

Disability is Diversity: Challenging perceptions about disabled people and improving our experience in academia Karla Sosa1*

Please note: this is an account written from my personal experience. I do not aim to speak for all disabled people, as that would be impossible. Hopefully it will still provide a stepping stone or valuable insight. In strength, Karla

What is disability?

The Center for Disease Control and Prevention (CDC) defines disability as "any condition" of the body or mind (impairment) that makes it more difficult for the person with the condition to do certain activities (activity limitation) and interact with the world around them (participation restrictions). "2 While it is true that many of the conditions that cause impairment are based upon health conditions (e.g. loss of vision, diabetes, ADHD), a disability is not purely a health problem and is not something that can be 'cured'. What is more, the severity of impairment of a disability depends greatly on the social, cultural, and physical context in which a person is living. For example, if there were a society where everyone was deaf, the physical and social spaces would have developed to accommodate this and it would no longer pose a limitation to participation and inclusion in the community.

The value of disability

As biologists, we understand the importance of biological diversity—for example, it leads to more stable ecosystems and makes for more complex interactions. Biological diversity requires heterogeneous environments to thrive, as these provide more niches. The same could be said for human diversity. By creating environments that allow a diversity of people to thrive, we can make our communities flourish and become more resilient. However, society as it is currently structured only allows a subset of people to thrive: our physical and social spaces have developed to favour young, white, abled, cis, straight males from upper classes. The more of these categories one belongs to, the easier it is to thrive. As such, our work is to create environments that support the full range of human experience by actively creating "new niches," so to speak.

Disability, just like other axes of diversity, can bring valuable perspectives into our communities. We must shift our thinking from disability as being a hindrance or something negative that a person has to *overcome*, to instead thinking of it as a valuable part of their identity. In order for this change to happen, we need to talk about it. Disability is still an 'othering' thing, something that is hushed and hidden around euphemisms—by speaking candidly we can begin to challenge and change these perceptions.

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² https://www.cdc.gov/ncbddd/disabilityandhealth/disability.html (accessed Dec. 2020)

Ableism and its impact

Ableism defines people based on their disabilities and regards disabled people as inferior to able-bodied people. It is similar to other forms of discrimination such as racism or sexism, which often view one subset of a person's identity as their whole being. Ableism can influence interpersonal interactions as well as what disabled people are allowed to do or what resources they have access to. It is especially important to combat the notion that disability makes people "less valuable" or that they require additional assistance so they can come "closer to normal." Disabilities are simply part of the human experience—1 in 4 US adults have a disability!³

Furthermore, **no single aspect of a person fully defines them**. In some cases, parts of a person's identity that are easily identifiable or that we think are important to them may in fact not be central to their sense of self. For me, for example, it is not part of my core identity to identify as a woman, even though I am cis and femme presenting. My core identity is instead defined by being a disabled mestix immigrant. In contrast, other disabled people may not find their disability to be central to their lived experience.

³ https://www.cdc.gov/ncbddd/disabilityandhealth/infographic-disability-impacts-all.html (accessed Dec. 2020)

Managing disability: a personal account

Below is a compilation of techniques and advice from my personal experience managing post-concussion syndrome, diabetes (insulin resistance), and PTSD/depression.

- Be a self-advocate. This is an incredibly hard task in a society that will doubt your experience at every turn. Unfortunately, nobody can know your exact experience, and so you must speak up for yourself.
- When navigating school/professional environments, be aware of who will listen to your requests. As much as possible, find advocates in higher places.
- Listen to your body!! Do not push past your limits and do more than you can. Putting in more hours doesn't necessarily mean you'll get more work done, or produce better quality work. Your body is your true home and it should be cared for.
- Remember that everybody's path is different. All the knowledge you create is valuable, no
 matter how small. The pursuit of knowledge is not a competition (although academia is
 currently structured to be a competition, and this is something we must fight against).
- Build a community in which you can find support. Ableism will remain with us for some time
 yet, and it is valuable to have people that can be a source of strength and connection. This
 is especially true for graduate students, many of whom already find the nature of the grad
 school isolating.
- Notice patterns for how you are most productive, and try to incorporate these into other aspects of work. Some examples of things that have worked for me:
 - Writing on a Word document is hard, but emails are easier. Try doing your academic writing as emails to a friend.
 - It's easier to talk over scientific ideas than to get them on paper. Record yourself talking to someone about what you need to write, then transcribe it.
 - Reading and writing are more easily done on paper, and research is easier when using tangible things. Take notes and outline research approaches on paper.
 - It's easier to solve hard problems in a language other than the one you need to report in. Translate later.
 - Setting hard deadlines on a daily basis. For example: I need to work on data processing before 8pm. Force yourself to meet this deadline, even if it means only working on the task for 10 minutes on some days, and don't let yourself work on it afterwards.
- Also notice patterns of what you need on a daily basis to feel well. A few personal examples:
 - Needing to get 8h of uninterrupted sleep
 - Needing to take a nap during the day
 - Avoiding large meals/riding on the edge of hunger
 - Limiting screen time to 30min intervals
 - Allowing time to connect with friends/engage in hobbies
- You will mess up. Be kind to yourself.

Some classroom tips for instructors

I encourage you to start off your semester by establishing that you are interested in creating a space for inclusive learning, and to set up ways for students to provide suggestions and feedback (including anonymous avenues.) Below are a few additional suggestions:

- Make syllabus available ahead of time, clearly stating expectations and including a statement about accommodating disabilities. (And follow through with your commitment!)
- Present the same material in different forms. This could be as slides, as text, as drawings, as videos, as audio, etc.
- Realise that your experience is not the same as those of your students, nor are their
 experiences homogeneous. Do not expect them to know what you know; for some, their
 disability may mean they have reduced access to reliable sources of information or reduced
 recall of facts. Set up important statements with background knowledge. This will also help
 students from backgrounds different from your own.
- Create diverse assignments. This will benefit all students, as they will be challenged to step
 outside their comfort zone at some point or another, while also being able to feel
 comfortable in other tasks. This is especially valuable if the same learning goal can be
 addressed more than once through different approaches. Allow for diversity in assignment
 presentation (for example, accept handwritten assignments, or oral assignments.)
- For final projects, provide a range of possible options that accomplish the same goal. Some students may be more inclined to formulate large, overarching ideas, while others will prefer to look at patterns within local settings. Both of these are important scientific enterprises, and flexibility will allow people with different abilities to create meaningful work.
- These tips and practices may be more important for some students than for others:
 - Be willing to provide students with specific tasks. Especially for some neurodiverse people or some with mental health problems, concrete, accomplishable tasks may be essential in maintaining motivation.
 - Write out the agenda and learning objectives of the day so that students know what to expect.
 - Summarise key points at the end of the day.
 - When giving a prompt, write AND say it to the class.
 - o Schedule breaks into the class time. Attention span varies student to student.
 - Allot time to think and process material.
 - Provide pre- (or post-) lecture written notes and visuals, and recordings.
- Create accessible content (presentations, spreadsheets, documents). Some general suggestions:
 - Make text selectable so it can be used with text-to-speech tools.
 - Use clear headings to make document structure easy to follow.
 - Make the layout simple: minimum font size 12, left-aligned, pages numbered, non-serif fonts.
 - Ensure key images and diagrams have alternative text descriptions, and prefer multimedia with captions or transcripts.

Further reading:

Some scientists' perspectives on disability

- → What it feels like to be autistic, an interview with Temple Grandin https://www.youtube.com/watch?v=1qPFAT4p8Lc
- → NPR Interview with Geerat Vermeij, a blind scientist
 - http://www.npr.org/templates/story/story.php?storyId=4665906
- → What I've learned from my learning disabilities, by Collin R. Diedrich https://www.sciencemag.org/careers/2017/10/what-ive-learned-my-learning-disabilities

Reading for disabled students

- → UK resources including personal stories from students with different disabilities:
 - https://www.disabilityrightsuk.org/sites/default/files/pdf/IntoHE2017.pdf https://www.kent.ac.uk/studentsupport/disabilities/
- → Self-advocacy resources for North Carolina:
 - http://www.disabilityrightsnc.org/education-postsecondary-self-advocacy-resources
- → Time management strategies:
 - http://dyslexiahelp.umich.edu/tools/tips-organization-time-management
- → Executive function problems:
 - http://dyslexiahelp.umich.edu/professionals/dyslexia-school/executive-function-disorders
- → Disability in the classroom:
 - https://www.heath.gwu.edu/students-disabilities-college-classroom

Reading for instructors

- → Common problems as well as specific accommodation suggestions for autism, hearing, mobility, mental health, and visual disabilities:
 - https://www.kent.ac.uk/studentsupport/accessibility/requirements.html
- → Limitations and accommodation suggestions for psychiatric disabilities:
 - http://www.washington.edu/doit/academic-accommodations-students-psychiatric-disabilities
- → Further strategies for creating an inclusive classroom:
 - https://www.kent.ac.uk/studentsupport/accessibility/inclusive-practice.html https://cft.vanderbilt.edu/guides-sub-pages/disabilities/
- → Creating accessible content:
 - https://www.kent.ac.uk/studentsupport/accessibility/accessible-resources.html