Graduate Students with Disabilities: Myths, Misperceptions and Resources

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National Graduate Experience Taskforce May 06, 2016



Icebreaker

 What issues and/or barriers do you envision being faced by trainees (especially graduate students) with disabilities in the research enterprise?



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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)



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Glossary: Reasonable Accommodation

- 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)



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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*)



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The Research Training Pipeline



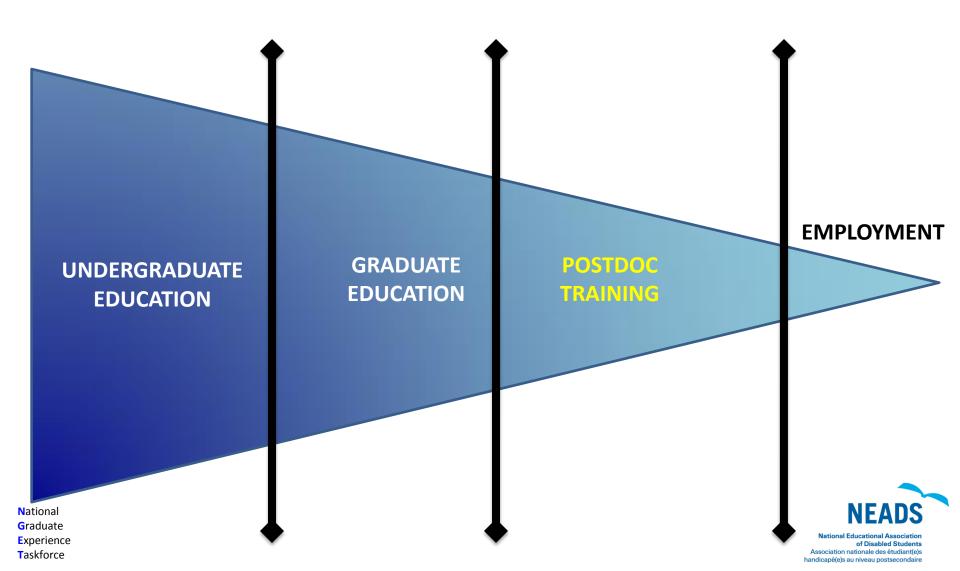
GRADUATE EDUCATION POSTDOC TRAINING

EMPLOYMENT



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Glass Ceilings in The Research Training Pipeline for Persons with Disabilities



Solutions?



- 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

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Current Landscape for Trainees with Disabilities

- Established, new and evolving legislative frameworks
 - UN Convention on the Rights of Persons with Disabilities
 - AODA (2005) and associated standards
 - Provincial human rights codes
 - Evolution of a Canadians with Disabilities Act
- Increasing numbers of trainees with disabilities entering graduate education
- Evolving needs

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- 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

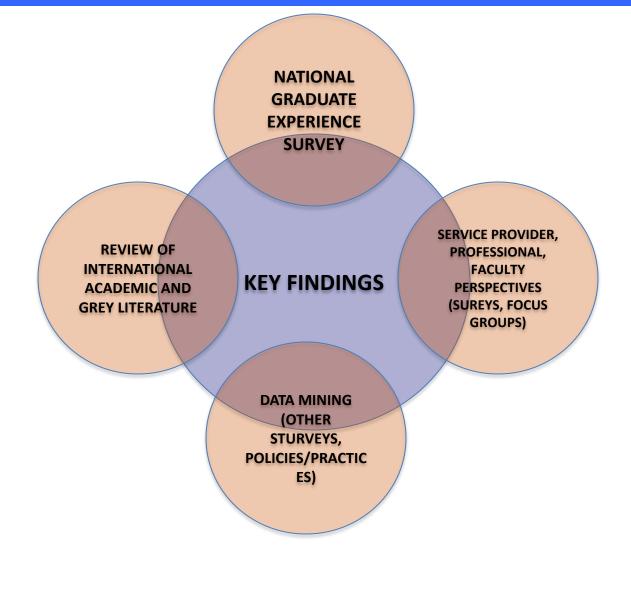
- To examine the experiences of, and barriers faced by, trainees with disabilities
- To develop discussion papers outlining the current system issues for trainees with disabilities
- To produce information and develop strategies to facilitate the success of trainees with disabilities
- To develop recommendations 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 "toolbased" approaches for trainees, faculty and institutions to use in addressing issues faced by trainees with disabilities



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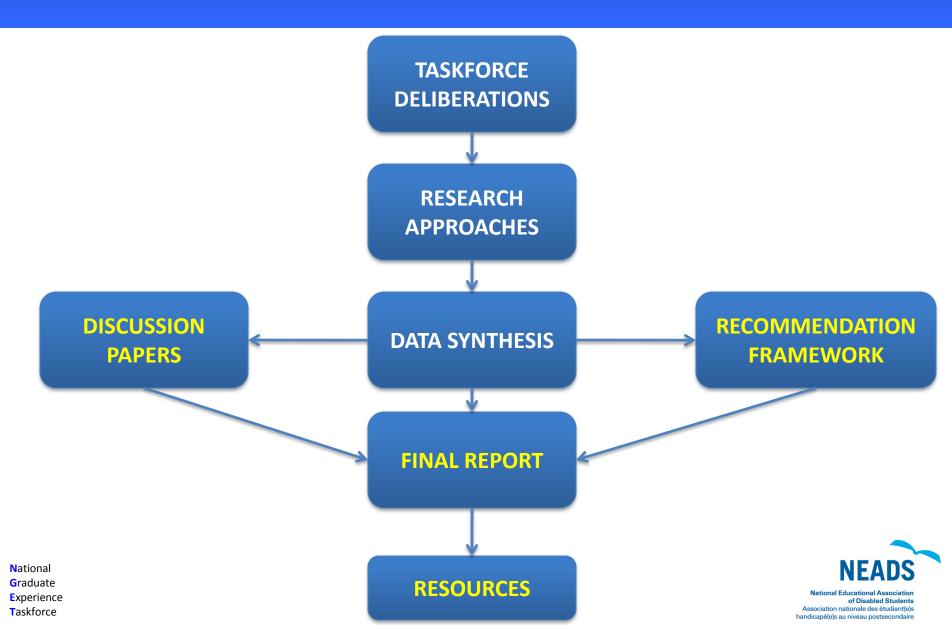
Research Methodology



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Project Outputs



 MYTH: Graduate students with disabilities as a group take longer to complete their programs of study than nondisabled peers



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- MYTH: Graduate students with disabilities as a group take longer to complete their programs of study than nondisabled peers
- **REALITY**: Time to completion is very dependent upon type of program, and the student's disability.
 - Students in professional stream Master's programs take longer to complete
 - No evidence that this is true for students in PhD programs
 again, except in specific cases influenced by disability
 and field



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• MYTH: Disability accommodations negatively impact academic rigour



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• MYTH: Disability accommodations negatively impact academic rigour

 REALITY: Appropriately designed accommodations take into account the essential requirements of the discipline and program, and have no impact on academic rigour



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 MYTH: Disability accommodations are "cheating" – the student has to complete the program on their own



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 MYTH: Disability accommodations are "cheating" – the student has to complete the program on their own

 REALITY: Much of research – particularly in the sciences – is team-oriented and collaborative; the student needs to be held to the same standards as their peers

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 MYTH: Disability accommodations are "cheating" – the work the student produces is not their own, and the student doesn't know as much as their peers as a consequence



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- MYTH: Disability accommodations are "cheating" the work the student produces is not their own, and the student doesn't know as much as their peers as a consequence
- **REALITY**: Human assistance in the context of accommodation (e.g., scribes, technical assistants in labs and fieldwork) requires the student to be over-prepared compared to their peers, rather than under-prepared. If appropriately designed and implemented, this type of accommodation forces the student to take additional ownership of their subject matter.



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 MYTH: Disability accommodations lead to academic integrity and intellectual property challenges



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- MYTH: Disability accommodations lead to academic integrity and intellectual property challenges
- REALITY: Students reported very few discussions or concerns raised around academic integrity, intellectual property or responsible conduct of research in the context of disability and their graduate training.



 MYTH: Disability accommodations are expensive



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 MYTH: Disability accommodations are expensive

 REALITY: 90% of accommodations cost less than \$500 to implement. Accommodation planning requires careful and collaborative thought on the part of the supervisor, Accessibility Services and the student.



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 MYTH: Graduate students will only need classroom accommodations



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- MYTH: Graduate students will only need classroom accommodations
- **REALITY**: The breadth of the graduate environment is extensive – class work is a minor component of graduate degrees, especially in research stream programs at the PhD level. The graduate student with a disability may well require accommodations in additional graduate settings – seminars, labs, libraries, archives, fieldwork, conferences, etc.



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• MYTH: Accommodations at the graduate and undergraduate levels will be similar



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• MYTH: Accommodations at the graduate and undergraduate levels will be similar

 REALITY: Accommodation in the graduate setting needs to be evaluated based on the likely scenarios the student will find him- or herself in, and should be approached without an "undergraduate bias"



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 MYTH: Faculty do not need to be engaged in the discussion around disability in graduate education



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- MYTH: Faculty do not need to be engaged in the discussion around disability in graduate education
- REALITY: The student-supervisor relationship is critical in many aspects of graduate training; faculty need to be educated about disability issues and the interaction between the graduate environment and disability



The Research Training Pipeline

UNDERGRADUATE EDUCATION

GRADUATE EDUCATION POSTDOC TRAINING

EMPLOYMENT

- 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

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The Research Training Pipeline

UNDERGRADUATE EDUCATION

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- Attitudinal barriers
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- Disclosure

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• Essential requirements

• 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



Recommendations

Building knowledge

Incorporating reasonable accommodations

Leveling the playing field



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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

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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

National Graduate Experience Taskforce Incorporating reasonable accommodations

Leveling the playing field

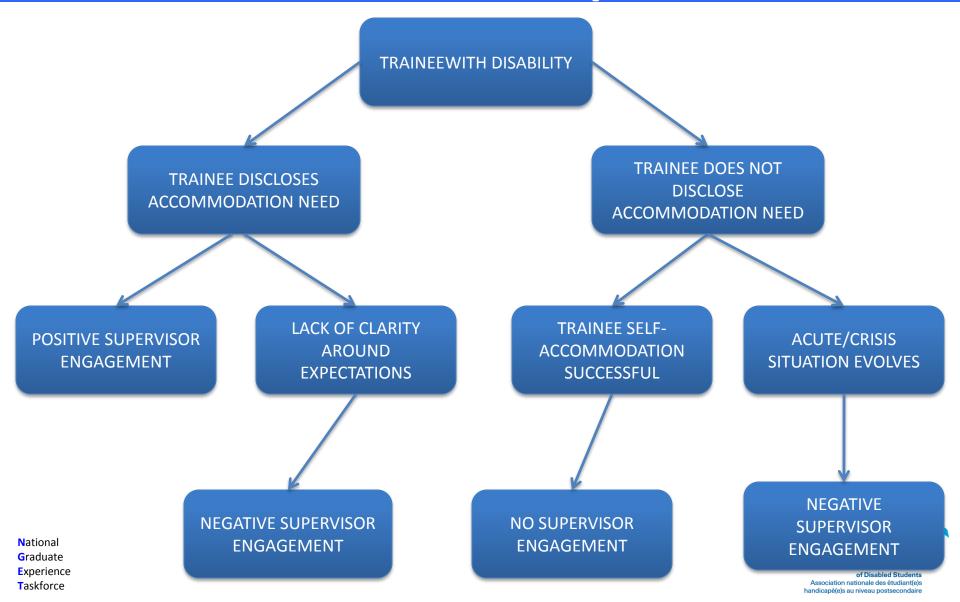


Disability and the Student-Supervisor Relationship



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Four Domains of the Student-Supervisor Relationship



Factors Influencing the Student-Supervisor Relationship: Supervisor 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

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Factors Influencing the Student-Supervisor Relationship: Student Perspective

- Disclosure and Stigma
- Preparedness for and Expectations of Training Enfironment
- Awareness of the Role of the Trainee/Mentor Relationship in research training
- Trainee Identity: Timing and Comfort Level with Disability(ies)
- Self-Accommodation

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Defining a New Culture: Essential Requirements in the Graduate Environment

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



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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).



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")?



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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!

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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



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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?



Student Disclosure and Accommodation in the Graduate Environment

Disclosure Discussion Paper, Submitted, CACUSS Communique

Student Disclosure tipsheet published, CACEE Career Options



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Disclosure in the Graduate Environment

- At the graduate level, disclosure of a disability or accommodation need is as much a process as it is an event, and will evolve throughout a student's course of study
- Disclosure of the accommodation need by the student may occur to several individuals (faculty, department heads, etc) before the accommodations can be discussed by a team



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Graduate Students are Developing their own Accommodations



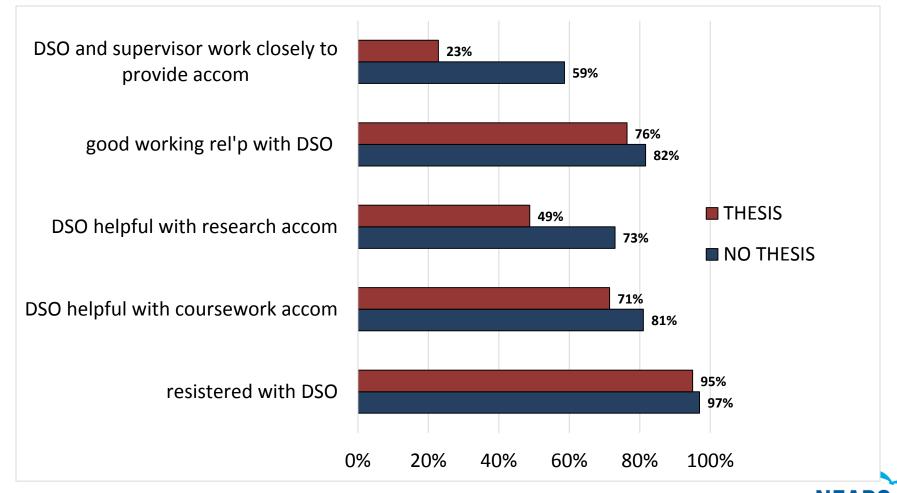
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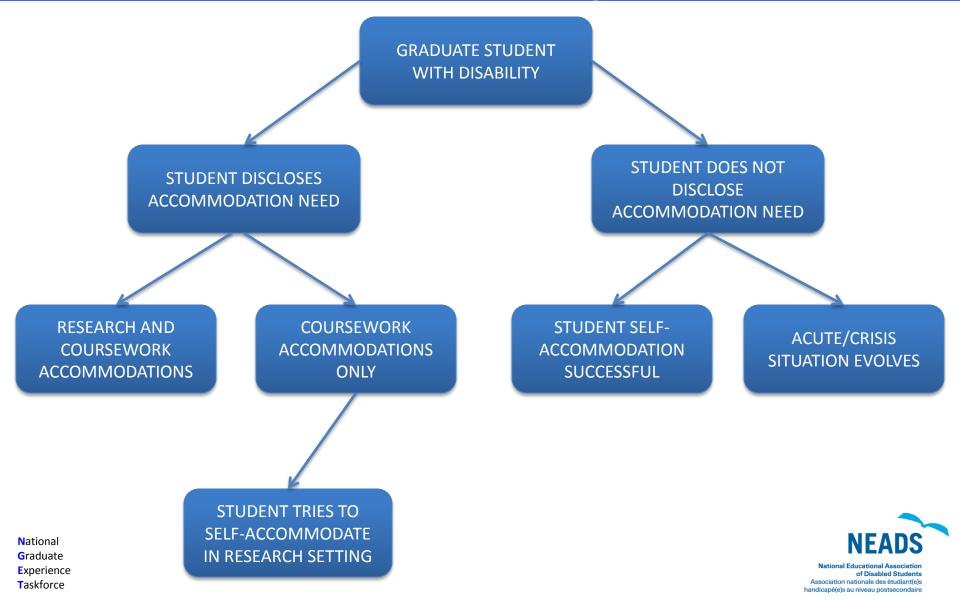


Student-DSO Relationship



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Four Domains of the Student-DSO Relationship



Mental Health and Graduate Education



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Context and Framing Thoughts

- High-Stress Environments
- Mental Health Stigma
- Invisible and Ignored
- Critical areas to be addressed:
 - Self-assessment
 - Awareness of signs of undue stress
 - Challenge as a disability
 - Needed resources
 - Best practices
 - Accommodations for a healthy workplace



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Research Trainees Face Unique Challenges

- Establishing a professional identity
- Seeking balance
- Competing for fellowships/grants
- Launching career
- Self-promotion

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- Relating and working with supervisor
- Coping with perfectionism
- Getting adequate sleep
- Dealing with research and graduate culture



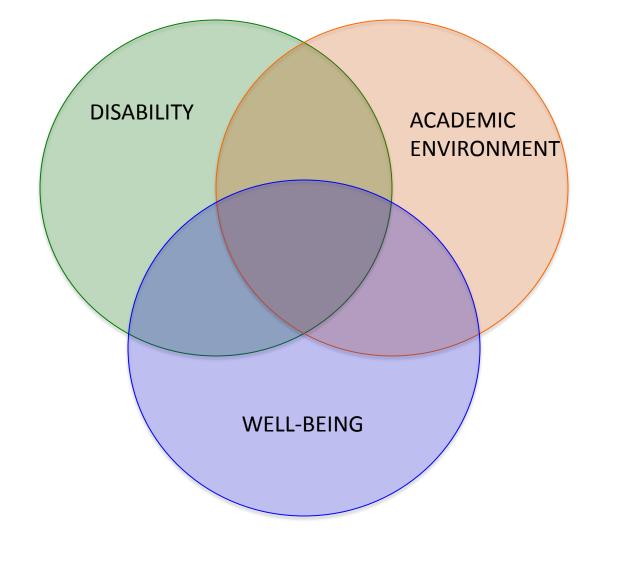
Where can Mental Health Issues evolve from?

- Power dynamic between trainee and mentor
- Culture shock and acclimatization/assimilation
- Separation from family and support network
- Isolation
- Imposter syndrome
- Earlier stresses (e.g., undergrad, life events)
- Family situations
- "Confounders" (e.g., disability)



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Factors Influencing Mental Health in Graduate Education



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Key Findings – Students with Mental Health Disabilities in Graduate Education

- Two populations:
 - Students with mental health and psychiatric disabilities primarily
 - "Co-occurrence" of multiple disabilities
- Disclosure, Stigma, and Advocacy
- Attitudinal Barriers

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• Student-Supervisor Relationship, Support Systems and Identification of Times of Acute Stress



Key Findings – Students with Mental Health Disabilities in Graduate Education

- Institutional Provision of Accommodation vs. Self-Accommodation
- Leaves and Funding, Financial Aid and Scholarship Eligibility
- Safe Spaces for Dialogue; Peer Mentorship

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 Interface between Academic Employment and Academic Program Environments



Resources

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Framework for Application: The IDP

• 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.

National Graduate Experience Taskforce 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



National Graduate Experience Taskforce Adapted from the Federation of American Societies for Experimental Biology

Thought Frame for Interacting with Issues faced by Trainess with Disabilities

- What is/are the issue(s) the trainee faces?
- Are they disability-related?
 Systemic/structural? Both? Neither?

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- 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

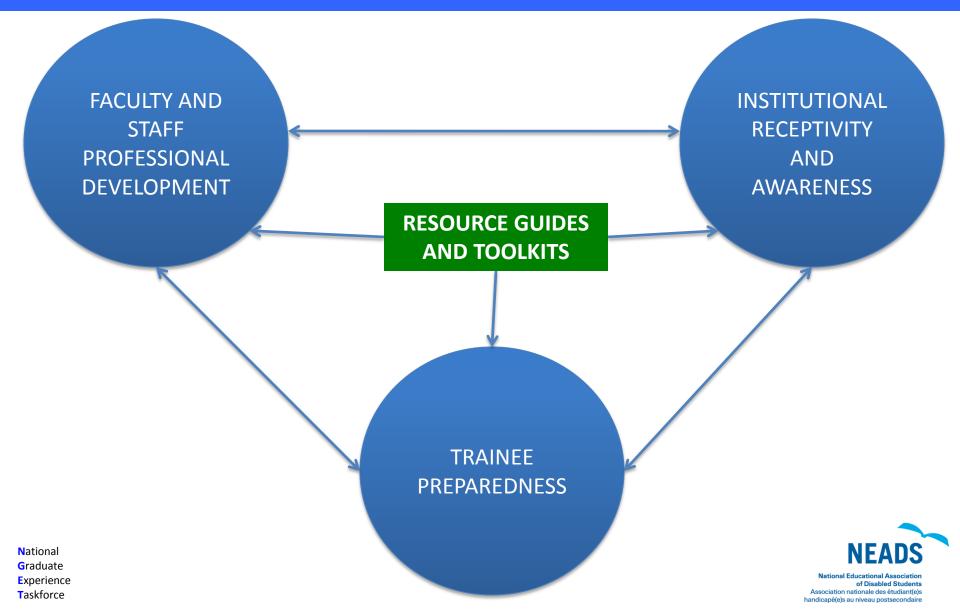
- Do they impact on the trainee's opportunity to participate fully in the field, research group, work setting?
- What are the likely solutions to these issues? What precedents do you have within the institution?
- Which solutions will meet the duty to accommodate without...
 - Contravening essential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



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Resource Development



Overall Conclusions

- Issues faced by trainees with disabilities in 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



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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



Synthesis and Wrap-Up

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