Dr. Ashley Shew: Thank you so much for having me in this forum in the field laboratory and computational science.

I know I'm part of conversation five.

And the first conversation was really about intersectionality, disability and diversity. And conversations two through four were about best accessibility and then in field studies and then computational work.

I appreciate the work of these prior session to see focus on these topics.

But how we put all of these things together and thinking about access to careers and all their facets and their stages and inter recruiting, entertaining, disabled scientists, disabled scientists in the work we do and also recognizing people can become disabled during their lives.

This is also about keeping and engaging in scientific research and science work over our lifetimes too.

My title here is the dream which is to say my title is access at every stage which is the dream for all of the sciences in terms of disability inclusion and indeed beyond have access at every stage to be able to could through education and career steps and not encounter barrier after barrier to your own participation, enjoyment and inclusion.

The flip side is that this talk may also be called barriers at every stage which is how it can feel for people working through the accommodations process or wondering about disclosure or wondering how to creatively hack their own careers in terms of accommodations and then to be pushed back upon by artificial ideas about who belongs because often there's an assumption that if you're too disabled you do not belong.

The title could be wanting to belong in science or wanting to be, to be able to be in science and medicine, to be and to be with without struggle that access and commendation often currently represent.

So who am I to be talking about this work?

Well, my work, weirdly for the national academies and to be a speaker here, my work is about stories and story telling and the narratives we tell about disabled people, particularly in relationship to technology.

Typically when we see news and entertainment stories about disability, they set up technology as helping disabled people overcome their disabilities.

But stories from the disability community and from disabled people themselves aren't like this.

They don't tell the story.

Or if they do, it's far more knew answered.

Technology might play a role in helping people adapt.

It's a constant need for the need for maintenance and repair.

It might be something that helps in some aspect but it's not the sort of cure-all that it's pictured as in a lot of our news and entertainment stories.

I feel this story seeps into how people feel about accommodations, that you get this thing, this commendation about this technology and things are magically transformed, right.

We're always told the technology is life changing for people with disabilities.

Our stories vulnerable aren't about that but this is the general perception.

So and hear I'll use the terminology of TAYNA where they talks about includable, so much of the ableist environment we are in, demands to disabled people change themselves, function in particular ways to be worthy of being included and that's somehow how people feel about accommodations.

If a disabled person is normal enough then they might be includable and you can imagine how this might flow in doctor's first keynote here where he talks about NBCality and who fits in terms of who gets to be includable.

I want space so I'm working in a department of science technology in society, I work with humanists and social scientists but we won't get the things scientists and engineers are doing and my training is in philosophy technology with a specific focus on technology and disability.

I currently am working under a national science foundation career grant number 1750260, although this work does not represent the opinions of the national science foundation.

But I'm thinking a lot about disability community work later and lately.

I want a space for us to be proudly disabled in all the places we are for work and life, to be able too disclose disabilities without peer and get what we need even when we can't disclose and when there's no clear label to disclose.

Not everyone has the diagnosis they need to access accommodations.

We also need systemic change to how we approach business of disability more generally.

That is the processes at work in our workplaces as scientists.

I think this is particularly imperative in the sciences, engineering and medicine.

Non-disabled people have often been cast as experts about disabled people in ways that often reemphasize overcoming stories and a lot of the work of science technology and medicine is about addressing disability in various ways.

So having disabled researchers is incredibly important to getting what we're doing right serving the people we want to serve correctly to being in solidarity with disabled people around us.

And here's where it gets tricky because disability is an identity as well as a community as well as a social construct about how and frame and think about the world and how we serve people.

The category itself disability points to a wide array of people with different body configures rations, many husband who are disabled are multi-plea disabled.

We also have people from every other category of identity you can think of.

So it's important to plan for disabled people to be here, to be, to exist in these spaces without harm and without extra labor beyond what non-disabled people encounter.

So let's talk about this current approach to the business of disability and I recognize that my talk is going to be a lot about accommodations in ways that I maybe didn't expect when I started writing down my ideas for this talk.

In fact, so I need to say some things and probably some mean things, unkind things around accommodations.

Our mindset is well, those people have accommodations and we can make accommodations and TA-Da, we included them.

Disabled people show up or if you become disabled, it's a surprise and you then have to make a request to be included and that request isn't a simple process.

So, in fact, if you would like an commendation, first you have to identify barriers to our participation, right.

You have to know what the problem is in the environment you're encountering.

Sometimes it's a physical barrier and so you can literally point to there's no ramp into this building.

Other times sometimes the way work is set up can be part of the barrier, right.

The physical environment is part of it but sometimes it's the flow of work.

Sometimes it's, you know, a barrier to participation can be that it's really unclear what a process should be.

So once you've identified a barrier to your participation, then, in fact, in most workplaces, you are asked to get the appropriate documentation to show that you're worthy of this commendation, that it's an appropriate commendation and that usually involves a physician signing off and of course it's assumed that you have a physician, that they believe you and that they will fill out the paperwork to help you get an accommodation.

Not everyone has access, of course, to primary care or this documentation they may ask for from specialists if it comes to specific disability types.

Then once you identified the barriers, once you've gotten this appropriate documentation which is not an easy process in a lot of cases, then you're expected to present your documentation to the proper, properly disability services office or human resources department and hopefully they will know what to do when you approach them and ask for these things.

And then it usually initiates a conversation between the authority.

So the certification authority, whether it's disability services or Hirono, the person who is your direct supervisor and any supervisors what they have, then you can fix whatever the barrier is, whether it's screen reading software, whether you need to rest your eyes.

You can't get to the place, especially for people newly disabled, it's harder to get where you were going.

It can be a nearby parking spot if you experience a lot of fatigue or proximity to public transportation.

It could be the ability to come into work later or do telework and, you know, even simple things like the permission to sit down on the job are part of what constitutes an commendation in these cases.

And then you can get that one thing changed.

You go through this process and you get permission to get this one thing you identified as a barrier to change.

Hopefully you have a larger conversation.

In fact, a lot of disability resource offices are not really wanting to talk to you about accommodations you will need in the future.

They want to talk about the state you are in now and what you need at the moment.

This is really frustrating, you would like to have a way to have seamless transitions as you have more supports put in place that would help you work better.

You've gotten through all of this red tape and you get the one thing changed, whatever may be to allow you to be included but only be included in very specific terms where you have to navigate an often hostile process, the paperwork, authority, bosses and expectations that people may be unwilling to be flexible on constitute extra steps to being in science, research, this is a process unless you're disabled you're never really privy to.

You don't see all the steps it takes, the doctor visits to get bio certified.

Accommodations mean you can be here and included but only if we make alternate arrangements for you.

It's where you get called special and don't call us that, by the way.

Accommodations mean you'll be asked to prove yourself worthy to be disabled enough to be documented enough meaning that you know what your disability is.

Accommodations mean extra work for institutions who have set up this network, this stages of paperwork and things Rthey sometimes allow temporary access to a job or program and this assumes it's all gone, has moved efficiently and where you are trusted about your disability status.

This doesn't mean that disabled people hate accommodations.

It means that accommodations don't structurally change anything.

They don't make science more inclusive.

They don't open the gates of the academy for us.

They don't make lasting changes to the way we as researchers and colleagues go about our business.

There's no change to access and inclusion when everything is went off accommodations.

You probably want a story at this point when I said I study stories.

So gather around.

I was once asking one of my mentors about how she got accommodated at work.

She told me about arriving at her new job where she's someone with an apparent physical disability.

Needed some particular voice to text software so she could type to write up all the research and take notes.

Let's say the software is important to her work.

She presented her documentation to the ADA unit and they agreed she need that software and then started a process of months of back and forth where she had to repeatedly inquire about the software, when it would be ordered, how to get it on her computer, which unit would be paying for the software and this is where things got held up significantly where there was no plan on how to pay for the software package she needed.

She was an up and coming star in her field at the time and she was incredibly slowed down.

Her department shared a copy actually on a lot of this communication.

After months of her chair watching this communication, they had a discussion and this researcher of course had a startup package but that money is not supposed to be spent on assistive technology and you can see how that might put disabled researchers behind their peers when you have to pay for their assisted technology and not the things to do their experiments and to this chair's great credit recognized that this delay in getting the new faculty member the necessary work tool was going to impact her ability to write and publish.

The chair intervened and had the department administrator pay for the software for the department budget so that her new faculty member could get on with her research.

No more going back and forth between units about the software and who might pay.

No more discussion of it at all.

This is for an accommodation everyone agreed was appropriate and which was well documented and kind of obvious given the physical nature of her disability and for something not all that uncommon.

Voice to text software is a pretty standard accessibility tool.

It took about nine months into her new job for her to finally have that software.

We talk about this extra labor and the extra time at accommodations process takes.

We're looking at delaying people in their careers in significant way so we often talk about the leaky pipe worm when we talk about other minority groups.

This is one we can see where disabled people start behind because of the accommodations.

What my colleague encountered was not an uncommon situation and she was in a good position with the chair who was paying attention.

With the chair saying we shouldn't have to pay for that.

She was in a relatively good position, right, as a tenure track faculty member.

I know graduate students who have had to retaining, retaining to get retaining testing to get the documentation they need in order to be certified with services for students with disabilities and to get that testing, it took six months to get the testing and it costs $3,000 to get the education the testing she needed for a diagnosis she would have since she was five.

She bombed her first semester in her engineering program because she didn't have the accommodations that she knew she needed, that she had been certified in the past as needing and once she got the accommodations in place, she was a great engineering student, but this sort of lag, the extra certification, I know her GPa isn't what she would want it to be because it doesn't actually reflect her abilities.

Getting for her a little bit more time on tests makes a huge difference to her to be able to take those tests.

Getting the flexibility on time really mattered but she was held up in a way so many people are and this is where leaks often occur in this pipeline and this is often the case for disabled students and researchers but we're usually not tracked by University diversity initiatives.

People burn out from speaking accommodations or being afraid of doing so because of what it will take and always having the extra work of inclusion hoisted back on them as disabled people.

I think sometimes how it can feel being held back on purpose because of some of the barriers of work.

Many disabled people feel like they are caught in a loop whether it comes top accommodations processes especially if you have disabilities that are variable so it's not constant.

Sometimes you can do other things, people with pain flareups that shape their days.

Lots of are available including amputees.

I think about just the time to takes in terms of variability, even if it doesn't cause me physical pain what it means to get back on track when I'm waylaid.

What's called the disabled faculty study.

I want to talk about the study for just a little bit.

I think it has a lot of good observations about how faculty are encountering different processes in the workplaces and that includes scientific researcher as well.

This is a study that's been conducted over eight years now.

And they had themes that keep coming up for the people they are talking to or issues of disclosure like issues of telling people you're disabled and how and when.

The experience of space and time and this is an unrelated accommodations process as might be apparent from my stories just a moment ago.

Looking at different forms of support, the nature of barriers and differences in experience between different groups of disabled people and Margaret price has written and she has this piece time harms and she says although accommodations are often referred to as measures that level the playing field, this metaphor represents a dangerous misrepresentation.

Close study of the accommodations loop shows why.

The loop is arduous to traverse, must be traversed over and over again and exact costs not only of time and money but also of emotion.

The loop must be traversed by anyone seeking accommodations whether they are quickly granted or fiercely contested and perhaps most important the loop is almost always invisible to those not traversing it.

She talks about the need of constant labor and bio certification, that documentation and when people leave, drop out, the loop just closes.

We see a disappearance of both the need for the accommodation a disabled person in any trace of its history.

This is not structural change that we're seeing.

She also talks about how institutional and here I quote institutional discourses suggest that waiting for an accommodation is a value-neutral event.

It might be inconvenient or frustrating but if the commendation is eventually forth coming and if everyone has good intentions, no real harm is done.

I argue we must counter this assumption by recognizing a basic law of time.

Time can cause harm and this is her title, time harms.

So what can we do when we think about our current situation with access and inclusion and how many people think accommodations are how we should manage disability.

You're going to lose a lot of disabled people if accommodations are the process.

Not all of us have clear diagnoses, not all of it can get documentation.

What we need in some ways is to crip the sciences and crip is a term.

Crip is a word being reclaimed in the disability community like queer is and you see different people talk about queering things in study.

This is a term about cripping things and Margaret Price was talking about crip space time.

Samuels has written a lot about crip time and it's about this sort of acceptance of disability and expectation that disability will be part of where we are, what we go, how we plan and a sort of flexibility and approach to how we think about time in the case of crip time.

I think when we're talking about cripping the sciences, we often have an idea that things are supposed to look one way, right, that research follows a very clear path or plan but even within the sciences there's a great diversity of course in how science proceeds and there's no one perfect way to be even if that's what we often think and what eugenic receipt Eric that we should look particular ways.

We need to be open to honoring more ways of being.

Sometimes that means changing our pacing and our clocks and being more forgiving in terms of the attitude we have towards timing.

So crip as in crip time, our clocks move differently, sometimes very quickly or sometimes intensely.

Honestly the shift can here.

We have a disabled faculty writing group this year at the University that I'm apart of.

We have check-ins each week on a Google clock.

We're not leaving anyone out.

We won't be writing at all in person this year because of the ongoing COVID-19 situation.

But we're checking in on each other, checking in on writing but also checking in on sort of the barriers we're encountering and working with one another.

I think cripping the sciences also speaks to the flexibility that we see in the universal design movement and universal design for learning and it's really about fitting education careers and institutions for a wider variety of humans, not asking disabled people to bend or break to preconceived molds.

Of course this is beneficial beyond the disability community in what we call the curb cut effect.

They are used by wheelchair users but also used by people who have dollies and strollers and other wheeled implements to get around in various locations.

They work for more than just the disability community.

What time suggesting is we crip the sciences it will do that too.

I think also of the way in which cripping the sciences means letting disabled people work against some of the things we've been doing wrong in the sciences and allowing critique.

I think of the way in which Williams critiques the field of computer interaction and specifically robot development aimed at autism interventions.

Sometimes the experiments she critiques literally scare children but the researchers who are describing how the children react don't necessarily realize that that is a scared response from autistic children like her and other researcher can.

We have to shift avenues of research when we recognize harms to disabled people.

We have to also think about institutional change in terms of taking the opportunities we're given to make things more accessible and disability-friendly.

I think of Martina Syvantek's work.

I think about her work on my own campus which sticks out to me here.

The doctor did a deep dive for her graduate work over 25 to 30 years here where accessibility seemed to be an after thought and indeed we were going to master planning sessions for the current -- like a few years ago and even the master planning sessions where they said they were soliciting feedback from the community we're often in inaccessible spaces with bad acoustics.

She had to stand because all of the seating was on like stools that could move around.

And for lots of people in the disability community, high stools that move around are going to hurt your back, impact your sense of balance.

There's lots of reason stools are a bad thing and ironically she was also reading all of these past master planning documents and every one of them mentions the sentiment.

In fact, she's back to 1983.

The master planning document mentions this all new construction could be working to make things more accessible and not less.

And 30 plus years later we were still seeing this in action even as they were soliciting feedback.

It was clear they haven't thought about disabled audiences.

Earlier in that year the doctor and I participated together in an event to draw attention to newly constructed steps, to replace old steps where they had the opportunity to knock down several buildings, the steps were supposed to go through and there were no ramps than they installed.

The way around the building was actually blocked for a long period of time by construction fences, no way to get through if you're a wheelchair user or if you can't do steps, you would actually have to go into a different building, hoping the building was open at the time and use an elevator and this is still mostly how we access that space because the pathway along the accessible route is so much longer.

We also so to think about flexibility but it's something we need to elevate in value especially as we design laboratory spaces and research projects.

When you think about the variety of people you could have work on a project, we should think about how, how to make these things more flex only for use by different types of people.

That means some structural by which I mean physical structure changes to laboratories at times but also thinking about this in terms of programmatic work.

And we should be listening to those doing the feminist work of complaint.

This is a term from Sara around disability issues in our research spaces in our programs.

So we have to think about how we do prelims.

Are their multiple ways to do it or only one route.

So I think about this with particular students who encounter this barrier and might not have been able to get accommodations.

So many times our comprehensive or preliminary exams involves sitting for eight hours a day, five days a week for two weeks to sit and answer questions.

I thought about, I encourage my students, not even my disabled students, all students, to negotiate what it is going to look like to do their exams.

There's some flexibility in the program that I'm part of because we have a lot of non-traditional students with families and day jobs so we can't always structure prelims and comprehensive exams assuming people have two weeks to sit quietly in a room and there have been times when we've restructured instead of two weeks in a room, there are three sections to the prelims in my department.

This exists for a lot of different programs.

We do a section at a time with breaks in between.

It's the same questions, the same amount of time, just divided out specifically on our areas.

It allows for me people to do the work which is ideally what we want to make things accessible and inclusive.

It's not that any requirement that's been changed unless the requirement was a physical test of whether you can sit in a room.

That's not really what we want.

I think we also have to ask ourselves what are we requiring in terms of legwork.

I think about all of the extra steps to paperwork to different degrees in various work processes that can be simplified.

We shouldn't ask for more information than we need.

We think about this in our scientific research when we do survey methods but we can think about this and turn it inward on the work we do.

What are we requiring.

Are their forms that could be simplified, processes and paperwork, not even disability paperwork that can be simplified.

Also there a clear map for people on which paperwork happens when.

Particularly students with disabilities who may have executive dysfunction and filling out paperwork itself.

They are doing their good engineering work.

They are doing their good science work but filling out these forms that they will encounter once each can present an extra barrier so I often ask my colleagues like can you fill out the paperwork?

Can you set up the assisted tech.

Do you know how?

Do you know how to book your ASL interpreter?

Do you know how to get Braille ordered if you have someone requesting Braille?

Do you know which office to see even go to?

How do you figure out these things?

This is the work we're always placing back on disabled people but it belongs in our hands as administrators, as supervisors, as mentors to be ready for these things too.

I have literally filled out the paperwork for a number of disabled students who just couldn't finish paperwork.

I see the paperwork a lot as someone who serves on various committees and it doesn't cost me nearly the time it will them and the time and work of filling out that paperwork but it's easy.

The barrier was one that is unnecessary to begin with.

It doesn't change anything about what the student knows or whether they are a good scientific researcher.

This is my last slide.

We exist better with rich disability communities as a reference and a resource, to know how to navigate processes, to sympathize with one another, to laugh at hilarious stories and have the release of laughter with one another when we're encountering ridiculous situations.

It's a place to engage in process disability understanding and solidarity with others.

The disabled artist collective valid talks about how none of us need one issue.

So our communities shouldn't just be about disability when we gather as disabled people but all sorts of barriers that people encounter and mentorship in the disability community looks different.

It comes in different directions.

For me I acquired most of when I disabilities when I was 30.

I'm a hard of hearing chemo brained amputee with tinnitis.

Bingo, I've got the card.

Most of these disabilities I acquired at age 30.

One of my early disability mentors to what it was like to be disabled as a professional to be on campus was someone who became disabled many years before me but was also an advanced Ph.D. student.

With her and others we formed this disability alliance and caucus on our campus and I was learning from students and staff members at the time who were my elders in terms of being disabled.

You can be a much younger person and be a disabled elder and mentor in ways that speak to crip time and crip space that we already diverse from normal constructs of time.

We're out of time even when it comes to mentorship and advising too.

This can be hard for newly abled people to take advice from people they see as junior or lower to them in a hierarchy but when it comes to learning the lay of the land in which the land may be newly hostile to you, this is an incredibly important part of our community and a way to think about how we mentor each other as disabled people, as researchers.

I know when I became disabled I thought very seriously about quitting my job.

Every time I came to campus it was so hard to get to my building, my building doesn't have an evaluator.

I was moved downstairs so every time I went to my office which I had partially moved into and started unpacking, and then they change up space in my department and I was still too sick to come in.

I was on medical leave for a while and they told me the office I had just moved into was going to be taken by another department and they had a different office to move into and one of my graduate students packed up my whole office and moved it at that point.

The kindness, a shoutout to Keith, the kindness that was shown in that but it was hard.

I was also young enough as a disabled campus, I was on double crutches.

I was bald.

Most of my disabilities were acquired due to cancer and chemotherapy.

And it was just completely hostile in the new world and I was lucky to have a few disabled people on campus.

Martina, Jenny, the Ph.D. student on the department filling me in on how to do things here.

This was outside of accommodations.

This was just to go to my office.

And I think a lot of people, you know, dealing with the Slog it's difficult to understand that other people are facing that too and to have different hacks around that they've thought about and to be learning from one another and I'm still learning from the disability community, from Dr. O, from other people where I am and at other campuses and it's really important to keep paying attention, even each other as we do disability work.

So thank you.

I look really forward to doing this less asynchronously and having a discussion with some of you now, if you're watching this.

All right.

Thank you so much.

Oh, and I'll give you my slides in the chat when we're actually live together but I have a whole bunch of resources at the end of this slide show with links in case anyone wants to delve further on any of these issues.

Thank you so much.