Trainees with Disabilities in the Research Enterprise: Myths, Misperceptions and Resources

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Agenda

• Welcome and Introductions
• Brainstorm
• Project and Key Findings Overview
• The Trainee/Mentor Relationship
• Essential Requirements
• Resources
• Group Discussion
• Wrap-Up
Brainstorm / Icebreaker

• What issues and/or barriers do you envision being faced by trainees (especially postdocs) with disabilities in the research enterprise?
Learning Objectives

• Gain an appreciation for the complexity of the barriers faced by trainees with disabilities within the research enterprise, with a specific focus on transition into and success within the postdoctorate;

• Learn about resources and frameworks that can be implemented at an institutional level to enhance the participation and success of trainees - particularly postdoctoral scholars - with disabilities;

• Understand the national and international context of disability issues within the research enterprise;

• Understand the importance of ongoing data gathering and advocacy approaches in driving the inclusion, participation and success of postdoctoral scholars and other trainees in the research enterprise.
Contact Information / About Me

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Glossary: What is a Disability?

• Disability
  – “...an umbrella term, covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations.” (World Health Organization)
  – “…A complex phenomenon, reflecting the interaction between features of a person’s body and features of the society in which he or she lives. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers.” (World Health Organization)
• Reasonable Accommodation
  – Reasonable accommodation is any change to a job, the work environment, or the way things are usually done that allows an individual with a disability to apply for a job, perform job functions, or enjoy equal access to benefits available to other individuals in the workplace. (US Office of Personnel Management: OPM.gov)
  – [Employers] are required by law to provide reasonable accommodation to qualified individuals with disabilities, unless doing so would impose an undue hardship. (US Office of Personnel Management: OPM.gov)
Glossary: “Undue Hardship?”

- Undue hardship
  - “An action requiring significant difficulty or expense" when considered in light of a number of factors. These factors include the nature and cost of the accommodation in relation to the size, resources, nature, and structure of the employer's operation. Undue hardship is determined on a case-by-case basis. ([ADA.gov](http://ADA.gov))
The Academic Pipeline

UNDERGRADUATE EDUCATION
GRADUATE EDUCATION
POSTDOC TRAINING
FACULTY
The Research Training Pipeline

UNDERGRADUATE EDUCATION

GRADUATE EDUCATION

POSTDOC TRAINING

EMPLOYMENT
Glass Ceilings in The Research Training Pipeline for Persons with Disabilities
1. Filling the Pipeline – increasing the number of trainees with disabilities entering the pipeline

2. Breaking the Glass – increasing the number of trainees with disabilities moving from one stage to the next in the pipeline

3. Fostering Inclusion – enabling full participation of trainees with disabilities at every stage of the pipeline
Postdocs Face Unique Challenges

- Establishing a professional identity
- Seeking balance
- Transitioning to independent careers
- Competing for grants
- Launching career
- Self-promotion
- Relating and working with supervisor
- Coping with perfectionism
- Getting adequate sleep
- Dealing with lab culture
Current Landscape for Trainees with Disabilities

- Established, new and evolving legislative frameworks
  - UN Convention on the Rights of Persons with Disabilities
  - Americans with Disabilities Act

- Increasing numbers of trainees with disabilities entering graduate education

- Evolving needs
  - Mental health
  - Developmental disabilities

- Institution-specific policy and best practice frameworks

- No available data on issues, barriers and experiences
  - Extant studies limited in scope (small numbers; heuristic methods; local/regional)
Statement of Need

• There is a significant need to better understand the overall experiences of trainees with disabilities

• Currently, there is a critical lack of information in this area
  – Need to understand the “experience tapestry”
  – Need to catalogue institutional leading practices
Project Goals

• To examine the experiences of, and barriers faced by, trainees with disabilities

• To develop discussion papers outlining the current system issues for trainees with disabilities

• To produce information and develop strategies to facilitate the success of trainees with disabilities

• To develop recommendations for the continued improvement of training experience for trainees with disabilities, which can be translated into policy at an institutional, provincial, or national level

• Long term: To develop “tool-based” approaches for trainees, faculty and institutions to use in addressing issues faced by trainees with disabilities
Project Outputs

- Taskforce Deliberations
- Research Approaches
- Discussion Papers
- Data Synthesis
- Final Report
- Recommendation Framework
- Resources

National Graduate Experience Taskforce
The Research Training Pipeline

- Attitudinal barriers
- Accommodations in lab, fieldwork setting
- Lack of role models
- Lack of educator and service provider support
- Limited access to summer studentships, internships
- Disclosure
- Essential requirements
The Research Training Pipeline

- Attitudinal barriers
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- Student-supervisor relationship
- Accommodations in lab, fieldwork setting
- Lack of role models
- Lack of educator and service provider knowledge & support
- Lack of funding
- Financial aid
- Academic employment
- Materials in alternative formats
- Flexibility in program design
- Transitional barriers
- Disclosure
- Essential requirements
The Research Training Pipeline

UNDERGRADUATE EDUCATION
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- Flexibility in program design
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- Essential requirements

POSTDOC TRAINING
- Relationship with mentor
- “Selling” probability of success to mentor
- Accommodations in lab, fieldwork setting
- Lack of role models
- Lack of formal support structures (unless in employment setting)
- Differences between employment accommodation and student accommodation frameworks
- Lack of funding
- Materials in alternative formats
- Transitional barriers
- Disclosure
- Essential requirements

EMPLOYMENT

National Graduate Experience Taskforce
Recommendations

- Building knowledge
- Incorporating reasonable accommodations
- Leveling the playing field
List of Recommendations

• Data Gathering
  – Demographics, data collection, data management, data sharing

• Funding and Financial Aid
  – Financial aid landscape, grants and fellowships, accessibility of application processes and information

• Student-Supervisor Relationship & Essential Requirements

• Disclosure and Accommodation
  – Disclosure, accommodation framework, part-time status, leaves and remote residency, alternative formats

• Breadth of the Graduate Experience
  – Online learning, academic employment, admissions, career transitions

• Mental health

• Universal design

• Sustainability & future directions
Recommendations – Graduate Student Applicable

- Demographics and data gathering
- Employment transition
- Admissions
- Online learning

- Building knowledge

- Funding and financial aid
- Universal design
- Mental health
- Role models
- Transition to the postdoc
- Breadth of graduate experience
- Professional development

- Student-supervisor relationship
- Essential requirements
- Disclosure
- Accommodation
- Alternative formats
- Part-time, leaves
- Academic employment

Incorporating reasonable accommodations

Leveling the playing field
Recommendations – Postdoc Applicable

- Demographics and data gathering
- Employment transition

- Funding
- Universal design
- Mental health
- Role models
- Breadth of postdoc experience
- Professional development

- Trainee-mentor relationship
- Essential requirements
- Disclosure
- Accommodation
- Alternative formats
- Part-time, leaves

Building knowledge

Incorporating reasonable accommodations

Leveling the playing field
Disability and the Trainee-Mentor Relationship
Four Domains of the Trainee-Mentor Relationship

- Trainee with disability
  - Trainee discloses accommodation need:
    - Positive supervisor engagement
    - Lack of clarity around expectations
  - Trainee does not disclose accommodation need:
    - Negative supervisor engagement
    - Trainee self-accommodation successful
      - Acute/crisis situation evolves
        - Negative supervisor engagement
    - No supervisor engagement

Factors Influencing the Trainee/Mentor Relationship: Mentor Perspective

- Mentor’s Knowledge of and/or Willingness to Participate in Disability Related Processes
- Mentor’s Knowledge of the Interface between Essential Requirements and Academic Accommodations
- Research Integrity and Accommodations: Authorship Issues
- Academic and Social Integration into the Academy
- Boundary Issues
- Funding Issues
- Trainees in Crisis
Factors Influencing the Trainee/Mentor Relationship: Trainee Perspective

• Disclosure and Stigma

• Preparedness for and Expectations of Training Environment

• Awareness of the Role of the Trainee/Mentor Relationship in research training

• Trainee Identity: Timing and Comfort Level with Disability(ies)

• Self-Accommodation
Defining a New Culture: Essential Requirements in the Graduate Environment

Published online as a 3rd Party Publication by the Canadian Association of Graduate Studies
Essential Requirements

• "Essential requirements of a course or program refer to the knowledge and skills that must be acquired or demonstrated in order for a student to successfully meet the learning objectives of that course or program" (Rose, 2009).
Discussion Questions

• What are the essential requirements of your discipline or program?

• In your experience, how have you thought about the issue of accessibility for trainees with disabilities in the context of the essential requirements of your discipline?
Essential Requirements

• Defined by two factors:
  – Skills that must be necessarily demonstrated in order to meet the objectives of a course
  – Skills that must be demonstrated in a prescribed manner

• It is extremely important to not confound the evaluation method with the actual competency.

• For example, if a student must understand how to design, interpret, analyze and troubleshoot a scientific experiment (“competency”), does this mean that the student must perform the experiment unaided (“measurement”)?
Essential Requirements for Graduate Education

- “General” Essential Requirements (applicable across all disciplines)
- Discipline-Specific Essential Requirements
- Technical Essential Requirements
- “Philosophy of research training” issue – what are the universal definitions of essential requirements?
  - Core competencies discussion!
Framework for Essential Requirements

• NPA Core Competencies
  (www.nationalpostdoc.org)
  – Discipline-specific competency
  – Research skill development
  – Communication skills
  – Professionalism
  – Leadership and management skills
  – Responsible Conduct of Research
Questions for Consideration

• What is being tested?
• What is the nature of the task?
• Does it have to be done in only one way?
  – If so, why?
• Will performing this task in an alternative manner ultimately interfere with the student’s successful performance in the discipline, program or course?
Resources
• From FASEB:
  – “Individual Development Plans (IDPs) provide a planning process that identifies both professional development needs and career objectives. Furthermore, IDPs serve as a communication tool between individuals and their mentors.”

• As applied to graduate students with disabilities:
  – [Graduate students with disabilities] will have a process that assists in developing long-term goals. Identifying short-term goals will give them a clearer sense of expectations [of their program requirements and performance] and help identify milestones along the way to achieving specific objectives. The IDP also provides a tool for communication between the [student] and a faculty mentor.

Adapted from the Federation of American Societies for Experimental Biology
Implementing an IDP

For trainees with disabilities

• Conduct a self-assessment
  – What are my skills?
  – What do I know of the program requirements?
  – Are there areas of potential concern I need to discuss with my mentor?

• Longer-term and short-term goals – research, performance, coursework, professional development and career

• Develop an IDP framework, share with mentor and revise based on their feedback

• Implement IDP

• Check-ins with mentor as needed

For mentors

• Understand the essential requirements of the specific discipline your trainee is in

• Understand available resources and opportunities to assist trainees with disabilities on campus

• Become familiar with available career and professional development opportunities

• Discuss opportunities with the trainee

• Review IDP and help revise

• Establish regular review of progress and help revise IDP as needed

Adapted from the Federation of American Societies for Experimental Biology
Thought Frame for Interacting with Issues faced by Trainees with Disabilities

• What is/are the issue(s) the trainee faces?
• Are they disability-related? Systemic/structural? Both? Neither?
• Is there any information that you don’t have that you feel like you need? Who might have this information? Where can you go to get it?
• Can the trainee’s issues be solved without accommodation or the application of universal design principles?
Thought Frame for Interacting with Issues faced by Trainees with Disabilities

- Do they impact on the trainee’s opportunity to participate fully in the field, research group, work setting?
- What are the likely solutions to these issues? What precedents do you have within the institution?
- Which solutions will meet the duty to accommodate without...
  - Contravening essential requirements?
  - Demonstrating undue hardship?
- Who do you need to work with to implement these solutions?
Resource Development

FACULTY AND STAFF PROFESSIONAL DEVELOPMENT

INSTITUTIONAL RECEPTIVITY AND AWARENESS

RESOURCE GUIDES AND TOOLKITS

TRAINEE PREPAREDNESS
Overall Conclusions

• Issues faced by trainees with disabilities in the research enterprise are complex and multi-faceted
  – Disability-specific considerations (disclosure, accommodation)
  – Systems issues influenced by disability (student-supervisor relationships, employment)

• Perceptual disconnects can exist among trainees, faculty and staff as to the “real” issues

• Trainee expectation vs. reality – importance of the systemic differences across the length of the training pipeline

• Community ownership of the project outcomes is required in order to move toward a universally accessible training environment
Axioms

• Research training – including the postdoctorate – is not “one size fits all”

• Training programs are dynamic and evolve in the lifetime of a trainee’s path to completion

• Disability issues in research training require collaboration – information/accommodation compartmentalization is inefficient
Discussion Questions

• What kind of resources, training etc would enable you to better assist trainees with disabilities in obtaining the supports they need to help them with the completion of their program?

• What action do, or have, you taken to help trainees feel comfortable in disclosing their disabilities to you?
Discussion Questions

• What are your institutional best practices (departmental, faculty, university) that have been successful in working on these issues? How do you assess that these best practices are working as intended?

• How can we foster increased collaboration and dialogue among relevant stakeholders at the institutional level?

• How can we move beyond dialogue to actually implementing action that benefits stakeholders?

• What resources/support systems would be most helpful to you in future work in this area?
Synthesis and Wrap-Up

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