Illmarks.com at Yale Disability and Accessibility Symposium

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Hi everyone, This is illmarks: Symptom Mapping Art

How body mapping for disability affirms our lived experiences,
and unites us in creating hopeful,
transformative futures

For a copy of the deck, please go to illmarks.com/yale-deck or scan the QR code.

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I’m Nyx Mir. I use fae/faer and they/them pronouns.
My visual description is I’m a non-binary white person with dramatic square glasses and fauxhawk haircut.

I make art where I visualize chronic illness symptoms, as part of my advocacy project, illmarks, which is what I’ll be sharing today.

This includes some abstract body horror and art nudity drawings. If that isn’t for you, please just listen, or come back in 5 minutes.

I had a mobility disability before moderate-to-severe chronic illnesses, and I’m neurodivergent. My symptom mapping art helps me navigate these disabilities.

Also, I’m nervous speaking in front of groups, so thank you for your kindness with me.

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My art stems in part from a genre of work called body mapping.

It evolved in from the work of women with HIV in Subsaharan Africa, Latin Indigenous Ecofeminism, and labor rights movements.

At its most basic you take what you are feeling and mark it on a representation of your body.

I strongly encourage you to learn more about body mapping.

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Let’s get to it!

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After Long Covid made it clear I had to leave work, probably like many of you, I had been trying different ways of symptom tracking.

I picked up some bookmarks with printed body outlines, and I started drawing on them.

To visually describe my work: I use a manila-hued anatomical bookmark to constrain & set a clinical aesthetic, and vibrant inks with light-interactive properties to subvert that structure.

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This art wasn’t a perfect symptom tracking solution for me, and I do use apps.

But the art helped me relate to my disabilities in new ways, then build hope for myself, my communities, and our planet, which are the themes of this talk.

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I also expanded the types of experiences I drew.

I went from depicting purely physical symptoms, to adding the emotional experiences of illness, then the systemic impacts, and the interpersonal.

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This series of autobiographical bookmarks became the ongoing “illmarks” project.

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Here are some of the major themes I’ve identified in my work in case you want to try it at home!

These aren’t the only ways:

There’s no right or wrong way to do subjective, perceptual work.

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1. Visual depiction: for “symptom: nausea and reflux”, I use swirling, bubbling acidic colors, which rise up, against the typical flow of the GI tract.

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2. Writing and description:

This bookmark is a poem about blood & queerness over a drawn circulatory system.

Some other people write single adjectives across different body areas, and others do abstract stream-of-consciousness writing.

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3. Comparison and metaphor: In this piece I depict a long, heavy metal brick in my leg.

Some other visual metaphors I've done include being drilled into, drowning, or butterfly chrysalises.

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4. Abstract Shape and Color:

Here I use neon green and purple, with tangled zig-zagging in the belly, and short energetic lines in the face and shoulders.

Abstract shape & color is one of the most common styles I see in body mapping.

I love this because there's especially no wrong answers and people get less stressed about their perceived artistic skill levels.

- 5. Representative Shapes: I use a head & shoulder shape and a lightning shape, two symbols which when combined can convey meaning.

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- 6, Size and scale: For blood pooling in extremities, I used oversized feet and an oversized anatomical heart filling the body.

And any of these can be combined too. If you explore this & want to share what you made, I’d love to see it. My email is on the last slide.

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These art practices are so helpful, they sort of became my thing.

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I’ve published over 250 bookmarks and counting on my advocacy project website, illmarks.com

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Most importantly, I really wanted this work to try to help our communities. I’ve been astounded by the reception and reach.

With University of Washington’s School of Nursing, I taught fellow disabled and sick folks symptom mapping, and it was so rewarding. I’m looking for partners to help me continue hosting disability body mapping workshops, so please email me if you’re interested!

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Now that you understand the project, here’s some of the most important things it’s taught me so far.

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We know our bodies better than anyone else.

There might be people who know more about how different antibodies relate to a specific autoimmune arthritis condition, but no one else knows you specifically better than you.

Even when being ourselves is really confusing or going through a period of great change, we are still our bodies’ best allies and advocates.

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By externalizing our internal experiences we are able to:

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- make them real / tangible:

- this can be deeply important if we have less visible disabilities or for any experiences where we lack support for our reality and perceptions.

- process them:
- this has been important for me, as a neurodivergent person with a fair bit of alexithymia, aka difficulty recognizing/feeling emotions

- track how they change & how we change:

- I was really moved in my workshops to hear multiple people realize symptoms they were used to avoiding thinking about had actually recently improved.

- I get that — there are certain symptoms I avoid thinking about too.

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- Communicate them to others:

- this takes a lot of vulnerability, but it can be immensely meaningful and connective to feel less alone in some of our most difficult feelings.

- This was unexpected for me, so, thank you for being here. I can’t believe I’m talking to a bunch of people about this. (I’m terrified but thankful)

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Body mapping for disability & chronic illness is a way of solidifying our internal truths.

Through our symptom maps, we create our own biomarkers, and substantiate what others cannot see.

We also connect to community. By affirming each other’s internal knowledge we destabilize epistemic injustices.

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To close, let me share how I see this work helping us moving forward:

There’s a great quote from Sonya Renee Taylor, the author of The Body is Not an Apology, where she says (summarized) that as varied and divergent humans are, we all have bodies.

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Because we all have bodies, I believe

healthcare is is uniquely situated as an issue that can unite people across political spectrums to create systemic change.

We will all at some point in our lives experience illness, and death.

Any of us fortunate enough to not have had to fight for critical care during already difficult times in our lives probably know someone who has.

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Increasing attacks on public health and government care systems, are harms against every being, not just humans in public-payer health or disability support systems.

Pandemic denial is causing lasting damage we’re only beginning to fathom the effects of.

In order to survive, I believe it’s critical we envision different, hopeful systems of health&care.

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Thank you.