Before I start, let me note that I have a copy of my scripted remarks available for anyone who wants to read along as I speak—if you anticipate you might have trouble understanding my voice, or prefer to process written rather than auditory material, please feel free to take one. I have also made the script available for download on my website, which is sites.udel.edu/kersch/presentations in case any of you would like to download it and have the remarks available on your mobile device or laptop.

In her presentation at this conference on Thursday, Melanie Yergeau raised some essential questions about autistic identity and how that identity is claimed by autistic people even as it is simultaneously rejected by a variety of dominant discourses, such as widely-circulating narratives told by organizations such as “Autism Speaks” and academic writing by scholars researching autism. Her presentation highlights that no matter how articulate she is, no matter how she “stories” her identity, people around seem just as able to craft compelling—to other people—narratives about what autism is, what it means, and therefore, who she is. She writes, “In my adult years, as I’ve struggled to locate a sense of identity, the idea of storying brings both comfort and distress. Autism is core to my very being. It’s how I sense, interact with others, and process information. But what’s at risk here is who tells my story and, more broadly, who tells the story of my people. What’s of concern is who gets to determine whether we are, in fact, narrative creatures, whether we are even allowed to call ourselves human.”

The conundrum Yergeau describes is not solely the province of autism: disabled identities of all kinds are often considered suspect, for lots of different reasons, and those disabled identities also intersect with other identities, identifications, and forms of privilege. My own identity as a disabled person is different from Yergeau’s, not only because we have different disabilities—I’m deaf, she’s autistic—but also because we differently navigate questions about when, where, why, and how our disabled identities are made perceptible, a term I have been using instead of the more-commonly employed visible/invisible binary (NOTE: I won’t go into detail on that term here but if it’s something people want to ask about during the Q&A, I’d be happy to elaborate).

I’m going to use the remainder of my time to briefly raise three questions about disability, identity, and perceptibility that have been preoccupying my thinking lately. These questions are also on the handout I’ve distributed.

**Question 1: When and how is my disability (identity) perceptible to others? When and how do I make my disability (identity) perceptible to others?**

Because I need people to behave and act differently around me than they do with most others in my everyday environments, I have to call attention to my disability all the time in all kinds of situations. In doing this work, I’ve also learned that in many cases it is in my best interest to
make perceptible the ways that I am asked to or have to put in efforts that others around me do not. For example, I am often asked to help make and coordinate interpreting arrangements, an additional layer of scheduling that my other colleagues do not experience. Making this apparent to others, rather than hiding it, is a way of ensuring that people not forget the ways in which my lived experience is not their lived experience. However, in today’s neoliberal climate for higher education, these differences of identity and experience are just as often co-opted as they are embraced and mobilized—a point Roderick Ferguson powerfully makes in his book *The Reorder of Things*, so the perceptibility of my disability is also potentially dangerous to me and my own sense of identity, as Yergeau eloquently points out.

**Question 2: Is it desirable to get to a place where disclosures are not necessary? Or just not important?**

People sometimes imagine a disability utopia where accommodations are the norm, the built environment is welcoming and amenable to all kinds of embodied differences, and overt disclosure—announcing that one has a disability—is not a requirement for participation. And yet, there are many ways in which disclosure, even in welcoming environments, is unavoidable. Let me illustrate with a quick example of sign language interpreting.

When measures are put in place without any consultation or interaction with actual disabled people (as happens far too frequently), often, those measures will fail to meet people’s needs. There is so much variation in deaf people’s fluency with sign language, their comfort with English, with lip reading, with ASL, that you can’t just find sign language interpreters—no matter how good they are—and put them in place for all events. Indeed, when events are advertised and there’s a small blurb about sign language interpreting being provided, I know that even if I go, I can’t guarantee that the style and type of interpreting will suit my preferences, and I often still email the organizers and ask about other kinds of accommodations, such as a printed script or detailed outline. [CUT for time: Here’s another example: in *Design Meets Disability*, Graham Pullin discusses a crucial tension between simplicity and universality—designs that can be adapted to suit all different kinds of bodies are also sometimes very complicated; simple designs that have limited functionality can sometimes be more accessible because they are easier to use.] The fact is that no organizer or environment can predict or anticipate every need. Thus, there’s a need to create flexibly and broadly, with access principles in mind, while at the same time working from a foundation in place that will help facilitate these access moves [NOTE: access as a way to move is a concept taken from Jay Dolmage’s work on access—see Dolmage, 2008 as well as his just-released book *Disability Rhetoric*].

The complexity of the interaction between an inaccessible built environment and the moves people make within those environments to enhance or amplify access also raise difficult questions about conflicting access needs (to take just one example: low light vs. brightly-lit spaces) and the different bodies who move in those spaces. Accessibility, as we have learned
over and over again, is not a set of rules or guidelines that can be put in place (although there are certainly ways we can have laws and regulations enforcing best practices).

Put another way, there is no way to completely eliminate the need for (some kinds of) disclosure in public spaces, and we must always be aware of the kinds of flexibility we demand, require, or ask of people in public spaces.

**Question 3: What are the moral and ethical issues that surround disability identity—and consequently, disability disclosure and (im)perceptibility?**

There are a lot of responses to this question. I will mention just one here as a starting point: there are ongoing questions about whether having one’s disability be more—rather than less—perceptible leads to productive change in one’s surroundings; about whether negotiating individual accommodations can also be a way of enacting needed broader structural changes. Choices about disclosure are made in very context-specific ways and are highly contingent on myriad factors affecting those decisions at every point of the process. For example, when Yergeau recognizes that being identified as autistic is both empowering and dis-empowering, the choice to make her autistic identity perceptible becomes fraught. The choices she makes about when, where, to whom, and in what situations to story her autistic identity are part of a never-ending process of disclosure characterized by questions about energy, short- and long-term investments, and degrees of knowledge.

Thank you.

**Works Cited**


