the effort and know that you’ll live to fight another day ... [as] the alternative is, simply put, suffering” (Weinstein & Bufalini, 2015, para. 17-18). Many of us with disabilities recognize the need to keep on fighting, whether it is struggling to maintain physical health or to take the next test, write the next paper, and read the next book.

An important step in becoming more resilient is to understand the abilities and disabilities we all have. When one has high expectations and sets goals that are lofty yet realistic, it is easier to play to our strengths to pick ourselves up after a failure (Field et al., 1998; Holly, 2020) If “[r]esilience is born from suffering and reflected in celebration” (Etmanski, 2020, p. 90), then there are some individuals with disabilities who actually have an advantage over the non-disabled—because they know what it is like to suffer regularly and they celebrate even small victories. They must if they are to keep going despite the obstacles they face.

Close, But Still Apart

Meredith was in my sophomore English class one year. She had significant visual and mobility disabilities. She was legally blind and used crutches to painstakingly move through the high school hallways, always arriving a few minutes late to class assisted by her aide, Jaclyn. The seat closest to the door was always left open for her, which seemed to highlight both her proximity and her isolation. She was inside the classroom, physically close to other students, but she was also outside the chatty cliques that laughed and complained together before the bell rang at the start of the lesson, or raced for the door and the freedom of the hallway when it rang again to signal the end of the period.

None of the students were outwardly cruel or mocking, but Meredith was not integrated into the life of the class. For Meredith, as for so many with disabilities, being disabled often feels as if belonging to the group is within reach, but you cannot ever grasp it fully; even when you make it past the door you cannot find your way in.

In a blog about words that encapsulated pandemic experiences, one writer talked about quarantining at home, where she was in the same house as family members, but she had to remain apart, experiencing “days of *proximity* but separation” (Checchio et al., 2020, para. 4). This was Meredith’s daily experience.

Most students treated Meredith with polite charity, clearly glad that the chair by the door was not theirs. Meredith’s interactions within the classroom were mostly with Jaclyn and me. She answered and asked questions and contributed to class discussions. She tried to participate in groupwork when the students, whose desks were pushed toward hers to make a square, talked

with her—but did not fully engage with her. No one mocked her or completely ignored her but still, there was distance.

In the doldrums of late winter, students chose books to read in small groups. I do not remember what book Meredith picked, but her group was congenial and diligent. They read the book and shared their reactions in lively discussions. As the unit headed to its conclusion, each group worked on a Powerpoint to present to the class. I exhorted them to do more than merely put an outline on a set of slides and read it to their classmates. I encouraged them to be engaging and inspire their friends to read that book.

Meredith's group decided to embed a homemade movie into the slide show. They planned to record themselves enacting a crucial scene at the beginning of the novel that set up the rest of the plot. They decided if they left the class on a cliff-hanger, their peers would want to read and find out what happened. One student's mother worked for a local television station and had a basement studio where they could record and edit the film. As they worked out the details, they realized that Meredith would not be able to make her way down the curved metal basement stairs. So, they "accommodated," and suggested Meredith design the slide show and they would handle the movie.

When they presented their film to the class, I realized I had made a terrible mistake. I had allowed her to be present but excluded. Her name was on the introduction slide, I knew she had put together the creative and visually appealing slides, and she took a turn presenting a slide. But when the movie was played, we all watched the group, together but without Meredith. I knew failure at that moment, and it was not a good feeling. It was a lesson in inclusion that still bothers me today, twenty years later. Despite all I did to include her in the class, I was never completely successful in breaking down that invisible wall that kept her isolated. I am sure she felt "days of *proximity* but separation."

That spring, I had a conversation with Tina, who had difficulty processing auditory information. We talked about the lag-time problems she faced. In her history class, it took her a little longer than her classmates to formulate a response to the teacher's questions. She was insightful and attended carefully to the questions, finding topical links to the text, yet because she raised her hand to respond after the class had moved on to the next idea, it often appeared that her statements were not related to the discussion. She would get a "thanks for sharing" retort from the teacher and snickers from her classmates. She said it was just like the expression "out of left field." She was supposed to be part of the class team, but because she was farther away from the central action, her answers seemed strange to her classmates, who had moved on from the original question. She desperately wanted to hit a homerun one day and high-five everyone as she crossed the plate, but she thought it was unlikely as she, too, felt "days of *proximity* but separation."

Not long ago, I watched a video called “Today: A Day in the Life ...” that parents of disabled children put together to share with service providers. They wanted to tell the stories of their daily experiences that might not be in official case notes but were a significant part of their day (Debs, 2011). Many of the comments highlight the problem of being close to others but still isolated. One parent talked about the pain of being on the fringes at the playground, a common occurrence for disabled children: “I watched my son watch his friends running around the playground. He had longing in his eyes. My heart broke” (Debs, 2011, 2:17). Then there is the isolation from community members: “I had to construct a very tall fence to stop my child escaping from the garden. It makes us even more isolated” (Debs, 2011, 1:44), and “My child had a meltdown in the supermarket. No one offered to help. I was judged to be a bad mother of a naughty child” (Debs, 2011, 2:34).

Others mentioned how being part of a family still meant isolation because they had to leave disabled children at home with caregivers when they went out to a restaurant or on a family vacation. One said, “My family forgot about my son’s birthday. When we mentioned it, they said ‘he won’t realise, will he’” (Debs, 2011, 2:53) and another shared that “My child wasn’t invited to his cousin’s birthday party. They think he’s too disruptive” (2:42). Even proximity to family can still create separation. Disability complicates family life, but caring relationships remain of vital importance.

Presence Matters

My mother’s ninety-third birthday took place in April 2020 as we all began adjusting to the reality of our lives in lockdown. We could not be with her. Her nursing home was closed to visitors due to Covid-19. It was still early enough in the lockdown that we had not yet seen the haunting photographs of family members standing outside the windows of nursing homes, speaking through the glass with family members. The disease had started moving through long-term care facilities, but its ravaging effects on that vulnerable community were not yet documented.

I called the nursing home to arrange a Facebook video chat through the recreation office and invited my daughters, my brother and sister-in-law, my niece and nephew, aunts, uncles, and cousins. It was not what we wanted, but it was the best we could do. There would not be any brightly wrapped gifts or birthday cake. There would not be any hugs. But at least, I thought, my mother would not be completely alone.

Once the video event began, it became apparent that because her dementia left her confused, it was difficult for my mother to understand we were all in real time in our little boxes on the computer screen. I felt like a teacher trying to conduct a lively class discussion while students

who had not done the reading watched the clock waiting for the bell to ring. I called on family members, introducing them to my mother with summaries of who they were and what was going on in their lives. Each would in turn wish my mother happy birthday and share a little news. It was a stilted conversation lacking vibrancy and deep communication.

We tried. We did the best we could. My mother seemed to enjoy moments, joking with my aunt, asking my daughters about pieces of their lives that she remembered. It seemed a very short time before we all said good-bye and waved and told my mother we loved her. As each family member disappeared from the screen, I thanked the recreation director and the nurse and then the connection ended. All of us had struggled to be jovial, yet we still felt somehow diminished.

As I stared at the blank computer screen after the call ended, I realized I had been in this place before. The disorientation we felt on the video, the desire for regular relationships and shared celebrations, and the knowledge that we could not have what we wanted were reminiscent of disability experiences. The fact that the video call was not the best vehicle for my mother, who thought we were on the television, and did not seem to know that we could all have a regular conversation. It reminded me of the disconnect I saw in classrooms with students who were trying to work with a disability in a world that assumed no disability.

At the end of the video call, I am ashamed to say I also felt relieved that I could stay in my safe house and maybe outlast the pandemic. I did not have to travel. I did not have to do more than the online chat and mailing out some presents. I felt guilty too because I was not being a good enough daughter. Two days later when my mother tested positive for Covid-19, I had to dig deep into my well of toughness, a reserve I had developed in no small part from years of being disabled. I knew I had to face the fear and the grief.

Ultimately my mother survived two bouts of Covid-19 and there was another birthday party in Spring 2021. I was fully vaccinated and allowed to visit my mother outside at her nursing home for the first time in over a year. I drove over five hours on a cool cloudy day, pulled into the parking lot, and put on my mask. I registered at the front desk and was directed to the lot around the side of the building where a nurse would wheel my mother out to a bench beside the door. I gathered the gifts I had brought, the hot coffee and birthday cake, and my computer. I headed to the bench and waited.

That first hug in so long was special. I fired up my laptop and opened Zoom. The faces of my family appeared, and we celebrated, me by my mother's side and the rest from a distance. This time, my being with her produced a different outcome. It is hard to describe exactly how it was different because I was the only one physically present with my mother, but that human contact made all the difference. We faced the screen together.

Hugging and holding hands mattered. It emphasized how the close relationship I have with my mother is real, not just described in a story or played out on a screen. We needed to feel each other's hand; we needed to savor our embrace. All of us, disabled and not, need to feel our humanity in our relationships with others.

Life goes on and we can make it work if we do not think we need to do it alone; we all need someone else to help us. Indeed, as my own pain at the failure of the first Zoom birthday and joy and relief at the success of the second made clear, it is not only that my mother needed me. It would be easy to imagine that given her failing health and dementia, I was there as her charitable helper. The emotional disconnect of the first birthday and the joy of connection during the second visit reminded me that I needed her too, just as I needed her as a child, and as I needed her when I was trying to overcome disability-related illnesses. I needed to know we could keep on showing our love for each other despite the challenges of the times. These two birthdays reminded me that no matter what challenges we were both facing, it was the reciprocity of our relationship that brought it to life.

These birthdays may not have been ideal, but they made it clear that we are all our best selves when we are in one another's vitally felt, co-constructed emotional presence. The first Zoom birthday was a kind of proximity that heightened our sense of separation. Connections failed. We did not need every person to be physically present, but my mother and I definitely needed to be side-by-side to bridge the distances of the separations.

A year of Covid had passed and we had all survived. We had all kept fighting and hoping and doing what we had to do. The lessons across those two very different Zoom birthday celebrations were the same ones I had learned over forty years of living with a disability: presence matters; a family and friend support network is invaluable; patience and persistence pay off; finding creative solutions makes celebrating possible; we can be resilient despite sorrow and anxiety; and finally, saying "I love you" and sharing stories makes life worthwhile.

Reaching Across Differences Enriches Us

Meredith needed someone by her side as she faced the many obstacles and isolation of her high school years. She developed a close relationship with Jaelyn. As her aide, Jaelyn accompanied Meredith throughout the day. The care they felt for each other was much more than a supporting arm, a kind word, or a repeated direction. Meredith may have needed her aide to increase the size of the text, carry a lunch tray to a cafeteria table, or navigate the confines of the bathroom, but what was much more meaningful was the reciprocal devotion they felt for each other.

Meredith did not develop close relationships with other students in my English class. That was the result of a failure in the curriculum (e.g., the video assignment), but it was also a failure of

the other students to recognize that a friendship with Meredith could be reciprocal. She had as much to offer them as they had to offer her, maybe more.

If we look for it, or recognize it when it surprises us, we will find that reciprocity across differences brings richness to our lives. Too often relationships with disabled individuals feel like charity when the non-disabled lack the imagination to see the possibility of enriching their own lives in these relationships and not just by feeling like they have done a good deed. That was me at one point too.

As a child and teen, I knew there were students who struggled, but I did not have much contact with them because they were always in different reading circles, different math groups, and different classes once tracking started in the upper grades. There was a girl in my grade I never saw during the school day, but my mother insisted we visit her often because she did not have many other friends. Frequently on Friday afternoons, we would drive over to her house after school. Our mothers would sit at the kitchen table and drink coffee while Kerry and I headed down to the basement to play bumper pool. We did not talk much, just played game after game after game. I did not understand why she was different from me, but my mother made sure I knew it was important to care, to be a friend, and to learn from Kerry how to bank a shot and sink it in the pocket.

Today I can guess that Kerry might have been on the autism spectrum. I feel a bit guilty to admit that at the time, and with the condescension of someone who had known little academic struggle, I saw our afternoon games as charitable excursions engineered by my mother. But now I think what was behind them was my mother's understanding of parental grief.

My little brother had died of Reye's Syndrome when he was seven years old. Kerry's mother felt a different kind of loss, the loss of her imagined future for her daughter. Yes, she loved her daughter, accepted that her life would be different than she expected and moved forward, but she also felt sad and mourned the end of her earlier dreams. I think that shared pain, though very different in many ways, was what brought our mothers together.

In retrospect, I can see that somewhere along the way I started to count Kerry as a friend. I learned from her that there is not just one kind of friend; there are different ways to build caring relationships. And I remember in college playing pool with other friends in dive bars just off campus. I was pretty good, and when someone asked how I learned to play so well, I laughed and said I had a friend who was an amazing pool shark.

Non-disabled people can develop more humility if they realize they are not the only ones who have something to offer, that they too have limitations. Who is really helping whom when a

disabled/non-disabled relationship has genuine reciprocity? Loving relationships transform us, whether we are disabled or not. And care does not have to be patronizing.

While Meredith learned how to celebrate her triumphs and take the setbacks in stride, Jaclyn learned how to be creative and compassionate. They both learned that relationships can be reciprocal and bring great gifts to both people, despite the precarity and limitations of life. And I think that maybe Jaclyn was the one who learned the most in our class. Their friendship continued long after Meredith graduated, when they were no longer an aide and a disabled student but two friends who enjoyed each other's company.

Accessibility is an Act of Love

Individuals with disabilities often talk about finding their people, developing a support network that will bring them joy and help handle life's challenges (Clarke, 2020; Field et al., 1998; Thompson, 2021; Weinstein & Bufalini, 2015). That is what we did in that freshman English class. We connected with each other and concentrated on those who mattered to us. Instinctively, we all knew that we were there for each other, and those who "are always there, offer constant support and have your back ... are the ones that you need to hold onto, and [appreciate]" (Holly, 2020, para. 5).

Our lives are enriched by connectedness to others, although it is not always an easy process to find and establish meaningful relationships, whether one has a disability or is quarantined. The twelve students who came together in my freshman class stopped by to visit me over the following couple of years. We would reminisce and laugh together again. We would relive the legends. We knew we had created something valuable. We had been able to break down the separation caused by labels and create a strong community.

During the pandemic and especially in the beginning, there was a celebration of mutual care as people came to terms with being stripped of their usual modes of living. Establishing support networks became essential during lockdown in ways that may have not been necessary previously. People provided meals and grocery runs for vulnerable neighbors; the entertainment industry removed paywalls and broadcast free events; a massive amount of content was produced to help with the at-home education and entertainment of children; music was shared from balconies; frontline workers were recognized and shown appreciation. There were those whom we met weekly on Zoom or those in our "bubble." The close friends and family that offered support even if it was from a distance or the old friends that we reconnected with through video conferencing or texting probably helped us through the bleakest times. People recognized moments of grace and caring in the midst of hardship and tragedy.

Learning to Live with Precarity

Fear, grief, and longing have been part of my disabled life and my pandemic experiences. Anderson and Kornblum (1984) describe insulin-dependent diabetics as:

walk[ing] a tightrope, balancing between high and low blood sugar levels. ... Because stress influences blood sugar control, and blood sugar levels, in turn, influence emotional equilibrium, the diabetic ... copes with a complex feedback cycle between physical and psychological states. (p. 18)

Walking a tightrope requires an intense level of bodily control because with one slight bobble, it could all be over.

Fear of Illness and Death

The fear that comes with that intensity is very real for some individuals with disabilities, and it reflects the fear many non-disabled people have been feeling during the pandemic. In 2020 the stress and anxiety related to the pandemic were called “a national mental health crisis” by the American Psychological Association. A 2020 APA survey reported on unwanted weight gain or loss, disrupted sleep, increased use of alcohol and drugs, significantly higher self-reports of stress, delays in medical care, increases in mental health diagnoses, and unease about the future.

During the first days of the lockdown, I awoke from a nightmare in the early hours of the morning. My heart was racing. I felt disoriented. I bolted out of bed, and then I sat back down on the edge trying to breathe deeply and rein in my anxiety. I remembered my dream, in which there had been a phone call from the doctor telling me that my daughter was experiencing severe Covid symptoms. The fear lasted long after the nightmare ended, and it brought back, in vivid, terrifying clarity, the memories of a near-death experience I had a few years previously.

It was a night that began with the simple act of going to bed and that ended with me hospitalized. The first thing I can remember after I fell asleep is coming to consciousness with the emergency medical technicians—the ambulance crew—working to revive me as I lay on the bedroom floor. I struggled to open my eyes, then quickly shut them; the glare of the bright lights was too disorienting. I thought I was in the middle of a nightmare, but I saw the wood ceiling beams above and felt the cold, hardwood floor underneath my body. It seemed like people were shouting at me, but I could not answer their questions. Then I felt myself lifted onto a stretcher, wheeled outside into the frigid early morning air, and hoisted up into an ambulance. I was shaking uncontrollably, both sweating and freezing cold. My glucose levels had dropped dangerously low while I slept, causing convulsions. I was close to death.

The fear of illness and death that came with the Covid-19 pandemic was heightened, but for me, it was not new. Such fears are not a rare occurrence for some people with disabilities, and they are something we must learn to manage. With diabetes, I had to overcome my fear of going to sleep at night. On nights when my husband was away on business, I set the alarm for every two hours to check my glucose level and send him a text. The text simply said “OK.” If he did not receive those texts, he would call me, and if I did not pick up the phone, he knew he had to call an ambulance. Eventually, the fear subsided enough for me to trust that my glucose sensor alarm would wake me in time.

The challenges of handling fear are not, in other words, something I learned to manage quickly, but time taught me that we have reserves of strength we don’t always recognize until we have no choice. With diabetes, I had to overcome my fear of going to sleep at night.

I had to find a way to minimize my fear. Planning for contingencies was one step. Texting my husband throughout the night may at first seem to be a bit of an overreaction, but early on, it gave us a sense of control and lessened the fear. There is also a sense of acceptance that comes at some point; yes, I may die, but I am going to do whatever I can to stay alive.

Focusing intently on those actions is helpful in mitigating the fear. My moment of pandemic fright during the dreamed phone call from the doctor was something a lot of people experienced although we brought different perspectives based on what our life was like before the pandemic. For some of us, there were disconcerting similarities and for others there were new fears we did not want to acknowledge.

Writing now, well into the rise of the Omicron variant, I can see all around me the struggle to accept that life is limited. This is one way to think about the struggle over masks, a proven Covid-19 deterrent, the wearing of which has become politicized to the point of assault and even murder (McEvoy, 2021; O’Kane, 2021). The failure to accept mask wearing is needlessly causing countless new infections.

Masks represent to many an impingement on “freedom,” but to me they represent coming to terms with our limitations, with doing things we do not necessarily want to do. One way to think about them is to recognize them as the inconvenient and uncomfortable signs of our frailty. Have not many of us, while wearing a mask, longed for this aspect of daily life to return to the way it was before? What, I find myself wondering, are the stories that lie behind the rage or refusal of mask-wearing? In the currently polarized United States, are there legitimate experiences of loss and helplessness that are denied both in the rage of mask-refusers and those who feel rage toward mask-refusers?

I suspect much of the rage comes from fear. As the pandemic has changed all our lives, it is important to remember that “We are never more (and sometimes less) than the co-authors of our own narratives. Only in fantasy do we live what story we please” (MacIntyre, 2007, p. 213). And fear is not just about dying. Learning-disabled students understand the fear of failing the test, the fear of being left out, the fear of being mocked, the fear of not being able to make friends, and the fear of a future filled with challenges and lost chances.

Wrapped up in all that fear are thoughts of inadequacy resulting from the expectations of an ableist society, and the anxiety of wondering what will happen if we do not measure up. Arielle (2020) writes:

This idea of (de)valuing lives has been at the forefront of my mind as COVID-19 has continued to sweep the world, leaving devastation and grief in its wake. First, there was the dismissal of “don’t worry—it will only impact chronically ill and elderly people” (implying that those two populations are expendable); followed closely by “people should really care now, now that we have seen it impacts even the young and nondisabled,” Some disabled folks with their own ventilators even had to reckon with the threat of having their ventilators removed to be given to someone who was deemed more worthy. (para. 6)

We will continue to face dangers from climate catastrophes, personal tragedies and trauma, cultural conflicts, or marginalization. Disability experiences are as valuable as other life experiences that are the result of academic scholarship or professional development or athletic training or practice in the arts. The area of expertise may be different, but it is just as important. It is just not always as visible.

A Heightened Sense of Loss and Grief

There has been a lot of loss because of the pandemic. Loss has taken many forms—the sorrow we experienced when people we loved died, the shuttering of businesses and the loss of jobs, the deferral or loss of events we had long dreamed of. I had imagined crossing the stage in cap and gown and hood as I graduated with a doctoral degree, but it did not happen. My husband and I shared a bottle of wine as we watched a thirty-minute graduation presentation from the university and then clicked on a link to hear my name read aloud.

There has been a lot of sadness for the celebratory milestones missed. Such loss is a common experience for individuals with disabilities. Whether it is learning that a disability has put an end to a long-held hope or dream or that the disability means the thing was an impossibility even before it could be dreamt, those of us with disabilities must adapt in our pursuit of happiness,

love, and a worthy life. Our inner resources can be illuminating, not because we are paragons of inspiration, but because we have figured out a few things from dealing with our challenges.

I would argue that at least some of the rage over masks and vaccines and lockdowns is due to challenges to ableist fantasies of a life without limits. The reality is all humans face constant limitations and disappointments in life. We cannot always get what we want. Dreams very often do not come true. Sometimes we have to do things or not do things because that is what is good for us or for our communities. Finding ways to live graciously and generously with limitation and loss is essential at the best of times and even more so during such trying times.

For individuals with disabilities, the obstacles that must be overcome are often intimately tied to discrimination, oppression, and injustice, and they frequently find ways to live with these realities without becoming depressed or cynical (Cureton, 2016). They find joy and survive. They struggle, yet they lead worthwhile lives. Carlson (2014) explained:

True happiness is really possible in a “broken” body. Most say they would rather die than live with a disability, which makes me laugh. That’s because most able-bodied people can’t imagine being happy if their body was ever permanently broken. But the truth is that the human brain is very adept at transitioning into someone with a disability, if you let it, that is. I thought I would never be happy again. But a few years after becoming paralyzed, I was happy. I found happiness through simply being alive, and through family and friends. I still wish I could walk again, but true happiness resides in me. (para. 3-4)

The key is adapting by managing the grief and anger and finding ways to thrive, despite longing for a different world.

I remember a conference I attended with the chair of the special education department and the mother of Charlie, a learner with Asperger’s Syndrome who was in my class. The special education teacher brought her chair around to the front of her desk where the mother and I sat, and we formed a tight circle of concern. It was a small room, and there was not much space between us. Charlie’s mother had a folder on her lap. She always came prepared. She did the research and understood her son’s disability. She knew what the laws required. She was demanding, but she was not unreasonable.

At first, Charlie’s mother talked about the accommodations he had in my classroom and how they seemed to be working. We discussed upcoming assignments and how he could build upon the success he had recently achieved. I thought it was going to be a quick and pleasant meeting. Then she started to cry. She talked about Charlie’s upcoming eighteenth birthday. He had no plans to celebrate. He would hear his classmates talk about parties they had attended over the weekend and see social media posts with photos of smiling, laughing teens, but he had never

been invited to a party during high school. He went to one dance and after a picture of him and a girl in his class was posted online with jokes and snide remarks, the girl was teased unmercifully. She stopped talking to Charlie.

For Charlie, there would be no prom, no senior trip to the shore, no Grad Night celebration. He had no friends. Charlie's mother was overwhelmed with sadness and worry. The stories she told us about his years of high school were among the most sorrowful I had heard. We offered tissues, hugs, and kind words, but it did not really help; she still lacked the control she wanted to help her son find happiness.

Sadly, many non-disabled teens became disabled during the pandemic as they experienced a variety of mental health issues. Some eighteen-year-olds felt desperation during the pandemic when their only contact with those outside their immediate family was mediated by technology. They missed a lot of events they had dreamed about for a long time. Parents of locked-down teens arranged drive-through graduations and virtual parties. But often, it was not enough to eliminate the feelings of loss and the longing for the way things used to be.

Grief has been described as "the cruelest element of this pandemic" (Checchio et al., 2020, para. 27), arising from the inability to comfort hospitalized family members to the impossibility of mourning their deaths through cherished rites and traditions. This is something we have all seen if not lived.

One of the worst pandemic images seared into my mind is turning into the driveway of my mother's nursing home on a bleak Sunday afternoon. The Covid-19 wing stretched from the beginning of the driveway straight back to where it curved into the parking lot. Standing outside the windows looking in were family members of the patients who were inside, facing death all alone. Adult children and grandchildren held balloons and posters trying to shout their love in phrases that might be understood. My mother had spent time on that wing during two bouts with the disease, and as I drove by, I was grateful that we had survived the worst.

There is grief with disability as well. There is the sadness that comes with the acknowledgment that one cannot do something that one wants to do because of an impairment; there is the despair of wishing desperately for the chance to go back to the way life was before the body became disabled or as it might be imagined if there was no disability; there is sorrow when the hopes and dreams of an idealized life cannot come true; and there is anguish from being left out, overlooked, ignored that comes from marginalization.

The Prevalence of Death

Since the beginning of the pandemic, death has been ever present in our lives, even if we have only seen it on the news, those graphs of horrible spikes in the numbers of people lost. For some members of the disability community, death can be a pervasive part of their lives:

[E]ach time a disabled friend dies I find myself questioning many things in my life.... How can I maintain my disability pride when I am always surrounded by death? It is not always easy. In fact, at times it can feel insurmountable. While some of my friends have died because of their disabilities, others have died because of broken systems that devalue the lives of disabled people.... Not everyone understands disability pride, which is apparent when a disabled person dies, and nondisabled people nearly always repeat the same ableist remarks: "They are no longer suffering." "She is now free to run." "He is finally cured and now dancing among the angels." I can't say hearing these things doesn't get to me; it does. These comments diminish the lives of both the dead and the living. Most of us are fine not running; we are not suffering, and we do not want to be cured. (Powell, 2019, para. 6-13)

Sometimes a disabled individual faces a choice between being part of a strong disability community that means they will face frequent loss, or stepping away from that community to avoid the grief and lose its loving support (Powell, 2019). One writer described how, during lockdown, his community "sustained him during these trying times; [and] made a profound impact" (Checchio, 2020, para. 45). He did not have to make that choice.

I see the parallels between disability life and pandemic life in narratives about death. On the one hand, the story of a person with a disability tells us about accepting harsh realities:

Death is unavoidable. But as a disabled person, I am all too aware that death and disability are inextricably linked. Because of my disability, I have an enriched life. I have also experienced tremendous heartbreak. In the end, I have come to understand that I will love, and I will grieve. (Powell, 2019, para. 16)

And on the other hand, a Covid-19 patient described surviving:

I touched death and I'm very lucky to be alive. What I'm now looking forward to is appreciating nature. You realise material things don't matter. When I get outside, I want to breathe the air, look at birds and enjoy the natural beauty of the world. I've been given a second chance. (Berg, 2020, para. 32-33)

I see the similarities between my own close call with death and that of someone who nearly died of Covid-19. When I wrote about my near-death experience, I quoted Billy Collins' (1995) poem, "The Art of Drowning," where he talks about the moment of death being like "an invisible

hand turning the pages of an album of photographs” or “a short, animated film, a slide presentation... an essay ... one model photograph” rather than a condensed image of a full life flashing before one’s eyes. It does not necessarily play out that way in real life, as one coronavirus survivor said:

I started hallucinating. I was getting flashbacks of conversations I’d had in my life and people I’d met. At one point I thought: “Am I alive or dead? Do these flashbacks mean I’m transitioning to death? Is this what people mean when they talk about your life passing before you when you die?” And then I’m saying: “No, I don’t think actually I am dead, because there’s no white light and no angels and nobody calling me.” (Berg, 2020, para. 17)

In these cases, the people survived, but in many others, there was death that led to grief. As Szabo (2021) describes, Covid-19 has generated grief that will haunt us for years. Political and economic battles can complicate grieving, sometimes making it hard to move ahead. With 5.66 million worldwide deaths (to date), pandemic grief threatens, Szabo says, to turn into a pandemic of grief.

Different Types of Grief

Those with disabilities and those who lived in lockdown have experienced several types of grief: chronic sorrow, ambiguous loss, and nonfinite loss. Nonfinite loss can be understood as loss that brings a dread for the future, a loss resulting from dreams and imagined realities that are no longer possible (Bruce & Schultz, 2002; Harris & Gorman, 2011). Ambiguous loss reflects my reality with my mother; in many ways, she is lost to us because of her dementia. It also reflects illness or disability loss where the body has changed. It is a “relational disorder ... [where] ambiguity ruptures the meaning of loss ... [and] people are frozen in both coping and grieving” (Boss, 2007, p. 106).

Barriers erected during Covid were not just physical, but the physical barriers contributed to the decrease in personal interaction and social isolation. We felt sad. Kerry Thompson (2016), who describes herself as “a forty-something blonde in charge of a wheelchair” reminds us that “It’s okay to feel sorry for yourself – once in a while ... The trick is learning when feeling sorry for yourself is healthy and when it is just making you feel worse [and] it’s different for everyone” (Thompson, 2021, para. 13). It is particularly important to remember this when we are experiencing grief, whether from disability, or isolation, or loss.

I once interviewed the mother of a young girl who was deaf. Penny knew she needed her sign-language aide to help her through the day, but she was sad that she couldn’t participate in typical conversations with her classmates. She was too embarrassed to ask her aide to tell the other girls that she thought a boy was cute or that her teacher was annoying. Her mother felt that sadness

too. She knew the experience of the mothers in the video (Debs, 2011) who said, “I listened to my blind son tell me about the car he wants to drive when he is older. How can I tell him that he will never drive?” (2:25), and “I gave my son his lunch via a syringe. Just once, I’d love to give him some chocolate” (1:28), and “I attended a course to learn Makaton. I want to communicate with my non-verbal child. I wonder what his voice would sound like” (1:33). These mothers understand grief.

Olshansky (1962) first described chronic sorrow as “the long-term periodic sadness the chronically ill and their caregivers experience in reaction to continual losses” (Lindgren et al., 1992, p. 27). It is “cyclic sadness over time in a situation with no predictable end; external and internal stimuli triggering the feelings of loss, disappointment, and fear; and, progression and intensification of the sadness or sorrow years after the initial disappointment or loss” (Lindgren et al., 1992, p. 27). Patrick-Ott and Ladd (2010) argue that disabled individuals and their families “experience the continued grief of chronic loss over and over again as [the] ... disability prevents normal development and expected life” (p. 75).

After my own disability diagnosis, I felt the effects of my sorrow. I grieved for what I had lost, and I despaired that my disability was permanent. Each day there were specific triggers like deciding what to eat that illustrated the “disparity between past and present or future situations” (Livneh & Antonak, 2005, p. 12). Throughout the lockdown, many individuals felt touches of chronic sorrow as one planned celebration after another was canceled and one life milestone after another was experienced in isolation. It was difficult to plan for, hope for, and anticipate future joy as the pandemic stretched on and there seemed to be no end in sight.

Betz and Thorngren (2006) wrote that “when people lose their previous state of health because of illness or injury, they may no longer be able to do the things most important to them. ... They lose their identity and way of being in the world” (p. 360). As we were isolated in our homes, unable to do what we most enjoy, or forced to work in a dystopian landscape of masks and social distancing, fearing the chance of infection yet needing to support a family, we experienced loss. During the pandemic, students and teachers felt a loss of their schoolroom identity as they moved to online education. Their teachers and classmates were still there, but it was not the same.

Nonfinite loss is about what “should have been, could have been, or might have been” (Harris & Gorman, 2011, p. 2). This is the painful loss those mothers felt as they recognized how their children would not have those typical everyday experiences of gossiping with friends or tasting sweets. Green (2002) describes moments as a parent of a child with a disability when she grieved for the “loss of an imagined reality, a reality that is no less important or deeply mourned because of its imaginary nature” (p. 21). There are times when individuals who were born with disabilities feel this same nonfinite loss as they realize that their impairment will not allow them

to enact the life they imagined. During lockdown there was sadness and dread of nonfinite loss of the imagined future that could no longer occur as dreamed.

Sometimes these losses are not allowed to be grievable. How can one mourn the missing of a graduation, a prom, a sports championship, a leading role in the play when others are grieving a lost parent or grandparent or friend or teacher? These milestones may not be a concrete death that we manage with traditional rituals, but they still provoke disappointment and grief. Sometimes disabled people are told not to mourn their own losses, but fight against ableism within society, and while we need to work to make our society more just and inclusive, we cannot deny someone their right to feel sorrow over their loss.

During the pandemic, “There is no great gathering of family and friends to honor our mothers, fathers, grandparents, spouses, brothers, sisters, children or friends so suddenly and cruelly ripped from our lives. There is no wake, no shiva” (LaMotte, 2020, para. 2). It makes the mourning more difficult, more like the grieving many individuals with disability feel, the type of grief that does not have closure. Not only have too many people died and continue to die from Covid-19, but there is also a loss of feeling safe, a loss of social interactions and personal freedoms, a loss of financial security. We are still dealing with the pandemic, and we do not yet know the losses that may be in our future.

Using Stories to Deal with Grief

Betz and Thorngren (2006) described storytelling as a form of narrative therapy that can offer individuals a place “to be heard and validated and also to explore alternate meanings around their experience of ambiguous loss” (p. 363). Communicating through personal stories is also a way to limit stigma (Etmanski, 2020) and diminish othering.

One of the dangers of telling stories of grief is the possibility that this simply reproduces stories of disability as tragedy. The fear and reality, for example, of in utero genetic testing for disability is that it will lead to the elimination of lives that cannot be imagined as worth living. The rationing of health care further proves this fear. If we see the lives of those with disabilities only as tragic lives, then we are laying a dangerous ground.

Accepting reality is an important part of disability, and “unfortunately we live in a society that assumes joy is impossible for disabled people, associating disability with only sadness and shame” (Brown, 2020, p. 117). Part of finding happiness is about learning to accept what we cannot change. We did not have the power to change the lockdown rules (although many flouted them). We felt the grief of the loss of the missed events in our lives, and we had to let go of our images of what those times would have been like.

I had a student one year in my sophomore English class whose family had a long history of attending a top tier liberal arts college. His mother talked about it all the time. Max seemed to believe it was a foregone conclusion that when he graduated from high school, he would continue the family tradition. He had visited the school often growing up and longed to be an independent college student roaming that familiar campus.

Max had a learning disability that made reading and writing extremely difficult. I did not see a spot in that college's freshman class as a likely possibility, and knowing what disability grief was like, I wished fervently that I could help Max see a path of many possibilities, if not this one in particular. I spent my time with him concentrating on helping him to improve his skills and maybe expand his dreams a bit too. Max eventually accepted his reality and attended a different university. He knew joy and excitement as a college student despite experiencing the loss of one dream due to his disability.

Isolation and Longing

We have all experienced longing at some point in our lives. For me, “What stands out in my memories of the moment of diagnosis is the strong sense of the disconnection of longing that I felt ... The feelings of being alone and recognizing that a significant change had occurred” (Rogers-Shaw, 2020, p. 18). A blind woman remembered, “I spent many of my teenage years wishing I was like everyone else, wishing I could fit in. But over time, I realised that fitting in and being like everyone else is overrated” (Holly, 2020, para. 3).

During the many months of lockdown, we all longed for the days before the pandemic; we wanted desperately to go back to the normal life we once had. We felt “the earnest, heartfelt desire for something, some state, or some relationship, without which one's life [did] not feel complete [and we experienced] longing as feelings of grief, anger, sadness, despair, hurt, abandonment, and vulnerability” (Pehler et al., 2014, p. 137). Although we wanted to hold onto hope, it was difficult.

Teaching during times of national trauma and looking for ways to deal with longing is not easy. When in the spring of 1999, I first learned about the shooting tragedy at Columbine High School, it was the last period of the day, and I was in the computer lab with my senior English class as they finished a research project. I do not remember exactly how we learned about it; maybe a student went to get a drink of water and heard it in the hallway, but I knew right then that things would not be the same again.

For me, it was the first step on the long journey to locked building doors and sign-in procedures, school lockdowns, and active shooter drills – Run, Hide, Fight – where I wondered whether I

could throw a laptop at an intruder or if I was strong enough to throw a desk chair, or whether the filing cabinets and rolling bookshelf would provide enough coverage of the door.

Just prior to the shootings, I had given my students a final writing assignment, one in which they wrote a story about saving me from a life-threatening situation. For years, my senior classes had enjoyed relating how they climbed a stalled rollercoaster on the trip to Great Adventure Amusement Park to carry me down from a precarious perch where I dangled by a thin seatbelt or how they dragged my unconscious body down the smoky stairway after an explosion in the science lab. The assignment was no longer appropriate, despite its required happy ending and hero status for the writer.

While Columbine seemed far away, and they did not believe it could happen in their school, they recognized in our class discussion that things had changed and no amount of longing for the past or for imagined heroism would alter the present. We moved on to writing adaptations of Shakespeare in the style of *10 Things I Hate About You* or *The Lion King*. We recognized our longing, we accepted the changed circumstances, and we adapted. Although, I think that in the back of their minds, they felt sad that they had missed out on something, that infamous assignment that classes before them had relished.

Then again on 9/11, I was teaching high school English in a suburb of New York City. We had just started the unit on *Hamlet* and *Macbeth*. Students had been assigned to bring in photographs that represented evil, or that spoke to acts of revenge. That day the students lost family, friends, and community members who had touched their lives. When we returned to class the next morning, I offered the students the opportunity to end our study of Shakespeare and the heavy themes that were just too close to home. They jumped at the chance and their choice of literature reflected that overwhelming desire to go back to the way things were before; they opted for *Be True to Your School* by Bob Greene (1987).

Still, with personal or national trauma, or the pandemic, or a disability, there is no ability to go back completely; these experiences change us, and we need to recognize this and keep moving on to find at least some happiness or meaning or peace despite the continued grief. We talked about the similarities between Bexley, Ohio, the setting for *Be True to Your School*, and our suburban community, glossing over the horrific changes that community was experiencing as we attended funerals. We laughed about Greene's dating disasters, and the students recognized some of their own teenage insecurities on the book's pages. The distance provided by this text was necessary, but it was not denial; grief was always hovering in the stagnant classroom air.

The slight relief provided by shifting texts helped us move rather than remain paralyzed by the effects of our personal and national trauma. They were a respite of a few minutes each day when

we could think about something else. They provided us with a little bit of time to build up the reserves of strength and resilience that we badly needed to face what was all around us.

That is what happened when families across the country joined each other in Zoom board game nights; how we built courage and togetherness standing on balconies to bang pots and pans or sing together or cheer essential workers; why we had maybe a fraction more confidence and felt slightly more optimistic when we woke up after an evening movie night when friends turned on a streaming service's shared screen feature. These moments, like the ones in my classroom many years ago, eased some of the pain, lessened our feelings of languishing.

Languishing has been described as a midpoint on the continuum of mental health between depression and flourishing, but it can lead to serious mental health issues (Keyes, 2002). Grant (2021) references a study of pandemic healthcare workers whose feelings of languishing often led to post-traumatic stress disorder diagnoses:

Part of the danger is that when you're languishing, you might not notice the dulling of delight or the dwindling of drive. You don't catch yourself slipping slowly into solitude; you're indifferent to your indifference. When you can't see your own suffering, you don't seek help or even do much to help yourself. (Grant, 2021, para. 9)

Many individuals with disabilities have experience overcoming mental health issues resulting from longing and languishing. Farrelly (2017) argues that we do not need a "perfect body to be happy. The ability to deal with physical and mental pain and the acceptance of weakness is a sign of good mental health. This is something that 'normal' people do not always understand" (para. 2). Many disabled people have come to recognize this truth.

I think about all the stories I helped students write over thirty-five years as a high school English teacher. I see the groups of desks scattered across the room as students compose drafts of the stories they want to tell. There are visual vocabulary pages plastered on the walls, untidy piles of folders on the windowsill, and well-worn paperbacks stuffed haphazardly on the rolling shelf. I see posters of William Shakespeare, Ernest Hemingway, Maya Angelou, George Orwell, Octavia Butler, Charles Dickens, Amy Tan, Sandra Cisneros, Billy Collins, Langston Hughes, Gabriel Garcia Marquez, and John Steinbeck. If I were in that classroom today, I would see books by authors who write about their lives with disabilities or characters with disabilities, authors such as Alice Wong, Keah Brown, and Leah Lakshmi Piepzna-Samarasinha.

If it was early in the school year, my seniors would be working on their college application essays, trying to tell the stories that are such an important part of who they are. This past year, after experiencing online schooling and social isolation due to the lockdown, the college application essays revealed that "students were a lot more depressed and ... used their essays to

talk about depression, anxiety, things like this” (Kelly, 2021, para. 8). Maybe they chose to answer the Common Application prompt that reads: “The lessons we take from obstacles we encounter can be fundamental to later success. Recount a time when you faced a challenge, setback, or failure. How did it affect you, and what did you learn from the experience?” The increase in application essays dealing with anxiety and depression reinforces the notion that telling stories is vital.

In the fall after 9/11, I reviewed story after story of that day. I wondered how to help my student writers add depth. I asked myself whether I should encourage them to include hope and understanding or if the overwhelming pain was sufficient. I think it was enough for them just to put their own words on paper, whether they described their after-school dance class where no one danced but instead sat in a circle and cried, hugging each other; or whether they told the story of going home at the end of the school day to an empty house, waiting for parents to return from the city, sobbing with joy when they knew they were among the lucky ones when the car turned into the driveway.

These narratives revealed the importance of telling stories of personal and collective trauma. That year, after the essays had been submitted, I received a phone call from a mother. At first it was hard to understand her because she was crying. She had just read her son’s essay. He had described the night before the attack, when he and his father and brothers and uncles had watched *Band of Brothers* (Spielberg & Hanks, 2001) together. His uncle died in the collapse of the Twin Towers. His band of brothers would never be the same. His mother told me that he never wanted to talk about it with his family, but he was comfortable sharing his written story. His essay was a way for him to tell his story when he could not say the words aloud.

Students with disabilities also value their true narratives. They might argue that sharing their stories would increase understanding and empathy for those with disabilities and those who have felt anxious and depressed due to the pandemic. They might argue that their disabilities are the perfect topic for those college essays because “[b]eing a part of the disability community has made me who I am—and I don’t just mean in the physical sense. I have had beautiful and rich experiences, not in spite of, but because I am disabled. I have met truly amazing people whom I would never know if I weren’t disabled” (Powell, 2019, para. 12).

What is important is that these stories must be honest ones. I have tried to tell honest stories about disability and about the pandemic because I believe in the power of telling stories to connect people.

Learning from the Disabled

The *Disability Visibility Project* published a blog in the spring of 2021 titled, “What the Disabled Community Offered the World This Past Year” based on a Twitter thread by Hell on Wheels. In a concise list, Kaalyn M. summed up the many ways disabled people have adapted to their disabilities and thrived, revealing how they have become experts whose skills were lacking in many non-disabled individuals facing the pandemic. Her list included: how to remain in touch with family and friends, ways to work productively at home rather than in the office, coping skills, dark humor, ways to combat isolation and depression, resources for managing trauma and grief, sleep strategies, and exercise suggestions.

She pointed out that people with disabilities have

honest, raw conversations about death or hospitalization, [are educated] on virus transmission [and] effectiveness of any “hack” to avoid COVID ... resources to navigate healthcare and insurance hospital and ER survival guides ... tips on how to best support a sick loved one in your life knowing the system will not protect you, often giving lifesaving instructions on using [medical equipment], directives to the most trusted scientific journals and research, how-to’s for healthcare self-advocacy ... putting together post-viral strategies, [and] clothing recommendations for at-home, sick or hospital life. (M., Kaalyn, 2021, para. 2)

That is a lot of knowledge people could have used when they were struggling at home during lockdowns or dealing with a deadly illness.

In 1999, Treloar wrote an article on lessons on disability. Just as I have done, she asked her readers, “When [you] think of a person with a disability ... what comes to mind?” (p. 30). Here we are over twenty years later and learners with disabilities are often still viewed through the same images and deep-seated bias. Treloar (1999) suggested educators attempt “to create relationships that emphasize cooperation, personal attributes, and equal status. In so doing, we no longer focus on cane, crutches, wheelchairs, or other aspects of disability: We see beyond differences” (p. 33).

She called for delabeling and maintaining personal relationships with disabled learners: “Viewing each student as a person begins with self-awareness of personal biases and assumptions about disability. How do we see others: as having value and worth, capable, equal, responsible for self, able to make decisions?” (Treloar, 1999, pp. 2-33). While many individuals have worked diligently to move toward a greater understanding of disability and many educators have attempted to teach in a more inclusive way, it is a sad reality that we have not made enough progress since Treloar put her thoughts on paper.

So, what has changed? I believe that the pandemic experience has revealed to those without disabilities a glimpse into what it is like living with a disabled body. My hope—and I am hopeful—is that lockdown experiences might trigger greater understanding of disabled lives, more reciprocity in relationships between those with and without disabilities, and more recognition of the stories of wisdom people with disabilities have. So, what can you do now? You can reflect on your own experiences, “focus on knowing yourself better. Learn from others, unlearn your own implicit biases ... It doesn’t matter how much you do or how fast you do things in comparison to others” (Wong, A., 2019, para. 10). What matters is that you try, and you keep on trying.

My mother died soon after I submitted this article for publication. I was able to be by her bedside at the time of her death. Yet the Omicron variant was raging and we couldn’t say goodbye in the traditional way. The best we could do was a 15-minute gravesite blessing outside in the rain. Like a lot of things that happened during the pandemic, it seemed so very unfair. The sense of loss was crushing, and by not holding the funeral she had planned long ago, I felt that I was letting her down.

When I arrived home the afternoon she died, there was a package in the mail. It was a copy of a book of essays on profound living that I had just published with two colleagues (Kroth, Carr-Chelman, & Rogers-Shaw). My dedication read: “For my mother, with profound gratitude for the myriad ways that she has loved me and supported me throughout my life. Her strength, her kindness, and her love of reading have always inspired me. She has shaped my view of the world and how I capture it in my words.” My mother never saw the book and did not know what I had written about her. As I write these words today, I think that living with a disability and living during a pandemic both require strength and kindness, and I rededicate myself to trying to dig deep and find that strength, and to always remember to be kind.

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