Magnifying the Voices of Disabled Scientists and Reimagining an Inclusive Scientific Field

Art from Vasquez 2022

Maisie Smith

What is Science?

Science can be broadly described as the process of working to understand the natural world (Hogan and O'Flaherty 2022). The scientific process can take many forms including making observations, running experiments, and creating theories. Science also spans across disciplines including physics, chemistry, biology, and astronomy. Across these fields scientific knowledge represents a cumulative body of knowledge that is built from across disciplines, times, and communities of scientists. How people interact with and interpret this body of knowledge varies and will continue to change over time as new experiments and observations change how scientists think of the world.

The encompassing nature of science has allowed us to make amazing advances in how we understand ourselves and our world. This has in turn changed how we interact with our world and ourselves. From things like the weather reports, clocks, and infrastructure, to cell phones and antibiotics almost everything that makes up our lives has been touched by science. Science also has a large role in informing public policy, health decisions, economics, agriculture, and transportation. Therefore, it is crucial to consider whose voices are allowed to take part in science and who is excluded from it.



- Krystal Vasquez (2022)

Art from https://clipartix.com/.

How the scientific community discriminates against disabled individuals

Despite its tremendous role and promise, science is often limited, by the scientific community, to only include individuals with the resources, time, and support necessary to have a scientific career. This means that despite the countless perspectives and skills that disabled individuals can bring to science, the scientific community discriminates against disabled individuals.

There are many ways that the scientific field has prevented disabled scientists from contributing to the discipline. This includes exclusionary acceptance practices, inaccessible laboratory spaces, and inaccessible writing. It is also ingrained in the ethos of science which is built in a sink-or-swim attitude. In this mentality, it is expected that experiments are done at a relentless pace and that scientists commit their entire selves to the research process and their career. This leaves little space or time to be a full person. These practices keep scientific knowledge and the ability to participate in scientific inquiry in an ivory tower, excluding disabled individuals.

3

This discrimination against disabled scientists has resulted in a scientific workforce that does not resemble the general population. Whereas disabled people make up 27% of the United States adult population, representing the largest minority population in the United States, disabled scientists only represent 9% of the scientific workforce (D'Amico 2023). With only 2% of NIH funded scientific researchers being disabled. Additionally, individuals with multiple marginalized identities face additional challenges and discrimination based on these identities.

This is a detriment to science as the unique and diverse perspectives of disabled scientists can change science. Overall, it is important to change how science is conducted and to magnify the voices of disabled scientists.

Disabled Scientists

In this work I highlight two disabled scientists Dr. Emily Ackerman and Dr. Amy Bower. Dr. Ackerman is an early career researcher performing systems biology research as a Postdoctoral researcher in the Lahav laboratory in the Systems Biology Department in Harvard Medical School (Emily Ackerman n.d.). While Dr. Bower is an Oceanographer in the Department of Physical Oceanography at the Woods Hole Oceanographic Institution and the Chair of the Department of Physical Oceanography there (Amy Bower n.d.). Both, have worked to make science a more accessible field and have done extensive advocacy work for disabled scientists.

Dr. Emily Ackerman

At 16 Dr. Ackerman thought: "Hey, math sounds like a good thing to commit to. Math will always be there for you.' And math is in everything. It's all around us like ghosts who make sense and have our back" (Allie Ward and Emily Ackerman 2022).

On right, stylized photo of Dr. Ackerman in blue, red, and yellow in her wheelchair with biology symbols, connected in white in the background. At the bottom it says "Emily Ackerman" in white font over a navy-blue background.

(Photo adapted from Emily Ackerman's website, background adapted from <u>https://www.frontiersin.org/research-topics/11935/application-of-systems-biology-in-molecular-characterization-and-diagnosis-of-cancer</u>, created in PhotoRoom and BeFunky Photo Editor)



Dr. Emily Ackerman's Career

Dr. Emily Ackerman is a chemical engineer and a systems biologist. Currently, she is a Postdoctoral researcher in the Lahav laboratory in the Systems Biology Department in Harvard Medical School (Emily Ackerman n.d.). She received her Bachelors degree from Rensselaer Polytechnic Institute in 2015 and her Doctorate in Chemical Engineering in 2021 from the University of Pittsburgh. Her main research interests are developing computational methods to understand how the tumor suppressor protein (p53) dynamics influence cell fate. Her recent work has focused on predicting biologically relevant protein candidates for SARS-CoV-2 (Covid-19) drug positioning. She has also worked on virus-host, protein-protein interactions by examining the immune response to influenza infection. The goal of this research broadly is to understand these networks to discover antiviral drug targets. Furthermore, she has also researched how technology impacts the disabled community by looking at how automated machines impact disabled individuals using sidewalks. Throughout her career she has also been an advocate for the Queer community and the disabled community.

Experience in Science

Dr. Ackerman describes systems biology as the "Frankenstein of biology" (Allie Ward and Emily Ackerman 2022). In which scientists invent algorithms and make models to understand the huge amount of data that represents biological systems. The goal of systems biology is to get a new picture of what is happening that you would not be able to get from running a wet-lab experiment. Her work captures how the scientific community's process of understanding viruses should include the people most impacted by these diseases, which often is the disabled community.

Dr. Ackerman's love of biology and the natural sciences was influenced in part due to her disability as she found that by having a disability and medical conditions, she always found how bodies are different and how they work to be very interesting. However, as a disabled person she feared, similar to many disabled students, that science, technology, engineering, and math (STEM) were not for her. This idea is built on the idea that STEM can be very physically demanding. But beyond the physical restrictions, STEM culture is focused on proving your worth as a scientist by working long hours and devoting yourself completely, which at its core means devoting your physical energy and body. Dr. Ackerman has had to work and continues to work to fight this mentality as "you can't do the science if your body's not there" (Allie Ward and Emily Ackerman 2022). For Dr. Ackerman this means fighting this pervasive mentality and if needed asking for accommodations, changing your schedule to work with your body, and making space for your entire self to be present.

In college, Dr. Ackerman did not have any disabled scientists as mentors and found it challenging to see how she could conduct research like her peers. This changed when she was introduced to computational research by Dr. Curt Breneman, leading her to pursue computational chemistry research. This changed her career direction as it showed her that "Wait, I can do that" (Allie Ward and Emily Ackerman 2022).

From her experience she has become a disability advocate in science research, becoming a part of the "Board of Directors of Future of Research," speaking at disability conferences, and writing papers focused on the intersection of disability and technology.

Overall, Dr. Ackerman has had valuable contributions to systems biology, cancer, and viral research, while also improving the field of science by helping to create a more accessible and inclusive field. It is exciting to see how much she will change the field in years to come! "You can't do the science if your body's not there" -Emily Ackerman

(Allie Ward and Emily Ackerman 2022).



Dr. Amy Bower

"I find it so interesting that the object of my research is mostly invisible. No one, sighted or not, can "see" ocean currents below the surface... So how do we find out what's 'going on down there?' We use sound." (Amy Bower, "Sound for Science" 2018).

Image on left is a stylized photo of Dr. Bower in purple, yellow, and red. "Amy Bower" is written in white down the left. The background is a blue and white blurred graph.

Image adapted from Amy Bower's website OceanInsights (2023) and the background is from Zou et al. 2023. Created in PhotoRoom and BeFunky Photo Edito.¹¹

Dr. Amy Bower's Career

Dr. Amy Bower is an Oceanographer in the Department of Physical Oceanography at the Woods Hole Oceanographic Institution and the Chair of the Department of Physical Oceanography there (Amy Bower n.d.). She completed her Bachelor of Science in Physics at Tufts University and her PhD in Oceanography at the University of Rhode Island. Dr. Bower also has macular degeneration and retinitis pigmentosa (RP) and is legally blind.

So, what is an oceanographer? An oceanographer is a scientist who studies everything about the ocean. Including examining the physical characteristics of the water and the living, biotic factors of the plants and animals. As an oceanographer she studies the structures and dynamics of the ocean currents. Specifically, she studies the boundary currents which flow along the edges of the ocean basins and deep mesoscale eddies, which are swirling masses of water. She has also worked extensively to advocate for blind scientists and expand people's perspectives about what blind people can do. One way that she does this is through sharing with blind students and researchers about the different assistive technology that helps her to complete her research.

Experience in Science

When Dr. Bower was diagnosed with Macular Degeneration, she was told by her doctor that she should consider leaving science to become a scientific assistant or secretary instead (Amy Bower n.d.). He said this as he could not imagine what a blind scientist would look like or how they could be successful. This was heartbreaking to her and only after working with other doctors on using and creating adaptive technology, which would help her throughout her scientific career, did she again see how she could be a part of science.

Ever since then, she has worked to change the narrative of what it means to be blind to encourage other blind and visually impaired youth to pursue their passion and change how science accommodates for and accepts disabled scientists. Part of her advocacy and outreach efforts include creating Ocean Insights, an outreach program for blind and visually impaired learners. This program aims to create accessible content to share the exciting oceanographic research with the visually impaired and blind community. This has even led her on an ambitious project to work with a team of researchers to map out visual information, like charts and graphs and ocean phenomenon, through sounds (Randy Showstack 2021). Through this project which uses "data sonification" she hopes to broaden the accessibility of her research and of science communication in general. To do this, she has worked with scientists, teachers, and visually-impaired students to get the feedback necessary to determine how best to map out the data.

As a part of Ocean Insights, she also focuses on introducing careers in geoscience to students who are blind or visually impaired. To do this she has worked closely with educators and students at the Perkins School for the Bind to engage the students in scientific research (Amy Bower n.d.).

Her work and advocacy shows how disabled scientists are leading the way in creating a more accessible and equitable scientific discipline. She has also shown a new way to do science in which scientists are able to bring their entire selves to science and are able to have the assistance necessary to perform their innovative research.

Methods to Make Labs More Accessible

These scientists as well as many other disabled scientists have shown that science can be accessible if the scientific community is willing to put in the effort. To do this it is crucial to stop the discriminatory hiring and promotion practices that harm disabled scientists. There are so many ways that science needs to be made more accessible, but some major ways that this can occur is through changing the culture of science, changing physical lab spaces, and providing accommodations for disabled scientists. These changes will both support disabled scientists but also all of science.

1. Change science culture to prioritize full people.

The culture of science must change to prioritize allowing everyone to bring their full selves to science. This means creating a culture where scientists at all levels are expected to have outside passions and needs. It also means being able to go at your own speed; prioritize mental and physical health; celebrate differences; acknowledge institutional power and privilege; and create a culture of collective responsibility: where people are responsible for their actions and respecting one another. It also means changing the hierarchy of science to allow all voices to be heard and to impower young scientists. 2. Making accessible lab spaces.

Science labs are notoriously inaccessible. This needs to change and go beyond The Americans with Disabilities Act (ADA) standards to create spaces where disabled scientists can thrive. It is important for all labs to know the needs of scientists in their lab and to find ways to adapt their labs to these needs.

Lab spaces should have (some ideas from D'Amico 2023):

Wheelchair accessible benches, hoods, and appliances

Accessible safety equipment

Large and clear print

Make lab equipment as hands free as possible

Take advantages of accessible software tools

Visual and auditory graphs and resources

These steps have been implemented in labs like Accessible Biomedical Immersion Laboratory (ABIL) (Institute of Accessible Science n.d.).

Additionally, making accessible lab spaces also means providing accommodations such as additional support personnel for disabled scientists, such as interpreters or technology assistance.

Accessible Science Tools









Accessible sink with modified handle (Institute of Accessible Science n.d.). Lower hood with accessible knobs (Institute of Accessible Science n.d.).

Accessible benches and layout (Institute of Accessible Science n.d.). 3-D Model of
the North
Atlantic Ocean.
(Amy Bower
2019) 17

Sources

Allie Ward and Emily Ackerman. n.d. "Systems Biology (MEDICAL MATHEMATICS)." Online. Ologies. Accessed May 4, 2023. https://www.alieward.com/ologies/systemsbiology.

Amy Bower. 2018. "Sound for Science." OceanInsight. June 17, 2018. https://web.whoi.edu/oceaninsight/sound-for-science/.

---. 2019. "An Exciting Day of Science for Perkins Outreach and WHOI." OceanInsight (blog). June 13, 2019. https://web.whoi.edu/oceaninsight/an-exciting-day-of-science-for-perkins-outreach-and-whoi/.

----. 2023. "About Amy Bower." OceanInsight. 2023. https://web.whoi.edu/oceaninsight/about-amy-bower/.

D'Amico, Dana. 2023. "How Accessible Labs Can Support Scientists with Disabilities." Life in the Lab. April 7, 2023. https://www.thermofisher.com/blog/life-in-the-lab/how-accessible-labs-can-support-scientists-with-disabilities/.

Emily Ackerman. n.d. "Emily E. Ackerman." Private. Emily Ackerman. Accessed May 4, 2023. https://www.emilyeackerman.com/.

Hogan, Deirdre, and Joanne O'Flaherty. 2022. "Exploring the Nature and Culture of Science as an Academic Discipline: Implications for the Integration of Education for Sustainable Development." International Journal of Sustainability in Higher Education 23 (8): 120–47. https://doi.org/10.1108/IJSHE-06-2021-0236.

Institute of Accessible Science. n.d. "Accessible Biomedical Immersion Laboratory (ABIL)." STEMEd Hub. Accessed May 4, 2023. https://stemedhub.org/groups/iashub/abil.

Randy Showstack. 2021. "Accessible Oceans: Making Marine Science Available to the Visually-Impaired." Oceanus: The journal of our ocean science. Https://Www.Whoi.Edu/ (blog). October 31, 2021. https://www.whoi.edu/oceanus/feature/accessible-oceans/.

Vasquez, Krystal. 2022. "Disabled Scientists Excluded from the Lab." Chemistry World. December 2022. https://www.chemistryworld.com/opinion/disabled-scientists-excluded-from-the-lab/4012695.article.

Zou, Sijia, Amy S. Bower, M. Susan Lozier, and Heather H. Furey. 2023. "Deep Ocean Circulation in the Subpolar North Atlantic Observed by Acoustically-Tracked Floats." Progress in Oceanography 211 (February): 102975. https://doi.org/10.1016/j.pocean.2023.102975.