

Title: EDI Colloquium - Accessibility in Research Environments by Dr. Mahadeo Sukhai and Ms. Ainsley Latour

Speakers: Mahadeo Sukhai

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Abstract: Learn more about the benefits of creating an accessible environment and how you play a part. Dr. Mahadeo Sukhai and Ainsley Latour are scientists, researchers, educators and IDEA professionals, who are passionate about and committed to inclusion in the scientific research and training enterprise.

Learning Objective 1 - provide an understanding of the "leaky funnel" in STEM training for persons with disabilities

Learning Objective 2 - provide an overview of the principles underpinning a culture of accessibility and inclusion in the sciences

Learning Objective 3 - provide an appreciation for the importance of accessibility in scientific conferences and publications

Dr. Mahadeo A. Sukhai (He/Him), Ph.D. is the world's first congenitally blind geneticist. Dr. Sukhai is Vice-President Research & International Affairs and Chief Accessibility Officer for the CNIB (Canadian National Institute for the Blind), having previously served as a researcher in cancer genomics at the University Health Network in Toronto. Dr. Sukhai also holds an adjunct faculty appointment in the Department of Ophthalmology, School of Medicine, Queens University (Kingston, ON, Canada), as well as additional Adjunct roles in the Faculty of Business and Information Technology at Ontario Tech University and in the Inclusive Design Program at OCAD University. In his role at CNIB, Dr. Sukhai is responsible for organizational employee culture-building strategy related to inclusion, accessibility and employee wellness. Dr. Sukhai is the Principal Investigator for "Creating a Culture of Accessibility in the Sciences," a book based on his ground-breaking work on access to science within higher education, and serves as the principal investigator for national projects to examine accessibility and inclusion within science education and healthcare. Dr. Sukhai co-founded IDEA-STEM, and INOVA, the international Network of researchers with Visual impairments and their Allies, a new professional society with the mission to improve accessibility and inclusion in the biomedical sciences for researchers with vision loss. Dr. Sukhai is the External Co-Chair for the Canadian Institutes of Health Research External Advisory Committee on Accessibility and Systemic Ableism and the Chair of the Employment Technical Committee for Accessibility Standards Canada.

Ms. Ainsley R. Latour (She/Her), B.Ed., MLT, M.Sc. is the president and co-founder of IDEA-STEM, an organization created to enhance the participation and inclusion for people with disabilities in STEM. She identifies as hard of hearing and neurodiverse. She also serves on the Government of Ontario's AODA Post-Secondary Education Standards Development Committee. Ainsley's work on the experience of students with disabilities in Canada has been presented at national and international conferences on science and disability, including SciAccess 2019 and 2020, the ISLAND 2020 conference, and the American Association for the Advancement of Science (2018, 2019 and 2021). She also maintains a practice as a licensed cytogenetic and molecular genetic technologist (MLT). She holds two undergraduate degrees, two graduate diplomas and will graduate soon with a masters in marine environmental genetics from the Memorial University of Newfoundland.

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Zoom link: <https://pitp.zoom.us/j/99867497693?pwd=ZDRkdE44dVBWRDdtS3J3ZzFOMFlHZz09>

# Creating a Culture of Accessibility in the Scientific Research Ecosystem

Dr. Mahadeo A. Sukhai, PhD

Ainsley R. Latour, B.Ed., M.Sc., MLT

November 03, 2023



# About Ainsley



## Ainsley Latour (she/her)

- MSc in biology (evolutionary genetics)
- Clinical Genetic Technologist (MLT)
- IDEA Researcher/Consultant
- Co-founder, IDEA-STEM





# Getting the Terms Right



# What is Diversity?

- Part of the range of human [phenotype] variation
- “Style of thought is the last bastion of diversity”



# What is Equity?



- **Equity** is the fair and respectful treatment of all people and involves the creation of opportunities and reduction of disparities in opportunities and outcomes for diverse communities.
- **Equity** also acknowledges that these disparities are rooted in historical and contemporary injustices and disadvantages.
- **Equity is not the same** as “equality” (i.e., treating everyone the same)
- “Same is not fair”

# What is Inclusion?



- **Inclusion** means creating an environment where everyone feels welcome, valued and respected, with **equal** opportunity for participation.
- Inclusion means creating the **conditions** to have the opportunity to fully participate in the organization.
- It is important to note that an inclusive group **may not be** diverse, and a diverse group **is not always** inclusive.

# What is Accessibility?



- **Accessibility** is the design (and implementation!) of *systems, policies, processes, ways of interacting with each other, and environments* to ensure that persons with disabilities have equal access to a given space.

Without being able to access the facilities and services found in the community, persons with disabilities will never be fully included.

- **Accessibility** is “an umbrella term for all aspects which influence a person’s ability to function within an environment.”

# Rethinking "Ability"

- Disability is differences in the ways we...
  - ...Take in or interact with information
  - ...Process information
  - ...Communicate information



# “-ism” Blindness

- Pre-2010
  - “I don’t see [skin colour, ability, gender...]”
  - On the surface, the right thing to do
  - An attempt to not be biased by a person’s lived experience
  - Does not take into account lived experience



# “-ism” Awareness



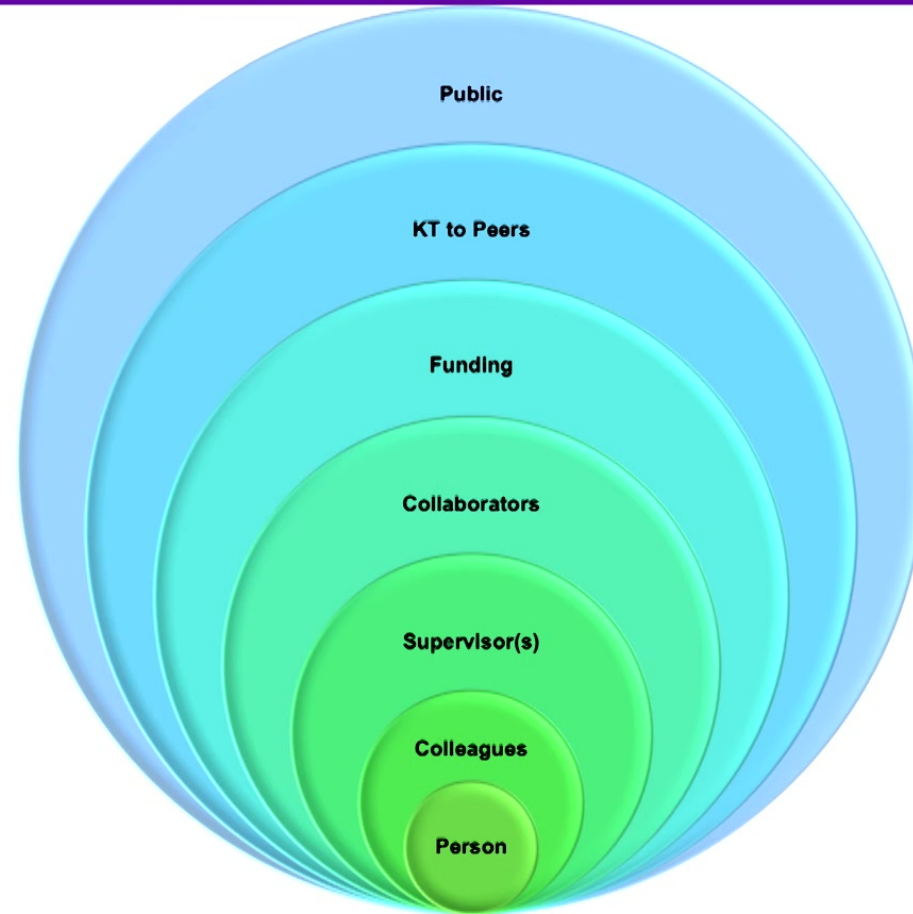
- Post-2020
  - “I recognize the totality of your lived experience”
  - On the surface, the harder thing to do
  - A recognition that it’s not possible to take a person out of context
  - Need to check biases



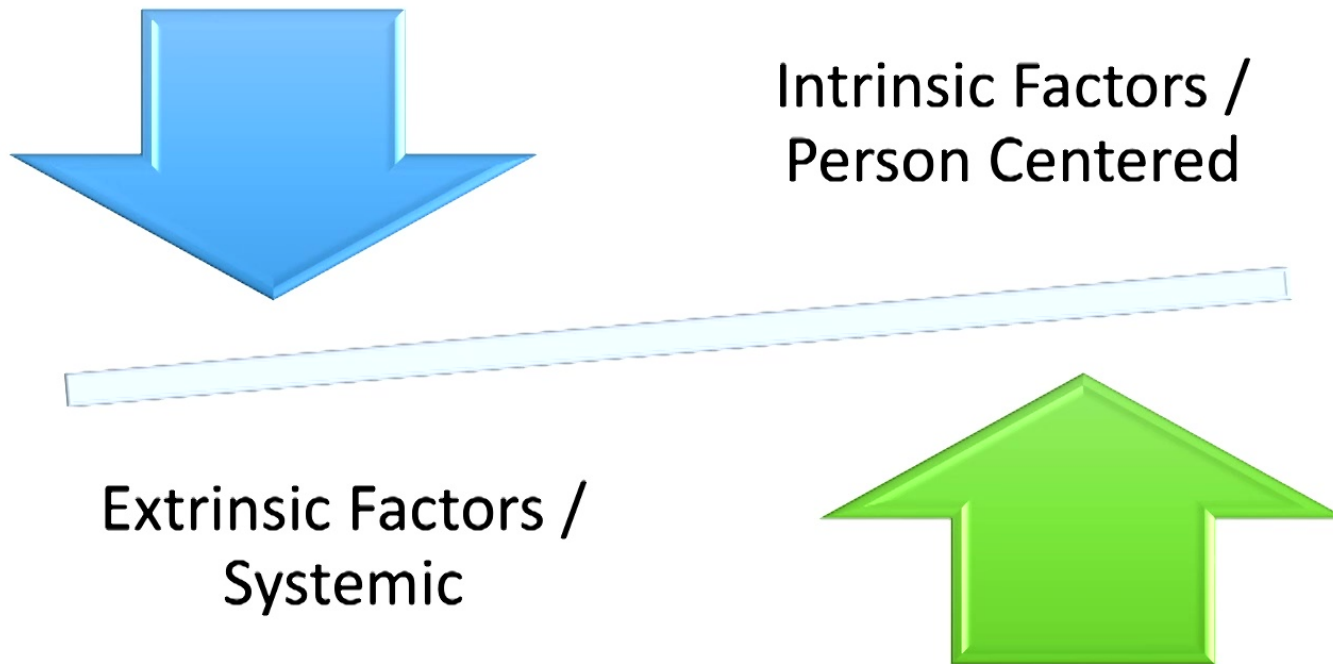
# The Scientific Research Ecosystem & Disability



# The Scientific Research Ecosystem



# Phenotype and Experience



# Genotype + Environment → Phenotype



- Genetics + Lifestyle → Cancer risk
- Genetics + Lifestyle → Cardiovascular disease risk
- Genetics + Lifestyle → Dementia risk
- Nature + Nurture → Psychology

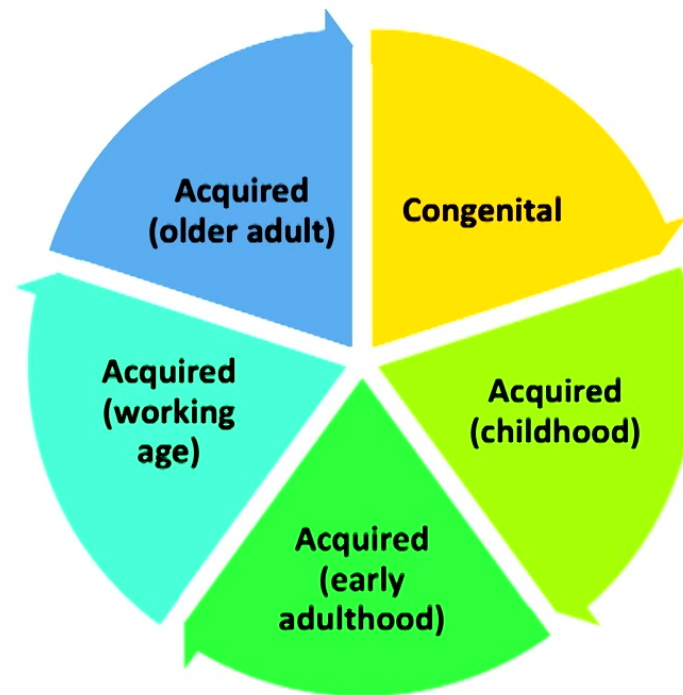
# Where the Model Doesn't Get Applied: Human Interactions

- Person + Training environment → Success in Education
- Person + Colleagues → Success in the Workplace
- Person + Policy Framework → Success in Navigating Spaces
- Person + Social Capital → Success in Career
  
- Persons with Disabilities in STEM

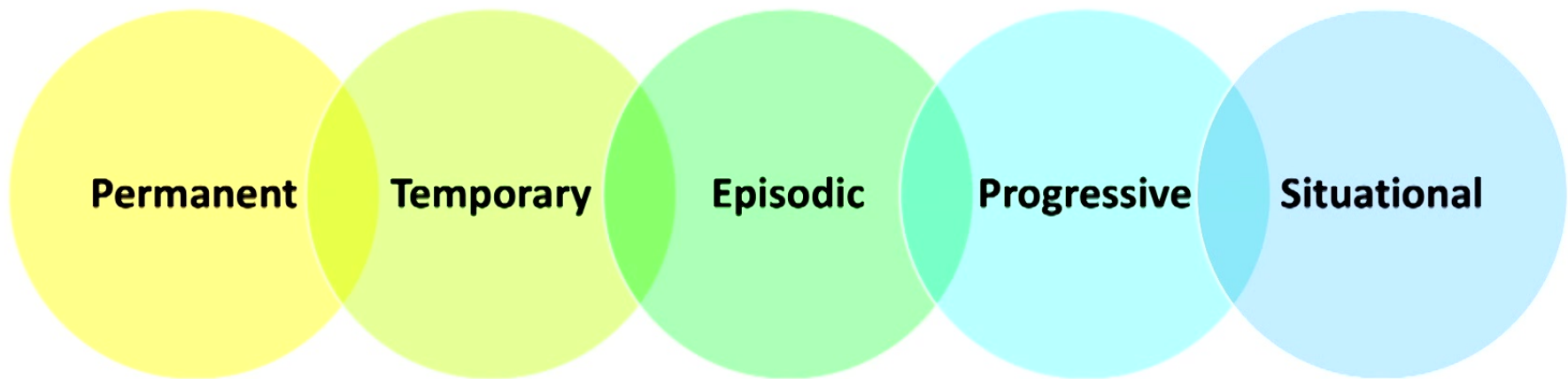
# A (Different) Disability Primer



# Disability Onset

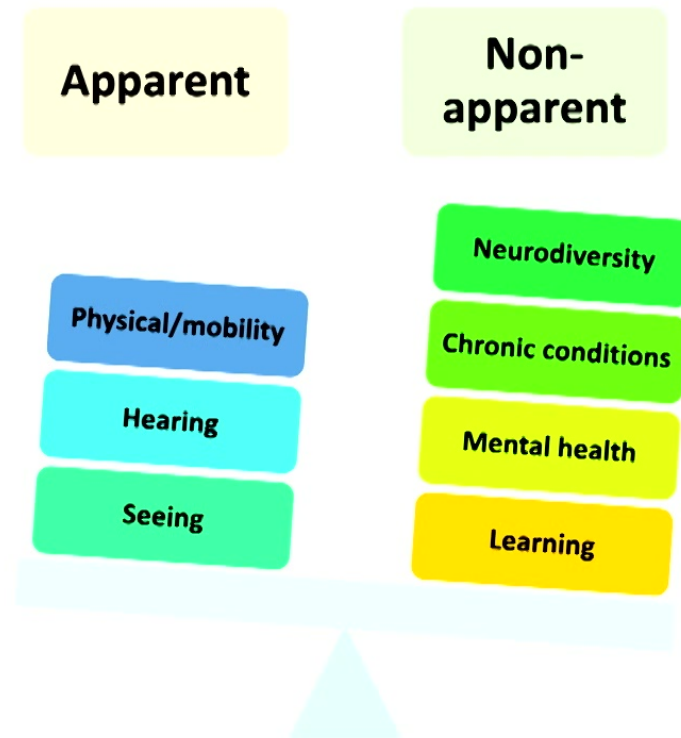


# Disability Context





# Apparent and Nonapparent Disabilities



# Two Reasons



# Assistive Technology



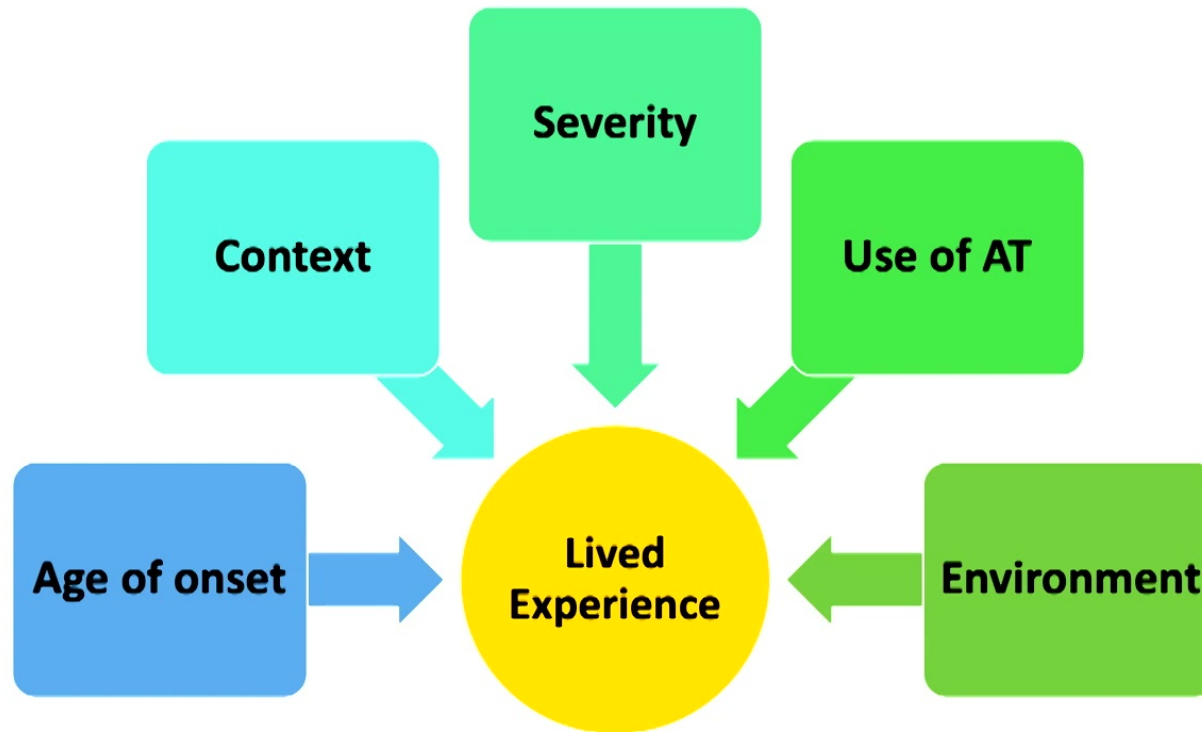
- **Any** device that facilitates a person (with a disability) doing daily tasks
  - Not just specialized devices
- By this definition, a smartphone and associated apps is a piece of assistive technology...
  - ...But everyone uses a smartphone?
- Assistive technology is used when needed – not necessarily something that is used all the time

# What is an Apparent Disability?



- A disability is “apparent” when a person is using an assistive device in a manner that helps them carry out daily tasks in a way that is obvious to an observer

# A (Different) Disability Framework



# Disclosure

- The practice of (self-)identifying as a person with a disability (considered to be synonymous with identifying an accessibility need)
- Sometimes called “self-identification”
- Considered a component of self-advocacy
- **Required** for accommodation supports in education and employment settings

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# Accommodation requires Disclosure



- Accommodation is a reactive process
  - “Need to ask for help”
- **Human rights requirement:** Disclosure of need for accessibility support
- **Assumed to mean:** Medical or similar documentation of diagnosis or functional impact
- **Who Translates between the two?**



# Disclosure Is...



- The functional route a worker or job applicant takes into the workplace accommodations process
- An expected and essential part of the process
- A declaration: “I need help”

# What's Wrong with Disclosure?

- Nothing!...
- ...But we need to understand the hidden assumptions and biases associated with it
- **Disclosure = “I ask for help”**
  - Hidden philosophy: “If you need help, it’s OK to ask for it”
  - In practice: “Why do you need help?” (the requirement to legitimize)
- **Disclosure = “I have to tell you about my disability”**
  - Legal requirement: accommodation need
  - In practice: Diagnosis documentation (medicalization of disability)

# What's Wrong with Disclosure? (Continued)

- **Disclosure = putting the person with a disability “in charge” of the conversation**
  - Intent: Person-centered approach
  - In practice: Person with a disability at the centre of legitimization and justification efforts (“on the spot”)
- **Disclosure = Making the need obvious**
  - Principle: Never assume – the person with a disability knows themselves and their needs best
  - Reality: Accessibility supports can be denied or watered down due to a lack of understanding and/or consultation

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# The “Ecosystem of Employment” (1)



- A worker interacts with...
  - Their manager
  - Their team mates
  - Their peers
  - Collaborators inside the organization
  - Collaborators outside the organization
  - Stakeholders
  - Customers/clients

# The “Ecosystem of Employment” (2)

- A worker uses...
  - Internal business systems
  - Third party digital tools
  - Virtual meeting platforms
  - Software specifically required for their job
  - Online learning management systems
  - Training material
  - Built environment (including furniture)
  - IT

# Accessibility in the Research Training “Pipeline”



# The STEM Training Pipeline



**K-12 EDUCATION**

**COLLEGE /  
UNDERGRADUATE  
EDUCATION**

**PROFESSIONAL /  
GRADUATE  
EDUCATION**

**RESIDENCY /  
FELLOWSHIP /  
POSTDOC**

**EMPLOYMENT**

**CULTURE OF ACCESSIBILITY IN STEM, 2016**



# Disability and the Training Pipeline

- Two “points of entry”
  - Scenario 1: Lived experience with a disability **prior to or during** training (childhood, adolescent, young adult)
  - Scenario 2: Lived experience with a disability **after** one has already gotten their first job (adult)

Which group of individuals with disabilities do you think experiences fewer disability related barriers in engineering?

Do we have any data on this? Is this reflective of unconscious bias?

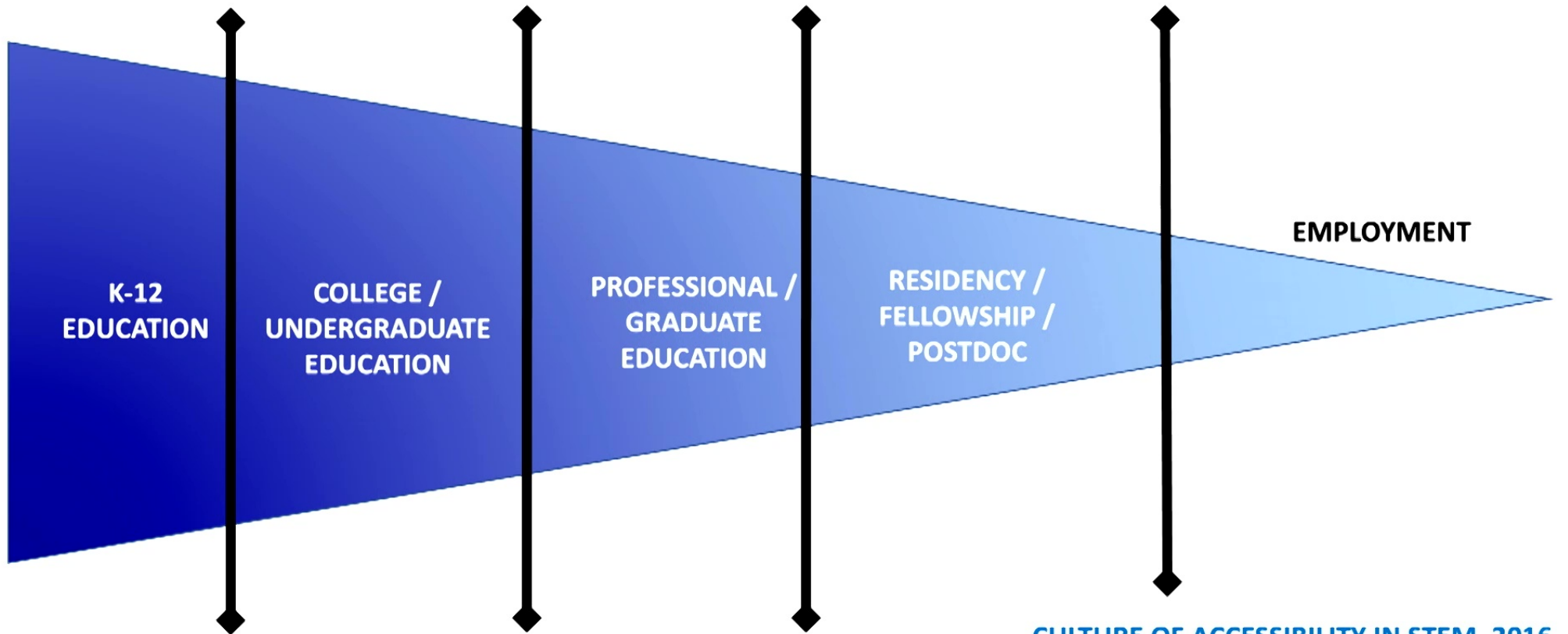
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# Blockages in The Pipeline



CULTURE OF ACCESSIBILITY IN STEM, 2016

# What Kinds of “Blockages” Are There?



## Transitional Barriers

- Barriers to employment
- Barriers to entry into college/university
- Barriers to entry into graduate school
- Lack of professional models who identify with a disability

## Environmental Barriers

- “Gatekeeping”
- Colleagues’ attitudes
- Design of learning spaces
- Design of co-op learning
- Access to technology and information
- Online → in person

# Attitudes (1)

## **Of faculty, accreditors, employers**

- Gatekeeping
- “You don’t have the ability to do engineering”
- “You don’t need to do this lab experiment”
- “Why are you here?”

# Attitudes (2)

## Of students and professionals

- Trailblazing
- “I don’t have the ability to do engineering”
- “I don’t have to learn science”
- “I can’t do this lab experiment”
- “Why am I here?”

# The “Gatekeeper Function” (1)

- The “**gatekeeper function**” arises from the attitude on the part of an educator that the student ultimately is incapable, or is not fit, to carry out the essential functions of jobs in the student’s chosen field in the sciences.
  - Exclude students with disabilities from studying the sciences
  - “Trade” science courses for other curriculum content or life skills training in the best interests of the student

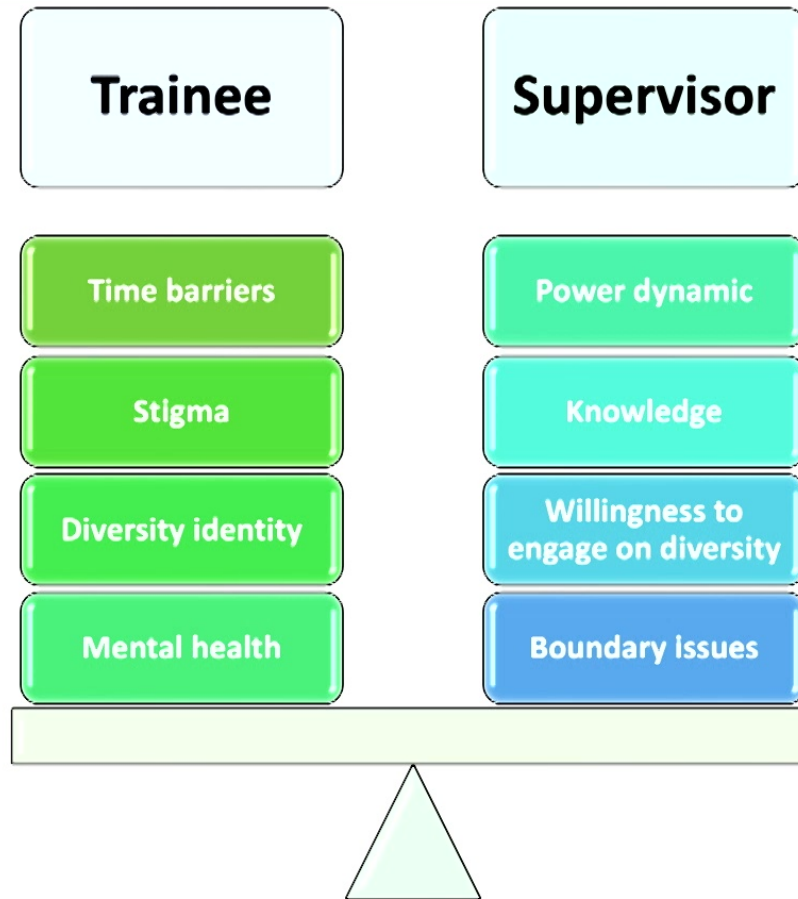


# The “Gatekeeper Function” (2)

- Often, this belief in lack of fitness, although grounded in an understanding of the discipline, is not grounded in an equivalent understanding of disability, accessibility and accommodation
- Alternatively, on the part of accommodation specialists/occupational health and safety professionals, the “Gatekeeper Function” may arise from an understanding of disability, but a lack of awareness of how accessibility and accommodation may be integrated into a person’s job or studies



# A "Seesaw"



# High-Quality Relationships Characterized By...



- A mutual understanding of expectations around the roles and responsibilities of student and supervisor
- High levels of interaction (accessibility, frequent informal interactions, and connections with many faculty members)
- Purposefully helping the student progress in a timely manner
- Flexibility, respect, and strong communication skills

NATIONAL GRADUATE EXPERIENCE TASKFORCE, 2016

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**NATIONAL GRADUATE EXPERIENCE TASKFORCE, 2016**

# Low-Quality Relationships Characterized By...



- Lack of definition and clarification of expectations around productivity and accommodation
- Student non-disclosure and trust issues between student and supervisor
- Fear of stigma and the evolution of potential crisis situations
- Attitudinal barriers on the part of the supervisor

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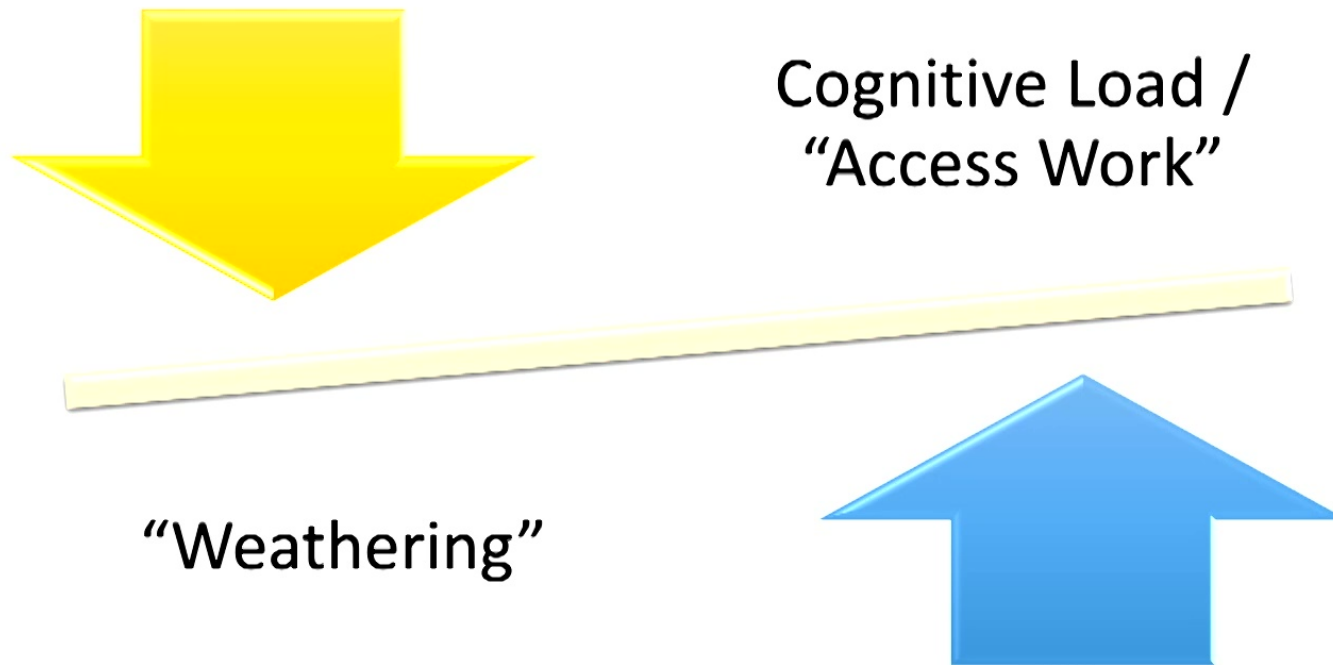
# Attitudinal Barriers



- Boundary issues related to the supervisor's clinical and/or research practice
- Social integration into the profession
- Supervisor knowledge about the interface between accessibility and essential requirements
- Supervisor willingness to participate in dialogue on accessibility and inclusion
- Appropriate clarification of expectations

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# Cognitive Load and Weathering





# Cognitive Load

- “Additional effort” that goes into being a person with a disability in the sciences
- Things we need to think about that our nondisabled peers don’t need to think about
- Can manifest as...
  - Extra financial costs
  - Extra time
  - Extra effort
  - Expenditure of social capital
- For e.g., conference travel



# “Weathering”

- Stress and negative impact on mental well-being that comes from navigating the scientific research environment as a person with a disability
- Depletion of emotional reserves
- Burnout

# What We Hope Happens...



# What Actually Happens...



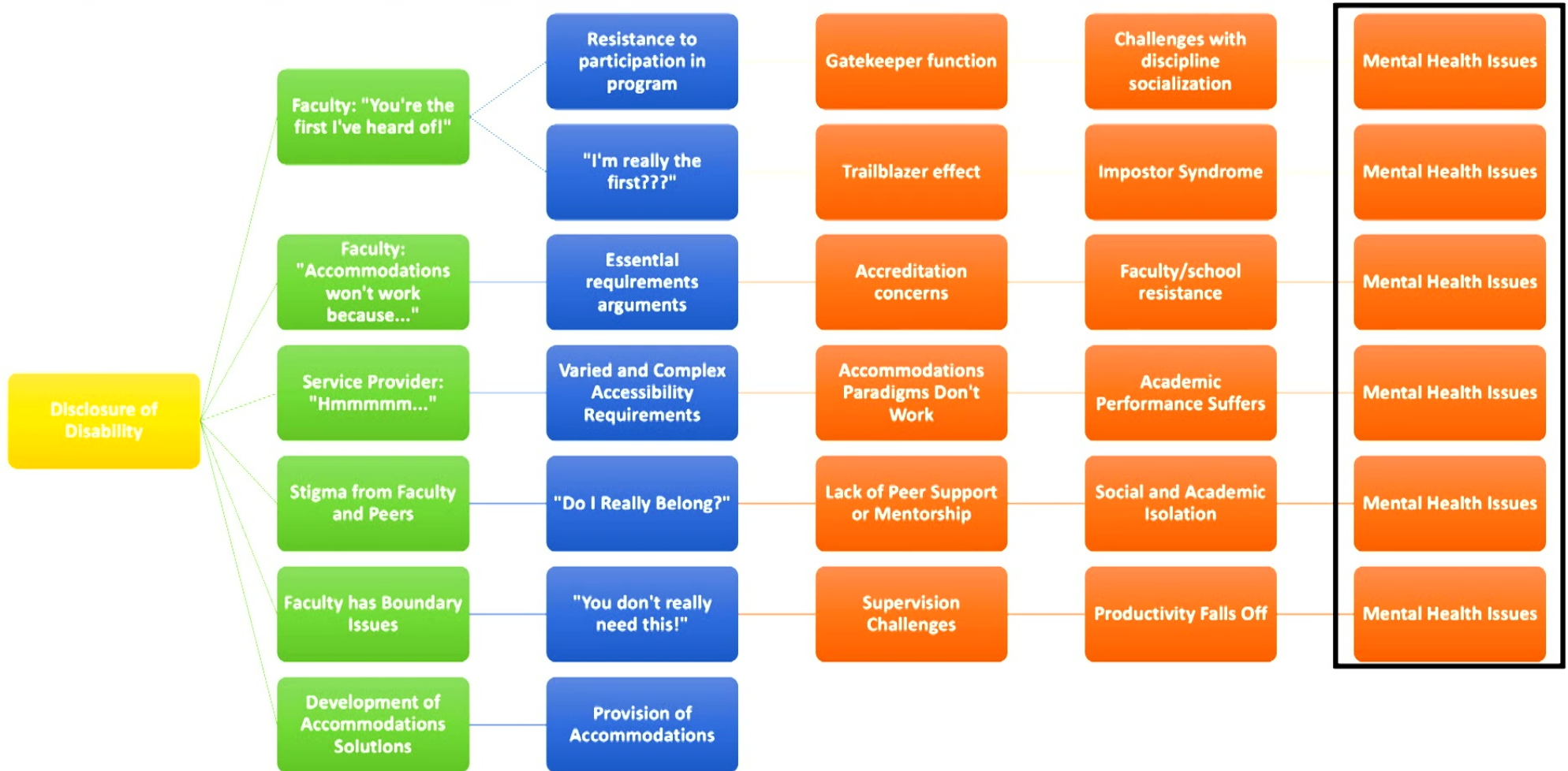
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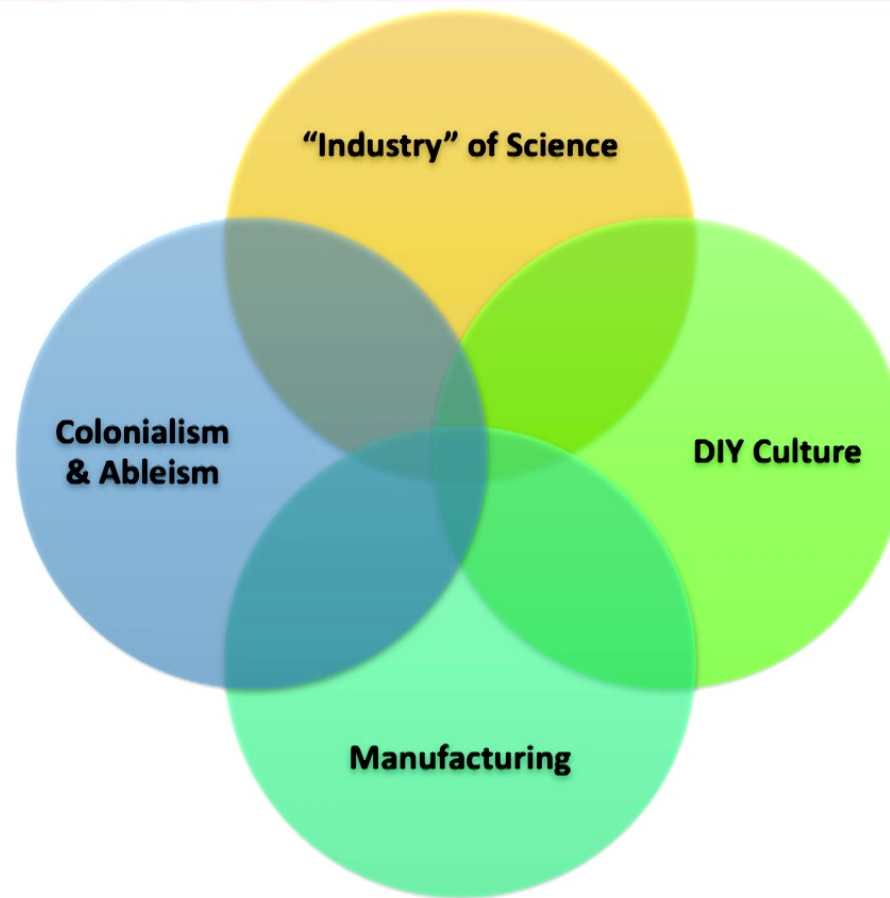
# What Actually Happens...



# What Actually Happens...



# Science and Disability



# Diversity in Thought





# Diversity in Thought (2)



# Diversity in Scientific Teams (2)



# Inclusion in the Research Life Cycle



# Inclusion In...

- Researchers are human, too!
- Who's on the team?
- “Colour-blind” vs. “Colour-aware”
- “Ability-blind” vs. “Ability-aware”
- “Style of thought is the last bastion of diversity”
  - Style of thought is very much dictated by our background and experiences

# Inclusion Of...

- Our research methods
  - Recruitment
  - Data collection
  
- Our research tools
  - Lab technologies
  - Survey platforms
  - Analytic tools/software

# Inclusion And...

- IDEA in research communications
  - Publications
  - Social media
  - Mainstream media

# Inclusion For...

- How do we frame our research questions?
- “If we don’t ask, we won’t know”
- Balance between {privacy, confidentiality} and {effective understanding of confounders and effects}
- Research ethics

# Pillars of Inclusion

- Inclusive perspectives (how we frame our thoughts)
- Inclusive teams
- Accessible documents
- Inclusive research and methodology design
- Accessible data collection methods
- Accessible tools
- Inclusive communications



# Contact Information



## IDEA-STEM

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- Website: [www.idea-stem.ca](http://www.idea-stem.ca)
- Creating a Culture of Accessibility in the Sciences: <http://store.elsevier.com/Creating-a-Culture-of-Accessibility-in-the-Sciences/Mahadeo-Sukhai-/isbn-9780128040379/>