VIDEO TRANSCRIPT

Exploring Difference in the Biology Classroom - Engaging with Genetic Disability and Difference

Link to video.

[**Rob O'Malley**]: Hello, everyone. I am Dr. Rob O'Malley of the Personal Genetics Education Project, or PGED. My pronouns are he and him, and in support of accessibility, I will provide a physical description. I am a middle-aged white man with light gray hair and a goatee in a light green shirt.

Based in the Department of Genetics at Harvard Medical School, PGED supports inclusive and impactful engagement about genetics. On behalf of PGED and our collaborators at the Center for ELSI Resources and Analysis, or CERA, and our invited speakers, it is my pleasure to welcome you to today's program. PGED strives to support genetics engagement that is people-centered, inclusive, and multidirectional.

We seek to empower individuals and communities to share and learn from each other, to advocate for themselves in decision-making, and to enrich science as a whole, including in the practice and the translation of research, in science education, in public discourse, and in policy.

And educators have been our long -standing and valued allies in this work. That is why we are particularly excited to be partnering with CERA to bring you today's program, the second of a four-part webinar series on exploring difference in the biology classroom.

The first event is viewable online at ELSIhub.org, E -L -S -I -H -U -B .org, on representing wide-ranging family structures and personal identities using the latest pedigree nomenclature.

Today's session is on engaging with genetic disability and difference. We will discuss how language and biology and medicine can frame disability as a deviation from what is normal, acceptable, and welcome and how some terms can reinforce assumptions that disabled people are less capable, less valuable in society, and less independent compared to people without disabilities.

Reflecting on what ideas or messages we are sharing in describing biological difference is an important step towards addressing barriers to student engagement, preventing potential harms, and creating more inclusive classrooms.

We know that this is a challenging time to be a teacher for many reasons. Among them, it is a demanding task to keep up with constantly evolving language, approaches, and material, particularly when it involves how we talk about people.

Accordingly, we greatly value your choosing to spend some time with us today. We hope today's session will provide a useful framework to support inclusive pedagogy around disability and difference to you in classrooms and in more informal learning contexts. Thank you again for joining us.

With that, I will hand things over to Dr. Mildred Cho to share about CERA, share some housekeeping and a code of conduct for our time together and to introduce the speakers.

[**Mildred Cho**]: Thank you, Rob. Good afternoon or evening or even morning, depending on which part of the world you are zooming in from today. I'm Mildred Cho and I will generously describe myself as middle-aged and also with gray hair.

My background is actually showing a beautiful scene taken from a photo that I took at Big Sur, California. I'm delighted to welcome you to the second ELSI Conversations event of the PGED and CERA collaboration series, which is in "Engaging with Genetic Disability and Difference." We're glad you'll spend the hour with us.

This session will run for one hour, but after this session ends, we invite you to stay for an optional discussion from 7 to 7:30 p.m. Eastern Time on classroom integration strategies facilitated by PGED. If you're interested and available to stay on for this session, please stay on this Zoom link.

So, in this session today, we'll hear from two presenters. First, Dr. Kara Ayers, Associate Professor and Associate Director at the University of Cincinnati Center for Excellence in Developmental Disabilities at the Cincinnati Children's Hospital Medical Center. And Dr. Joel Michael Reynolds, Assistant Professor of Philosophy and disability studies at Georgetown University. He's also senior bioethics advisor and fellow at the Hastings Center and faculty scholar at the Greenwald Foundation.

The last half hour of this main session will be retained for audience Q&A. For those of you who may be new to CERA, we provide resources to support research on the ethical, legal, and social implications of genetics and genomics, and serve to connect scholars, educators, scientists, policymakers, journalists, members of the public, and others to engage in these ELSI issues.

CERA is funded by the National Human Genome Research Institute at NIH and is managed by teams at Stanford and Columbia universities in partnership with the Hastings Center and the PGED team at Harvard University.

We encourage you to join the CERA mailing list to stay up to date on future events in this series, as well as other ELSI conversations and access the resources that will be mentioned in today's session. The link to that will be dropped in the chat. And note that all links mentioned in today's session, including the speaker and moderator biographies, will be linked in the chat. A PDF of the combined slide decks that you'll see here today can also be found in the chat box. So finally, just a bit of housekeeping.

The session will be recorded and uploaded to ELSIhub.org. You'll be able to access the recording after the session ends by signing up for the CERA newsletter where the link to the recording will be distributed in the post-event email or by visiting the exploring difference in the biology classroom page on ELSIhub.org.

We have a professional live captioner present today to provide captions for today's session. Please use the CC button at the bottom of the screen to access closed captioning if you'd like.

Please note that if you do not activate the closed captioning at the bottom of your screen, the live captions will not be present, although they are available. Please use the chat box to ask questions.

We'll post links to references in the chat and feel free to add your own. A recording of the session and all references will be available on ELSIhub.org. If you have questions during this session, you can also email info@elsihub.org. Okay, so with all that, let's just hand it over to the speakers, Dr. Kara Ayers and Dr. Joel Michael Reynolds. So Kara, please take it away.

[**Kara Ayers**]: Thank you so much. So, I am a white woman with shoulder-length brown hair. I'm wearing glasses and a red top.

And my virtual background showcases a green tree that I wish I had, but I have a kitten that does not cooperate with greenery like that. And while you can't see it in my Zoom screen, I'm seated in a manual wheelchair today and I will integrate my personal identity as a disabled person today, as well as my work as a researcher and someone who studies these issues that we're going to talk about.

So I am excited to be with you today. I come from a long line of educators. I'm actually the outlier that I am not a more traditional teacher, although my title says I'm a professor, but I'm not in the classroom every day. So I'm excited to be with many of you all who are. I'm going to share my screen and please let me know if you cannot see it.

I'm going to assume that you can unless you tell me otherwise. On this first screen, I have my disclosures and most of these were not in my introduction. The majority of my work is funded federally by the Administration in Community Living, but I don't anticipate that any of my roles listed here will be a conflict of interest tonight. So it is my hope that in the next few minutes that I'm going to encourage you to think differently about the way that you see disability.

So on this slide I have a pair of glasses illustrated and also some questions, like where does disability reside and who decides its meaning and what are the main barriers for disabled people?

So we're gonna think through these questions for a few minutes tonight, but I also think that I hope that you will take these questions and questions like these after tonight and see the different ways that they come up in your classroom, in your own thinking, in the way that disability is represented in ourselves and society. And I think you'll begin to realize that disability is much less about medical or genetic status and much more about social status and power differentials in our society.

So one point of this issue that I want to discuss is the language that you use around disability. And so we know that words have power, and I've actually been really fascinated by the way that our word choice around disability evolves over time. I see this as a great thing. I know some people are frustrated and some people say, just tell me what to say. But it is a great thing that we think about this, that we have different opinions, and that these opinions change over time. It is important that we're intentional and informed about the language that we use about disability.

On this slide, I have a QR code and this along with other references are in my resources that I'll share at the end. So don't feel like you have to get this now. You'll have another opportunity.

But this particular article that I published along with some colleagues relates to the two main approaches to talking about disability that you may have heard kind of termed And so these are identity first and person first languages.

And so, er, person first language approaches, they're not different languages. So the first thing I want to say about this slide where there's an illustration using a puzzle piece is that the puzzle piece itself is a controversial graphic illustration of disability.

I decided to use this in my presentation tonight because this illustration was created by an autistic person, but I wanted to point out that largely the puzzle pieces is not, I'd say, consistently embraced by the community. So I usually do not use it in kind of external communications about disability, but in this case I thought that it made an interesting kind of visual for this comparison.

So in identity first language, we would say, “autistic person”. Whereas person first language, we would say person with Down syndrome or person with a disability.

My disability is osteogenesis imperfecta. And so interestingly, my disability is fairly medicalized. It's characterized by bones that break easily.

And so there are some cases where people refer themselves as an OI-er, but it's generally pretty distanced and that most people say I'm a person with osteogenesis imperfecta.

It wasn't until several years ago that a friend and colleague of mine said, Why do you keep introducing yourself as a person with a disability. And I thought at that point that that was kind of what you're supposed to do.

I know that that person first language is very much emphasized in a lot of kind of formal training about disability etiquette. But this person said to me, well, you would never say that you're a person who happens to be a woman or a person who is a woman, would you? And I had not ever thought about the implicit messages that distancing disability as a part of my identity sent. And so for myself, I prefer to identify as a disabled woman.

Sometimes I even try to emphasize that as being intentional by saying, that I'm a proud disabled woman. And even with those efforts to kind of signal that I am being intentional in the way that I speak about this, I still get replies from editors and from other scholars in various fields that say, “Oh, you must have made a mistake. You must not be aware of person first language. You need to correct your bio to say that you're a person with osteogenesis imperfecta or a person with a disability.”

Um, course, there are lots of problems with this and telling someone else how to identify, but it also speaks to the importance of understanding the history of how different approaches come about.

Person first language is largely credited to an advocate who's a parent, a non-disabled parent of a person with a disability. Kathy Snow is her name and she has a wide range of resources, Many of which are I think useful in characterizing disability as a natural part of existence, whether it be in, you know, animals, people, nature, disability is natural, is one of her kind of sayings.

People really enjoy person first too, because it comes with a very straightforward, like, do -don't -table list of things. And I think that if you're new to disability, that level of concrete, do this, don't do that. can be helpful.

Identity first is often credited by being led and pushed through by autistic people and the autistic self-advocacy movement itself.

So there in itself is a major difference in terms of who leads and who starts a movement and that really matters. In my article that I talked about in the previous slide, we do mention the importance of validating both and other and future approaches to language. I've worked with many people with intellectual disabilities who advocating for person first language is a bridge into their own disability identity and to advocacy in a wide range of other things.

And so it is not up to me to invalidate either of these approaches, but I just hope that you'll leave this discussion um more informed about both is the goal.

I often tell my students that if you aren't sure, follow someone else's lead, and that, of course, slurs are not encouraged by either approach.

I grew up in Kentucky and had more than one person refer to me as “that little crippled girl”, and I am quite assured that they were not doing that from like a point of pride and, you know, reclaiming the word crippled, so it all depends on context as well.

I do want to leave you with kind of like one similar similarity across both is just saying the word disabled or disability so whichever approach you use don't avoid this word don't use euphemisms differently abled is not acceptable there's no history culture attached to that and I know that in education is can be really challenging to try to move away from special needs, but I would really encourage you to try to model and do that in as many places as you can. I know that you would be going against the tide there or the current in education, but again, there's no history related to special needs, no culture, no identity, and you know, denoting someone's needs as special when they really relate to similar needs, you know, as a right to education and equity is also not helpful or accurate.

So I have a little illustration here with a placard that says check out hashtag say the word. You can search for that hashtag on platforms like Twitter or Instagram, and you can see just a rich discussion led by disabled advocates about why it is so important to just say the word, and how many times it seems simple, but it is not done.

I also really wanna encourage you to be aware of language outside of your classroom and how that matters. Modeling, respectful, and culturally competent discussion of disability is so essential. I have three kids, 6, 12, and 15. We just had a birthday this week 'cause I had to remember. And they keep me on my toes about what language usage about disability is kind of up and coming, whether we are happy about it or not.

And while we've seemed to have made a lot of progress in decreasing the R word slur or retarded, unfortunately, you know, I'm hearing from my middle and high schoolers that it's replaced with the same usage intent, but with slurs like that's so autistic, or that's so special. And so we really see this devaluing of disability used in different slur choices, but I want you to be aware of that and push back against that just as I would hope you would do related to other slurs.

I also want you to think of how you describe barriers connected to disability, really moving your way of thought more to what we would, as disability scholars, call a social model of disability.

So instead of she can't get into the building because she's in a wheelchair, I'm in a wheelchair, I get into buildings all the time, the more accurate and in this case and helpful with our goal in mind portrayal this is she can't get in the building because it's not accessible.

So it makes it clear where the onus of the barrier lies. And specific to the field of genetics instead of saying or thinking, the field of genetics can help us prevent future generations of disability, which comes with all sorts of assumptions, we can think that the field or fields of genetics can help us understand more about disability, which is a much more objective scientific portrayal of what the range of our goals may be.

Anyways, this is a picture of my family. So, the three kids that I mentioned, I have, um, my two daughters are biological. My son has achondroplasia, and my husband and I have OI, oh and that’s our dog rocky. So we have a lot of genetic diversity going on here.

And it's interesting to me what assumptions folks have, people saying things like, oh, you must have been so happy or you're so lucky that your daughters didn't get it. And so I think genetic inheritance of disability is complex and personal and nuanced.

And being aware that people take these leaps to assumption without knowing someone's personal view, and for what it's worth, we are extraordinarily happy that each of our kids is exactly who they were meant to be.

And we don't feel-- any more lucky that our kids do not have OI than Eli has achondroplasia, as genetics are, to us you know, a flip of coins.

So we don't so much place luck or valuing or devaluing associated with that.

I want to leave you with a definition by T. L. Lewis, who is a scholar that I very much admire in the way that T. L. for many reasons, but also in way that TL defines ableism by connecting these ideas as deeply rooted in anti -blackness, eugenics, colonialism, and capitalism.

And so recognizing that this form of systemic oppression leads to people and society determining who is valuable and worthy based on a person's appearance and /or their ability to satisfactorily produce, reproduce, excel, and “behave”. An important note about TL's definition is that you do not have to be disabled to experience ableism. So we are all better off by working together towards anti-ableism.

We're all harmed by ableism and I think that can help in characterizing the importance of this goal that I hope you'll adopt or continue in anti-ableist work because it's really not just for a few of us who have disabilities, it's for all of us.

So on this slide, I have a few strategies. I'm just gonna read the highlights of passing the microphone to amplify disabled voices, doing your own work to unlearn ableism then incorporating that in the classroom, in trainings, and seeing advocacy really as an obligation that you'll help dismantle ableism through your work.

Another term that may be new to you is disability justice and this isn't just a synonym for disability rights or you know fairness related to disability it's actually guided by principles as defined by a group called Sins Invalid, but I really appreciate their work and that it connects our anti-abelist and anti-racist work. And it really lets us look to people of color with disabilities as leaders of this movement who can really help us see the intersection of racism and ableism.

So there are additional strategies not only here about sharing power equitably, but also last, I would just encourage you to curate your own media. We have a lack of disability representation in our lives every day in media in various forms, and one way you can push back against that is to make sure that you have more representation in your different places you see media.

So this QR code, which is also in your resources, gives you a place to start with books and accounts to follow, and I hope that you will also feel free to add your own in the chat box tonight. I look forward to your questions on this.

Thank you.

[**Joel Reynolds**]: Am I supposed to just start going?

[**Rob**]: Yes, please go ahead.

[**Kara**] Sorry. - So sorry, Joel. You're up.

[**Joel**]: No problem, no problem. So let me just first of all make sure that you can see my slides.

Is this looking okay? Can everyone see me and the slides correctly? Okay, awesome.

First of all, it's a real pleasure to be here. Thanks so much. It was wonderful to hear from Dr. Ayers.

First, I want to just always give a shout out to my colleagues and staff and students at the different places I work and advise for. And a quick mention, I received funding from the Greenwall Foundation, which is a bioethics foundation, but I don't have any conflicts of interest to disclose, except of course my undying love for my adorable miniature dachshund pictured here looking up at me after editing a paper of mine that he clearly didn't like that he shredded it into pieces. His name is Schnerp, S -C -H -N -E -R -P.

Also, very quickly, thanks to my family and the many caregivers who have been part of my life and my family member's life. Really, all of my work is a way of thinking through our communal disability experiences together. I'd like to begin with a quote from a book that came out in 2016 called "The Minority Body: A Theory of Disability." It's by Professor Elizabeth Barnes, who teaches philosophy at I think the University of Virginia. Can't remember now. Anyway, the quote says there is nothing about what disabled bodies are like that by itself unifies or explains the category of disability.

Depending upon what your background has been like, you might find this to be implausible. If you are like me or like the general population of most people on earth, you would have been taught as a kid that to be disabled involves something being wrong. And what unifies disability as a concept and experiences of disability is dealing with something being wrong with ones individual body.

And of course, this is one way of explaining differences that we categorize as disabilities, differences that arise from certain sorts of genetic variations.

Barnes, however, thinks that that's just an indefensible view. There's not only is it not true that all disabilities involve something being wrong or even different with one's body, there's literally nothing that unifies the category because disability is simply too complex, too heterogeneous for any one explanation of it.

And Barnes's work, there's going to be a little repetition here from Dr. Ayers fantastic talk, Barnes's work is in conversation with but not identical to the very famous distinction in disability activism and also in disability studies, between what is called the medical model and the social model of disability.

There's actually social models, plural, how people define this as complicated, but I'm giving just the kind of 101 version of this today. On a medical model, it's what I mentioned a second ago. It's this idea that what disability is, is, a term that references some individual tragedy or misfortune, maybe due to genetic causes, maybe due to something that happened over the course of a life, you name it.

On a social model, however, disability means something quite different. The word disability or the concept refers to the negative effects caused by societal responses, by the built environment, by you name it, too impairments.

Now you might notice immediately that a new concept has been introduced here, namely the concept of impairment. And it is crucial in the social model that there is still an understanding of difference, of bodily and mental difference. The concept of impairment refers to atypicalities, you could even say abnormalities of one's body and mind. But impairments don't explain the experience of disability because disability refers again to how people respond.

Now with this distinction in mind between disability and impairment, you can immediately start to imagine, well, okay, yeah, if to use the, uh I'll return to this example in a moment, and if someone can't get into a building because the way it's been built, the way it's been organized, doesn't allow someone using certain mobility devices, what is disabling them in that moment is architecture, right? It's not a fact of their body that keeps them, not a fact of their body in and of itself that keeps them from entering that space.

When people learn this though, there is a reflex and I think it's a quite natural one to say, but aren't certain impairments bad in and of themselves?

Or, even if it's true that impairments are neutral with regard to well -being, don't certain differences just make your life harder? And this idea that even if one has a social -model understanding, there's still going to be a causal relationship between being disabled and having a lower quality of life. This is something that shows up in general when you do studies on kind of general populations, their judgments concerning disability, you'll see this assumption popping up. You even see this assumption in spaces where people should have the expertise to know that it's false.

Here's an example. The study came out in 2021 by Lisa Izzoni at Harvard, who did a study of 756 practicing physicians in the United States.

And at one point they were asked what the relationship is between disability and quality of life. The study actually specified significant disability and quality of life. Over 80% of these physicians reported that people with significant disability have a lower quality of life.

The reason that's a problem is that is false. And we've known that that's false. We've had all sorts of social scientific studies for well over three decades.

People with disabilities, including significant disabilities, on the whole report similar levels of quality of life. Yes, there are certain disability subtypes where the quality of life will be lower, but we're still going to have an aggregate similarity in terms of, we could say, something like a life worth living. This is really worrisome.

And this study,I think there are social scientists in sociology, there's also people in psychology who have done this with different groups, and this seems to just pop up over and over and over again.

People mistakenly think that disability, even if understood in a social model, will still lower one's quality of life. Well, what's an explanation for this? Why does this misunderstanding keep, why is it so persistent?

One explanation, and this again ties into what Dr. Ayers just presented, one explanation that comes from research and critical disability studies and other pockets says that, well, part of what's going on here is ableism. It is an assumption that a normal, in quotation marks, a standard able body is just in and of itself better than non-standard or abnormal forms.

All other things being equal, you want the hypothetical healthy newborn, and that will mean someone's life is actually going to go well. And note that this ableist idea, when people first learn about this concept or even some who've thought about it a bit, it's very easy to get hung up on the idea that ableism is just about bias and what a particular individual thinks.

And that's not true. That is a component of ableism, but you can also, and it's very easy to identify ableism at the level of social structures, ableism at the level of the way the built environment is set up, the way practices and institutions are arranged, organized, and the way they function.

And so I just always, whenever talking about ableism, I want to highlight that it's always a mistake to merely reduce it to questions of individual bias, cognition, judgment, et cetera. It's also about how the world is set up.

Now, you'll note that-- let me slow this down just a bit. You'll note that ableism might seem a very plausible thing to think if one does not have a lot of knowledge about how disabled people of various sorts live their lives and how they find their lives.

So let me give you a few examples of what one can learn by taking the testimony of disabled people and disabled groups seriously. Here's a really important and pivotal example, and I think this is one that can be used quite explicitly, especially in a biology classroom. One might think that congenital deafness is something that is a defect, a deficit. It is a variation that is not merely a difference, but something that is bad and is bad precisely and so far as one is unable to hear. That is, for example, what I was taught as a kid.

If you actually talk with people who are deaf, there are a number of them, not all of them, but there are many, many deaf people who do not understand deafness in terms of loss, in terms of not being able to hear. They understand deafness in terms of the ability to communicate with other people who use the same form of communication, whether American Sign Language, ASL, British Sign Language, BSL, whatever it might be.

On this view, to understand deafness in terms of audiological loss, and as some sort of deficit or defect, fundamentally misunderstands, the experience of deafness for many, many deaf people across the world.

Now, there will still be some, let's say, difficulties that come along with deafness in so far as most of the world is set up for those who are hearing, but that just further reinforces an understanding of the social model that further demonstrates that thinking about disability as merely a property or feature or characteristic of an individual body misses the phenomenon and the complexity of disability when we understand it relative to someone's actual lived experience and the reality and messiness of social life.

Here's another example. Some of you might remember from a number of years ago, the famous sprinter, Oscar Pistorius, who in this image, you see him using what are referred to colloquially as his cheetah blades. He has no limbs below both of his knees. One might look or think about people with limb differences such as Pistorius and be like, oh, well, surely that sucks, right? He is missing something that naturally biologically homo-sapiens have, namely legs such that you can ambulate upright.

And the prosthetics, sure, it's a nice workaround. But still, this is something that is on the whole bat. Contrast that intuition with the fact that the reason Pistorius was not allowed to participate in the regular Olympics is that he was judged to have an advantage.

Right, the highest body of the Olympics, they had done some studies and they realized that his cheetah blades, he had less metabolic cost for his sprinting.

And so this person who on a medical model understanding has something wrong with them, when you combine existing technology, biotech, with his body, he actually has an advantage in a strict kind of sense of advantage as the Olympic organization would understand it.

Now this general, sorry, this specific point, you can see how this generalizes with all sorts of technologies and interventions that humans use, things like these that are on many people's faces, text-to-speech technology, there's all sorts of ways in which our interactions with objects in the world and the ways we can modify our experience completely upend and or let's say they modify what it is for something to be good or bad and how one's life will go and merely you know defaulting to a kind of narrow understanding of whether or not that individual's body and mind fits some set of standards or assumptions about what is normal. That is actually going to lead us in the wrong direction of understanding how disability works.

I just realized I completely forgot to set my timer. Do I have like two minutes left one minute?

[**Rob**]: I think that'd be fine. Go ahead. Go ahead, Dr. Reynolds.

[**Joel**]: Okay, I'll try and I'm pretty sure I'm getting near the end so let's just I'll speed this up.

I was going to give you two more examples and I'll just skip them and say what the point is I think you can understand similar things about blindness if you actually talk with people who are blind, and you can certainly understand similar things about a whole range of types of neurodiversity, where people will say no this is not only not a deficit a defect or something bad, it is actually something it is a disability gain. It gives me something special and provides me openings, new things in the world.

And I just wanna go back. Well, actually, because this was in the last slide, I'm gonna skip this. I was just gonna further belabor this point and further emphasize how utilizing a social model under a standing of disability that is also tied to social scientific research on the complexity of quality of life gives you a much richer understanding of organism environment understanding, organism environment interaction as it relates to things we categorize as disabilities.

So big takeaways. Ableism very unfortunately fools many people into thinking that disability is just experience similarly, that it in and of itself leads to one thing, namely that it's negative and that it suffered and bad. And that's just false. Right.

As a shorthand I just refer to this as the ableist conflation, the conflating of experiences of disability with pain and suffering. For those who are interested, I did write an entire book trying to analyze this from a kind of history of philosophy perspective. I can't promise you you'll like the book, but I do spend six chapters trying to understand why this has been such a prevalent way of thinking across millennia and traditions.

And I just wanna further really drive home the point that disability is fundamentally complex and heterogeneous. And the differences between things like deafness and something like degenerative multiple sclerosis, the differences between something like Down syndrome, which shapes one's world in a total sense body and mind versus infantile Tay-Sachs, which is as most of you I would imagine know is pediatrically fatal and also involves constitutive pain and suffering that can only be treated symptomatically where Down syndrome doesn't necessarily involve any pain and suffering beyond a percentage of people needing um uh cardiothoracic kind of interventions early on.

Contrast autism in its many beautiful forms with something like vitiligo, contrast achondroplasia with something like major depression. The point, if I had more time, I would do a really kind of rich comparison and contrast of not only the lived experiences at question here, but also social scientific work relating to life outcomes, health outcomes, and quality of life. And it would further drive home the point that disability is very complicated.

It is as complex and multifaceted as any other central way of understanding human life. It's as complex as sexuality and gender. It's as complex as any of the other ways we categorize people and identify ourselves for that matter. The end, thank you very much.

[**Rob**]: Okay, thank you so much to Dr. Kara Ayers and Dr. Joel Michael Reynolds for those presentations. They certainly given I think all of us a lot to reflect on. We'd like to shift now to Q and A with the audience, so please feel free to drop your questions in the chat box. We also have some questions that were submitted beforehand and we will address as many as we can.

To start us off, my PGED colleague, Dr. Marnie Gelbart, will be joining me to moderate this discussion. Hello Marnie, and would you like to start us off with a question?

[**Marnie Gelbart**]: Hello. Thank you to Dr. Ayers and Dr. Reynolds for your thoughtful presentations. And just as a visual description, I am a middle-aged white woman with glasses, mostly brown hair, and a maroon shirt. I am thinking about the people with us in the classroom and the kinds of shifts in our thinking about how we're teaching from a more reductionist frame to this, I think Dr. Reynolds, you said that, the complex and multifaceted.

So thinking about how biology is often taught, it's a common assignment in a genetics unit for each student to learn about um, a genetic condition and to report on it to the class. And this is a deficit framing as you know listening to both of you illustrates the ways that this can cause harm for students.

So how can biology educators encourage curiosity about genetics and at the same time avoid you know find assignments that can avoid reinforcing this medical model of disability.

[**Kara**]: Yeah, I take a shot at this first, Dr. Reynolds. This is a tough one, I think, because also, you know, understandably disability identity is developing across time for disabled students as well.

So, I mean, how I felt about my disability in middle school and high school, definitely very different than it is today. And so, you know, I think I have to remind myself that we don't have, you know, miniature proud disabled students rolling into our kindergarten classes necessarily that we hope to build in there.

And I hope that there will be more disabled people at younger ages embracing those identities. And that's not just like a feel-good hope for me. There's, you know, research that supports that identifying as disabled has a number of positive benefits.

But I think with assignments, like you mentioned, yeah, there's a fine line that you want to walk between like a curiosity kind of approach, which is natural and not inherently bad. But, you know, we want to avoid just an exclusively medicalized approach. And then if I think of something like Dr. Reynolds emphasized so well, actually talk to the people, but I don't know, I don't necessarily want to recommend that you send out classes of people to interview disabled people 'cause that has a number of challenges in itself.

I mean, I think small things that you can do too, and really pushing back against language that I know many of my psychology students often use without thinking about it, is they'll write about people suffering from… and so I always push back on that and say suffering from you know that's not first of all that's not objective scientific language we're putting a big assumption in there but you'll see that in the most you know scientific formal texts as they have these like lapses in objectivity so I think maybe teaching you know that standard of objectivity and really pushing back in a lot of judgment sand assumptions that are built into our genetic conceptualizations of disability might be helpful but pass it to you Dr. Reynolds for a little bit.

[**Joel**]: That's a great response. I think we have some background noise going on here. All right, I think that's a great response.

With the caveat that I am speaking as a philosopher, I do not teach high school biology. I've never taught biology at any level, so I just want to flag that very much.

There is partially a division of labor issue here, right? The goal here, I don't think necessarily is to turn a biology class into a social studies class and it's not like a biology teacher has the time to you know cover everything and so I just I do want to flag that this is very tricky to cover both the basics that the student needs to do at whatever the level is and have this more expansive and what ultimately amounts to an interdisciplinary approach to talking about this.

Having flagged the difficulty I will just say that folding together or finding ways to have a view of things that is coming from the sciences and a view of things that is coming from the humanities and the arts and having those in conversation with one another, I think that provides a sort of, let's use the metaphor of... binocular.

One of my mentors, Eric Perens at the Hastings Center, loves talking about the need for binocularity when we are discussing humans.

And that's whether we're discussing human life in the biology classroom or we're talking about human life in, I don't know, pick some other domain. And so I do wonder with that assignment, for example, take a... condition that is as well defined as a genetic sort of difference and describe it, merely adding something about the life of people who have that condition, merely adding a little bit of information beyond how it would be described under the strictures of a biological or a purely medical understanding that is interested in diagnostics and prognostics and you name it, that already I think moves things in the right direction.

I realize that's a tall order because i's not like anyone has time to then, “oh yes, now please stay up on everything in disability studies and about multiple types of”, you know, I realize it's a tall order, but having the binocular vision, I think is only going to enrich the student's understanding of the relationship between biological facts and features of the world and how those relate to fully complex living human organisms that are messy and weird and strange like us.

[**Rob**]: Thank you both.

[**Kara**]: I thought just one other thing that Dr. Reynolds sparked for me is, yeah, not, you know, your point about the value of life you know, doing what this audience does in terms of teaching biology.

I mean, they can't be, you know, minimized in your quest to do better and do things differently. I think of some of my research involves finding out what people with genetic disabilities understand about their own genetics. And so genetic literacy and then how they use that knowledge in their own reproductive decision making. And, I mean, I can't tell you how many adults don’t have basic genetic knowledge because they were not-- I think there's an assumption that, sure, if you have a genetic disability, surely somebody along your health care path taught you that you would have a 50 /50 chance of passing on your disability if your partner does not have-- and down the road.

But in many cases, people don't have this information. And I often think, gosh, I wish that there was just greater genetic literacy in general so that it was not this, it feels just very unfair that people don't have what is to many, you know, a very important piece of information, what they do with that and what they, you know, their family planning, or, you know, is a different question, but to not have that information is unfortunate, I think, and it could be a gap that you could fill.

[**Rob**]: Yeah, I think you're both those those great, those great great comments.

Dr. Ayers, one of the questions that we had beforehand actually calls back to something you mentioned about like, you know, the objectivity slipping or the veneer of objectivity that scientists have slipping where you're talking about suffering from.

And I think oftentimes educators are not in a position necessarily to choose their textbooks to choose resources that they-- maybe this is district-wide or school-wide or what have you. And sometimes that framing in those resources can be really problematic.

Can you share some, I guess, strategies or approaches or things to think about to maybe call this in or try to shift things to a more productive space in education contexts?

[**Kara**]: Yeah. Yeah, I think if instructors you know have the bandwidth yeah it would be great if we could have more people with a goal of anti-ableism on these textbook selection committees because not only do we need, you know, less problematic language like suffering from but we also need greater representation among, you know, disabled researchers as well you want to see cited so the list goes on as to what you could contribute to a selection group but I know we don't all have capacity to be on every committee.

So I actually, I am really interested in kids literature and how it teaches about disability and I share reviews on it sometimes, sometimes formally sometimes informally and I had somebody asked me afterwards gosh you, your kids must not have any books because I hear you very rarely like 100% like a book’s portrayal of disability. And that actually couldn't be more false.

We have tons of books, many of which we actually routinely push back on. So we'll read a book that is mixed in its portrayal because disability is complex and nuanced. And then I'll challenge ideas like the Hedgehog in this book, always needed help. What do you think about that? So I think helping our students think critically about disability isn't just... kind of censoring, it's also pushing back and having them identify.

That's really what we want is that, you know, not only that we have a perfectly kind of curated textbook, but that in the future as they go off they recognize problems and strengths and, and just the complexity of disability.

[**Marnie**]: Dr. Reynolds, did you want to add anything before we have a question in the chat?

[**Joel**]: We can jump to the next question.

[**Marnie**]: So this person asks, "We know that many studies on autism, ADHD, and other forms of neurodiversity have historically studied populations of young white boys, and this has informed how we learn about these disabilities in the classroom. And so can you speak to how this historical context informs our understanding of neurodiversity moving forward”?

And Dr. Reynolds, do you want to start us off?

[**Joel**]” Sure, that's a great question. Yeah, in addition to the reproducibility crisis in multiple pockets of the sciences, there is also the sample sampling crisis, and this is something that is going to take many, many decades and lots of concerted work to undo.

I think, well, here's one. This is not necessarily the direction your question was going, but I'll just throw this out there as some fodder. One thing, specifically in a US context, that I think is highly problematic in relationship to the larger connection or lack of connection between disabled people understood as a protected group of citizens under anti-discrimination laws and research, both basic research in the sciences and translational work that's trying to like help particular people, Is that most of our legal frameworks, our rights-based frameworks, don't actually provide the basic supports that anyone would need, whether they identify as disabled or not.

We have all the epidemiological evidence we would ever need on earth to know that giving basic housing, having access to basic health care, access to nutritious foods and whatever the other two or three things are, that would fundamentally transform everyone's life and increase quality of life, increase productivity, even on a narrowly capitalistic understanding of it. It would do all of these things. And yet, I swear this ties back to the question, and yet so much of what we have been focusing on are these, very, very narrow understandings of differences, very, very narrow understandings of here's where we should put our energy. This is where we should throw the next 10 million dollars of funding for this problem.

And I would hope that one of the things that could happen down the road as we stop focusing so much on white straight men, for example, in our studies and focus more on more representative and diverse groups of people is that a disability justice framework will be applied not simply to politics but even science and that might sound completely bonkers you know out of context but I do think there is something about or I could put it differently that a universal kind of design approach to how we understand doing research, funding research, and teaching research, I think would would really, really help undo the historical tide.

[**Kara**]: Yeah, I was also thinking universal design as one approach to recognizing that this is unfortunately not a problem that's our past, it's ongoing.

So we still have these gaps in identifying young people of color with various diagnoses. But I think one way that you could immediately kind of do your part in this is to recognize that the gatekeeping that we have set up for accommodations is really not helpful for many in terms of saying, well, sure, I'll provide you that accommodation, but where's your letter? Where's your diagnosis? And so recognizing that the more we design our classrooms with universal design in mind, you know, we're recognizing that diagnosis in itself is sometimes a privilege.

And there's lots more we could say about that too, because I think in some, you know, in some cases, community support of a disability without a formal diagnosis may actually protect some folks from the medicalization and the abuse that happens when you get in the medical track.

So there's no kind of like perfect road for many disabled people. But I think, yeah, universal design in the classroom in terms of access to accommodations and learning supports is one kind of small way that you can recognize that this is a reality.

[**Rob**]: Thank you both. So this is likely to be the last question.

Kind of building on that, thinking about classroom instruction and also its impact on all students' lives. What are some ways in which educators can be thinking about supporting students with disabilities who are interested in STEM fields?

Ways to kind of model best practices and encourage those students and support those students.

[**Kara**]: Yeah, I love this question. I want to work alongside more disabled researchers and I want to see more, I want to have an option to go to a disabled doctor and down the line, you know? I think there are more and more mentorship opportunities out there.

I'll make a quick plug for, I lead a group called the Disability Research Lab. We're multidisciplinary, arranging from undergrads through faculty members like myself. We're heavy on the social sciences side because that is my original background, but we're across the range, including some bench scientists.

There's also, you know, a relatively new group called Disabled in STEM that I'm a part of as a mentor and so these kind of pop up efforts to mentor I think also need sustainability through funding.

So many of us are working on that but I mean I also think we have to put our, not only our money where our mouth is but also. our actions in terms of, it's pretty disheartening to me how many students a week I meet with that are just facing barrier after barrier in their various programs, STEM programs, and so we say this you know we want diversity in STEM but I can tell you that the barriers that they face don't send them that message so anything you can do to be a part of supporting those students and recognizing that they will have additional barriers based on their identity, not again, snapping out of that deficits based disability thinking.

[**Joel**]: I'll drop a link to a piece that I was part of the team writing this thinking about how to expand and and really just include disability as efforts related to efforts of DEI. And in the context of that. it was in relation to biological psychiatry, but if you take a look at it you'll see the ways in which this could have some of the claims and suggestions would just apply to STEM you know more broadly and at multiple levels um and yeah just to just to piggyback on Dr. Ayers there's many many concrete steps that can be taken to undo some of the gatekeeping whether it's the way that certain tests are administered, whether it's the format of certain tests, whether it's the fact that, I think it was two years before I went to Emory for my graduate education, the Office of Disability Services was up two flights of stairs with no elevator. Like just let that sink in for a second.

You know, so like there's a lot of things stuff that can be done, but it's gonna require a ton of work. It's gonna require a lot of organizing and it's gonna require a lot of people like you all who actually care and are gonna try and change things for the better.

[**Marnie**]: Well, I think that that is, unfortunately I have to take, start taking us home. Thank you both for for your thought provoking discussion for for for the charge that you are bringing to all of us, as well as the empathy that I sense for for for the complexity of the task.

You know, I know that PGED, we have plenty of work to do at home, and we are discussing, you know, reviewing our own materials and, you know, trying to bring address issues of ableism in our curricular language and materials.

Like you alluded to, Dr. Ayers, this is a mindset, not a box to be checked. And so with that, you know, this is really, we're going to be moving into a discussion on classroom and strategies, where we invite everyone who's with us to, to join us in reflecting on today's program, how this will impact our practices, educators.

But before we start that, let me welcome back Mildred to share some closing remarks from CERA.

[**Mildred Cho**]: Yeah, I know you're anxious to move on, but I just wanted to be sure that you know that you are invited to register for the next event in this series, which will be held on April 11, the same time, 6 to 7:30pm Eastern time and it's titled “what genetic ancestry tests mean and what they don't”.

So that's the registration link in the chat right there. And we also have registration open for our next ELSI Friday forum, which is a monthly event, and this one this month is called “the genie is out of the bottle for polygenic screening of embryos” where to from here on March 10th at noon Eastern.

You're also invited to subscribe to our newsletter for the latest news and all these kinds of events and the all the resources mentioned in today's session as well as future announcements.

Lastly, we would greatly appreciate your feedback so please fill out our survey to discuss your experience and to make suggestions for topics and speakers.

And again, the survey link is in the chat. So I'll just hand it right back over to Robin Bowman, who will guide us in a discussion on classroom integration strategies. Thank you.