Ableism, On and Off the Page: Literature and Invisible Disability
Saturday, February 10th, 2024
1:45 to 3:00 pm
Room 2103B, Kansas City Convention Center, Street Level

Brad Buchanan is a retired professor and author of eight books, most recently LIVING WITH GRAFT VERSUS HOST DISEASE and CHIMERA. Diagnosed with T-cell lymphoma, he had a stem cell transplant that made him a genetic chimera, and left him blind for 18 months, disabled, and chronically ill.

Dianne Bilyak is the author of Nothing Special: The Mostly True, Sometimes Funny Tales of Two Sisters. Published by Wesleyan University Press, the hardcover was released in 2021, followed by the paperback and the audiobook. She's a Pushcart-prize nominated poet, graduate of the Institute of Sacred Music and Art, and a disability rights advocate. More about her and her work at diannebilyak.com

Leticia Escalera has worked with the Center for Independent Living and served two board terms on a California disability advocacy organization and the Oakland Mayor's Commission on Persons with Disabilities. She’s written a memoir, A Journey to Begin in Life, about life with cognitive/neurological disabilities.

William Hartwick is a retired first-grade teacher and elementary school principal (Del Norte County, CA school district) who now works as a motivational speaker and author. His latest work, The Invisible Backpack, addresses his bipolar disorder and Tourette's syndrome through verse.

Nika Beamon attended Boston College and is a TV Writer/producer in NYC. She is the author of the non-fiction book, I Didn't Work This Hard Just To Get Married (Chicago Review Press, 2009) and the critically acclaimed memoir, Misdiagnosed: The Search For Dr. House.

(Short self intro: Name, What type of writing do you do, your disability, publications to promote [bring a copy], 1 minute.)

Questions the moderator will ask/that the panel will discuss:

1. Do writers with unseen disabilities have an obligation to speak about their conditions?

LE: In my experience, I find it very useful and relevant to mention my disability because it affects my speech and I have difficulties while relaying information. It does help the audience to better understand the different accommodations you use to do your work and presentation as efficiently as possible.
**DB:** Only if that’s the subject of their writing. In readings or interviews, that’s a perfect place to speak about your unseen disability.

**BB:** I definitely feel an obligation to speak about my chronic illness/disability, which is graft-versus-host disease (GvHD), a side effect of my stem cell transplant. It’s still a poorly understood illness that none of my oncologists wanted to discuss very much before my transplant, and which they didn’t cope with properly afterwards.

**NB:** I do not feel obligated to talk about my condition but I am also aware that by doing so I may provide vital information to others about getting care and being better advocates for themselves, and that it provides a voice to people of color who often feel overlooked by doctors.

**WH:** Living with Tourette's syndrome and bipolar disorder, it's somewhat obvious of a difference, maybe not so invisible but maybe just not known. And I feel it's necessary to open up with something that shows that not only do I accept my condition but I find humor in it. Also, how we can make a difference through what I'm about to say in the moments ahead.

2. **Do you write about disability, explicitly or implicitly? Do you think disabled authors have the responsibility to advocate for themselves and others through their writing or to address the topic?**

**LE:** Based on my experience, advocacy can be done in various forms and writing is one of the ways to make your position stronger and visible to the public in order to advocate for those who are under-represented or are affected because of the lack of disability awareness. I personally feel a sense of responsibility to raise awareness of hidden disabilities because of the complexity of the conditions, and to support individuals with invisible disabilities who are being underserved because of the lack of understanding of their condition and its different limitations.

**BB:** There were no book-length patient narratives about GvHD before I wrote my memoir, *LIVING WITH GRAFT-VERSUS-HOST DISEASE*, so I felt I had a responsibility to write about it, to break a kind of taboo. I have also written poetry about GvHD, as well as about my 18 months of blindness.

**DB:** Yes, in the form of essays, memoir, and monologue I have written about anxiety and depression. I have written about my sister’s Down syndrome explicitly, using dialogue to bring her voice into the stories.
NB: I do not write exclusively about being chronically ill. I’ve written a memoir about my quest to find the correct diagnosis. I also blog about my trials and tribulations living with chronic illness and pain on my personal page. I have also contributed to dozens of articles and a half dozen podcasts.

WH: Living with Tourette syndrome neurologically is all encompassing. You just kind of live with it and that’s kind of what you write about, even when you are writing about something else. How you feel based upon your traumas and victories in your life and how people have affected you, how people have perceived and judged you. So yes I write about it, not exclusively but exclusively at the same time.

3. What sort of literary styles or techniques have you or others used to reflect the experience of being disabled, either physically or socially? Is it different for an invisible disability that isn't immediately obvious?

LE: I have used a short story style or form to inform the public how an invisible disability can affect you in different areas and aspects of life depending on the severity and areas of the brain affected and its condition. I also believe in the importance of having other writers share their experience living with hidden disabilities because of the diversity of brain and neurological limitations. I believe education is the path to knowledge and understanding of other individuals with diverse limitations including invisible limitations is vital. Definitely, education can be presented in different styles to cover the needs of diverse audiences.

DB: I’m working on a piece now that I’m hoping will be a documentary type of book. I want to include poems and real documents and use other styles/forms to convey the cold inherent ableism in state agencies, the health care system, insurance, and the group home system. I’m hoping the creative approach can help reach more people.

BB: I like to use paradoxes and oxymorons, as well as funky literary devices such as catachresis and zeugma to twist language into unfamiliar shapes that gesture towards invisible disability. I also like playing with spellings, as in my pet coinage “dys/abled,” that tries to express the idea that disability is not the absence of an ability, but rather a different kind of ability that deviates from or even subverts the norm.

WH: I write in complete rhyme, it’s called rhythmical writing. I have been doing it since the 7th grade. The Invisible Backpack is a series of rhythmical entries about how I live and how I’ve experienced life, things I’ve overcome and the beauties that were within all of it. It’s a rhythmical story that comes with the Tourettes and my ability to create such a story all in rhyming prose.
4. Plenty of people are out there raising awareness of various disabling conditions. How can writers go beyond awareness to actively undermine ableism through their writing?

LE: I believe that when you give a book reading, that can be a great opportunity to add a component of invisible disability awareness and speak about the importance of having the pertinent knowledge to accommodate people with hidden or diverse disabilities to improve their possibility for inclusion.

BB: This is something I struggle with. I have a lot of internalized ableism that I’m still grappling with, so to speak. I guess I’m still at the stage of raising awareness about my particular challenges.

WH: Why The Invisible Backpack? The Invisible Backpack is a labor of love created from the author’s life-long struggle to come to terms with who he is and accept himself as he was meant to be. We are all born with an invisible backpack on our backs. It is where we put all the hurts of life. When we are young and courageously climbing the stairs of life, it is extremely light, and we really don’t know it is there. As we get older, it gets heavier with whatever pain, grief, or traumas we experience. Unfortunately, we resist taking these feelings out of our backpacks and let go of them. Some of us hold on to them so tightly, we forget to make room for the things that lighten our load…forgiveness, acceptance, tolerance and love. For if we can put these items in our backpacks, it will cancel out all the negative things we have been holding onto, and our life journeys will become much lighter.

5. What are some new trends in writing about disability and what are some books you would recommend?

BB: The book I found most stimulating and rich in terms and ideas was Sins Invalid’s Disability Justice Primer. I’m also interested in the intersection of racial justice and disability justice.

LE: Because of my brain's limited strength, I haven't been able to read other books while I have been working on reviewing and editing the book I just finished publishing. However, I have been taking a brain injury class where the instructor has used books and written material from experts on brain injuries. I need to check my notes for author information. Also, I suggest that any American job seeker with a disability look into the Department of Labor’s Job Accommodation Network.
WH: Well… *The Invisible Backpack, “A Life of Courage”* Rhythmical Writing by William L Hartwick is very unique, just saying!!

Is it enough to "raise awareness" about one's condition?

How can writers also undermine ableist perspectives through their work?

BB: I want to explore how language can be used differently to make invisible disabilities visible on the page, and to think about a new concept I’d like to call “dys/ability,” which both leans into and pushes beyond traditional notions of disability. I also want to suggest that the use of poetic devices such as paradox, oxymoron, and catachresis can undermine ableist assumptions about disability and disabled writers.

NB: Is there a void in the number of books, essays about people living with disabilities, invisible illnesses? If so, how can this be changed?

DB: I think I would say that I can be very harsh when I talk about ableist views and systemic ableism. I’m horrified that most DEI mission statements don’t include people with disabilities. As for my writing, I’ve not found a way to convey that without being preachy or pedantic. That’s why I’m returning to writing poetry, which can accommodate more style and creativity.

WH: Writing has allowed me a way to escape all the trauma I have experienced over 58 years and counting. For me it has also allowed a stronger voice for those living with a “Label”. “You have demystified all written rules and allowed poetry accessible to everyone” (Randy Fuge, Educator, Northern California).

L.E: One of the reasons I wrote the book *A Journey to Begin in Life*, is to provide information about the hidden needs of individuals with brain injuries and neurological conditions. It is important to know and understand the underlying problems in order to accommodate individuals with brain injuries and other invisible conditions. This information will help to identify the pertinent and relevant needs of some individuals with hidden disabilities and will help to increase their potential to achieve their opportunities to succeed.