

Disabled in the field: navigating nature and academia as a disabled scientist



John Innes Centre

Unlocking Nature's Diversity

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Field Inclusive #FieldInclusiveWeek 2023

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Talk overview

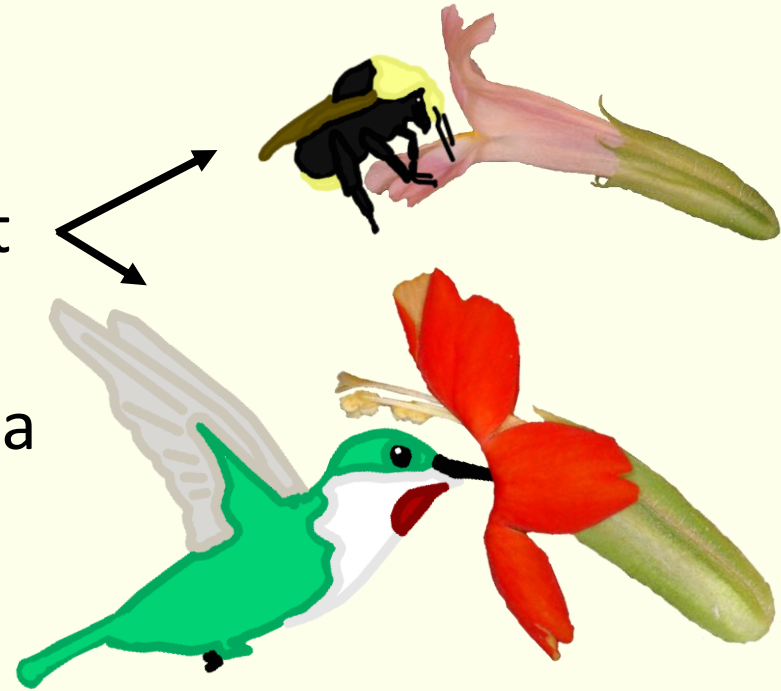
1. A little bit about me and how I identify
2. Some basic concepts around disability
3. Disability in the fieldwork setting
4. Disability in other difficult settings
5. Summary

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Who am I? How do I identify?

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- Research: plant-pollinator interactions, floral scent
- Originally from the USA
- From a family of scientists, 2/3 parents in academia

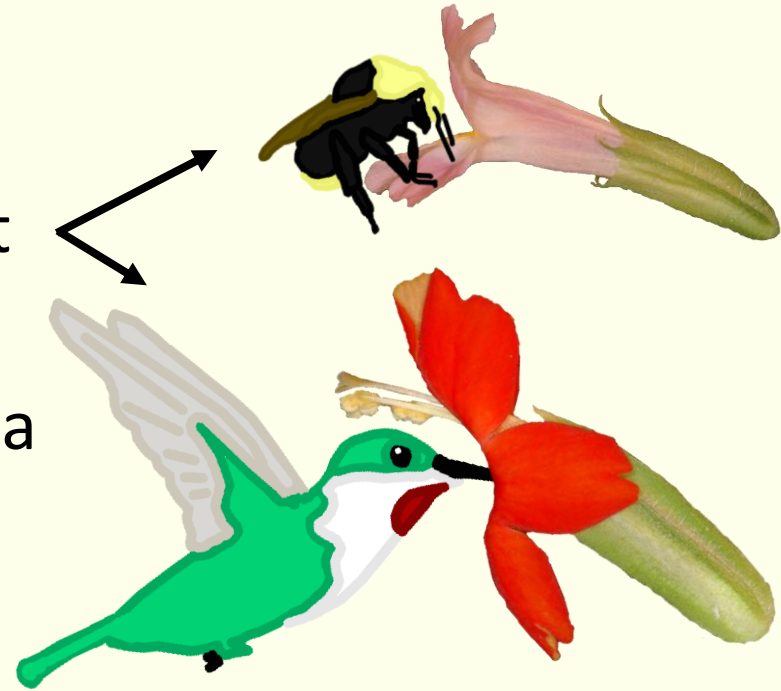
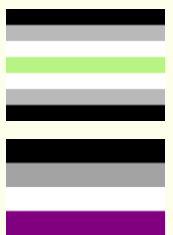


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- I identify as:

- Multiply disabled
- Agender (any pronouns are fine!), assigned female at birth (AFAB)
- Asexual
- Queer
- Otherwise carrying plenty of privilege (white, scientific family, etc.)



- Early childhood: **socially weird, issues with concentration, hearing** issues due to chronic ear infections
 - Age ~6-7: **stomach** problems start
 - Age 13: **knees** start hurting, get first joint braces
 - Age 15: **wrists** start hurting, **dislocate** first joint
 - Ages 18-22: everything else starts hurting, start **falling asleep** all the time
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- Age 23: diagnosed with **Joint Hypermobility Syndrome** (10 year delay post symptoms)
- Age 23: start occasional **cane** use
- Age 24: first start identifying as **disabled, start advocacy work**
- Age 25: **heart** starts acting up, start being **lightheaded** all the time
- Age 26: diagnosed with **Postural Orthostatic Tachycardia Syndrome** (6 month delay post symptoms)
- Age 29: diagnosed with **Hypermobile Ehlers-Danlos Syndrome** (16 year delay post symptoms)
- Age 30: diagnosed with **Gastroparesis** (24 year delay post symptoms)
- Age 31: diagnosed with **Narcolepsy** (13 year delay post symptoms)
- Age 31: start continuous **crutch** use
- Age 32: start **mobility scooter** use ~half time
- Age 35: start using **wheelchair** most of the time
- Age 35: diagnosed with **ADHD** (symptoms since childhood, ~30 year delay post symptoms)
- Age 36: diagnosed with **Auditory Processing Disorder** (symptoms since childhood, ~30 year delay post symptoms)
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What do I mean when I say “disabled”?

- Disability is “a physical or mental impairment that has a ‘substantial’ and ‘long-term’ negative effect on your ability to do normal daily activities” (UK Equality Act 2010) and a disabled person is a “person who has a physical or mental impairment that substantially limits one or more major life activities” (USA Americans with Disabilities Act 1990)
- People with chronic illnesses and/or Deaf people do not always identify as disabled, yet are entitled to the same legal protections
- I say “multiply disabled” because I have multiple health conditions that “count” as disabilities and affect different aspects of my daily activities differently

A brief note on terminology

- Why do I say I am a “disabled scientist” instead of a “scientist with disabilities”?
- Identity-first versus person-first language
- Usage varies depending on specific disability community norms (e.g. autistic folks generally prefer ‘autistic’ to ‘person with autism’ whereas professionals generally prefer the latter¹)
- For me, being disabled is inseparable from my life experience – it colours every aspect of my life – so I prefer identity-first language
- Important to respect an individual’s preferred terminology

¹Lydia Brown (2011) *“The Significance of Semantics: Person-First Language: Why It Matters.”*

Disability: invisibility

- Am I disabled?



Disability: invisibility

- Am I disabled?
- How about now?



Disability: invisibility

- Am I disabled?
- How about now?
- Does this “count”?



Disability: invisibility

- Am I disabled?
- How about now?
- Does this “count”?
- How about this time?



Disability as an axis of human diversity

- Disability often not considered an axis of diversity
 - Sometimes due to legal/privacy reasons
 - More often due to a history of exclusion/societal assumptions (e.g. assuming disabled people can't work/study) and seeing disability as a legal enforcement category rather than an underrepresented minority

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- Result: few scholarships, grants, DEI efforts, etc made with disability in mind
- End result: low participation of disabled folks in STEM due to lack of support, mentorship, exhaustion of constant access battles, etc

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- End result: low participation of disabled folks in STEM due to lack of support, mentorship, exhaustion of constant access battles, etc
- Statistics 1 (UK): 4.8% of higher education staff have a declared disability¹ vs. 19% of working age adults²
- Statistics 2: 10.8% of (mainly USA) evolutionary biologists have a declared disability³ vs. 26% of the US population³

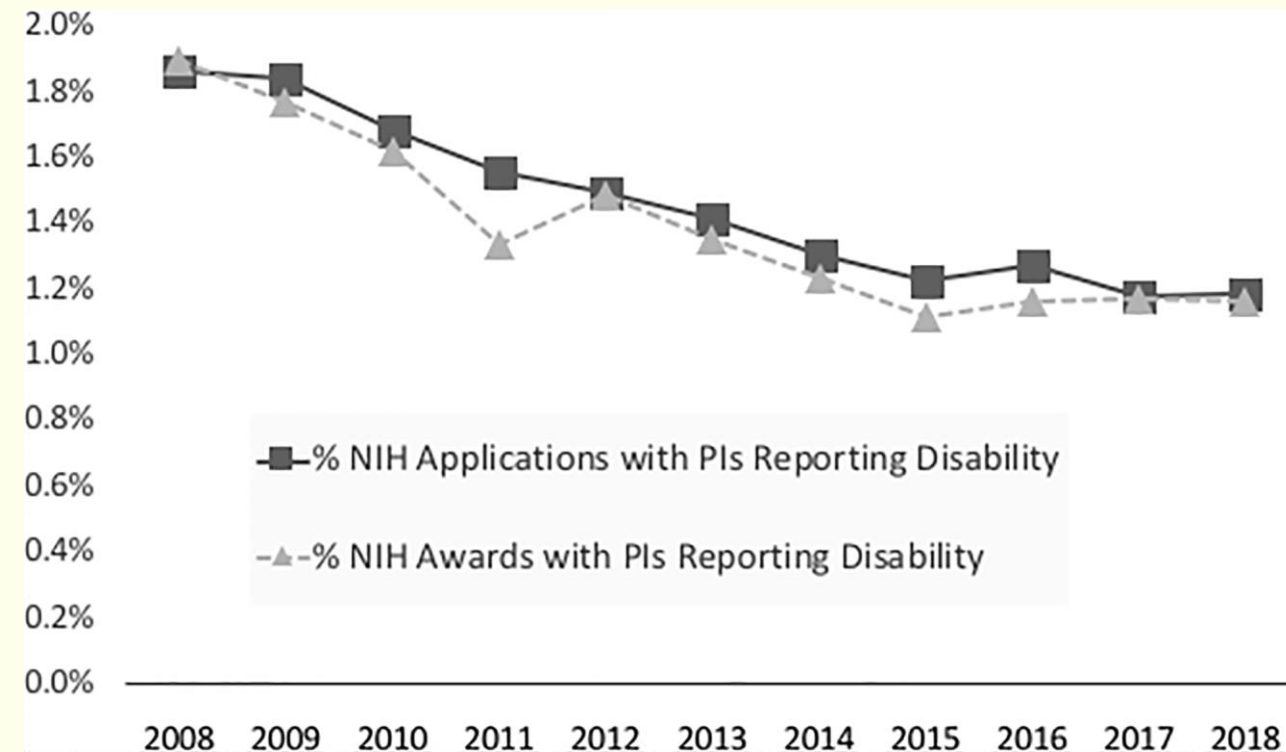
¹HESA data (2014-2020)

²SCOPE Family Resources Survey (2019-2020)

³Rushworth et al. (2020) *Evolution*

USA statistics: grant applications and awards

“The percentage of NIH grant applicants with PIs reporting a disability significantly declined from 1.9% in 2008, to 1.2% in 2018 ($p < 0.001$). Data on grant awardees was similar, 1.9% of awards in 2008, declining to 1.2% in 2018 ($p < 0.001$) had PIs reporting a disability. Across all years, the percentage of applications and awards with PIs reporting visual disabilities was lower than the percentage reporting mobility/orthopedic, or hearing disabilities (16.5%, 34.2%, and 37.8% in 2008, respectively). **Overall grant success rates differed by disability status** (27.2% for those reporting disability vs 29.7% in those reporting no disability, $p < 0.001$)... **These results underscore the underrepresentation of researchers with disabilities among grant applicants and awardees, and indicate lower grant success rates among PIs reporting disabilities.**”



Swenor, Munoz, & Meeks (2020) “A decade of decline: Grant funding for researchers with disabilities 2008 to 2018”. *PLOS ONE* 15(3):e0228686.

It's not just me... or the statistics

“Our personal experiences of academic careers in STEM suggest that **there are considerable barriers for people with disabilities**. In our home universities and research institutes, or while attending conferences or on research trips, **it is very rare for us to meet other colleagues with disabilities**. This apparent lack of representation and diversity reflects a reluctance to disclose disabilities where perceived stigmas persist (such as mental health issues), combined with barriers that tend to exclude disabled people, including assumptions by prospective employers and colleagues that people with disabilities will be less competent researchers.”

– Upchurch & Vann (2021), “Trends on students and staff with disabilities in STEM”, Royal Society (UK) blog post (emphasis mine)

A few major models of disability

- Medical Model: deficit model, “what is wrong with the patient” – the typical model within society
- Social Model: disability is imposed by societal structures (physical and otherwise) – the main model in disability studies/disability rights movements
- Biopsychosocial Model: incorporates parts of both – used by the WHO [my preferred model, mostly because the Social Model ignores that my disabilities can still be disabling even if society is perfectly accommodating]

Intersectionality

- Coined by Kimberlé Williams Crenshaw in 1989
- Idea: aspects of identity combine (intersect) to affect discrimination and privilege
- e.g. I am not a person who is white and disabled and queer, I am a white disabled queer person – you cannot separate my identities, the effects are not additive but instead combinatorial

Intersectionality: my specific situation

- As a queer disabled person, I am intersectional
- Issues I have run into:
 - Society says I am asexual because I am disabled...¹
 - Disability rights movement says I am asexual because of internalized ableism...¹
 - when in fact I'm just asexual and it has nothing to do with my disability
 - but! my gender might have something to do with my ADHD and autism²
 - queer-friendly spaces (bars, meetups, conference socials, Pride, etc) are often not accessible! and not all disability spaces are queer-friendly either

¹ Kim (2011) *Sexualities*; Lund & Johnson (2015) *Sex Disabil*

²Strang *et al.* (2014) *Archives of Sexual Behavior*

What are we being paid for?

- Are we being paid for our ability to do manual tasks, or our ability to think?
 - If manual tasks... why do we require a PhD for many independent positions?
 - This argues we could hire other people to do manual tasks if we cannot do them ourselves
- Labwork is a great example of an inherently inaccessible environment... but it needn't be
- Office work tends to be more readily made accessible – but this can be a trap
- Fieldwork requires creativity and planning but can be made accessible too!

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geography
 research
 anthropologist
 human geography
 survey
 beach
 clipart
 biology
 ethnography
 science



Royal Geographical Society - Fieldwor...
rgs.org



Summertime Geography Fieldwork ...
wgs.org



Royal Geographical Society - Fieldw...
rgs.org



Fieldwork within the geography curriculum
geography.org.uk



Fieldwork - Biology
edgehill.ac.uk



Fieldwork within the geography curriculum
geography.org.uk



GCSE & A Level Geography Fieldwork ...
field-studies-council.org



Geography fieldwork - Cranleigh ...
cranprep.org



8 Tips for Surviving Fieldwork ...
discoverphds.com



Geography fieldwork - University Of ...
worchester.ac.uk



Fieldwork: Geography and Environmental ...



Fieldwork in the rain ...



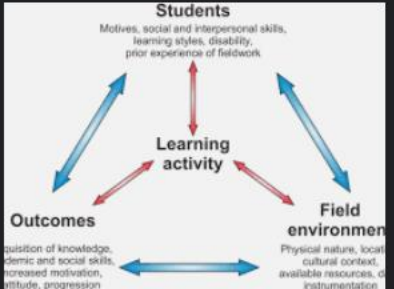
Geography Fieldwork - Notting Hill and ...



Year 12 Geography Fieldwork | All ...



Female researchers join forces to make ...



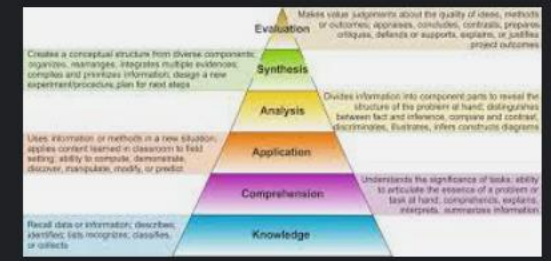
Fieldwork and disability: an overview ... cambridge.org



Accessibility and Fieldwork in the Ti... eos.org



Creating Spaces for Geoscientists w... eos.org



Fieldwork and disability: an overview ... cambridge.org



An accident didn't stop this ge... sciencenewsforstudents.org



Field trips and off campus learning ... plymouth.ac.uk



Academia's ableist culture laid bare nature.com



Geology for everyone: Making the fi... earthmagazine.org



ACADEMIA'S ABLEIST ... media.nature.com



How to play fair in fieldwork | Times ... timeshighereducation.com



Fieldwork at the DDDC | Douglass ... dddc.rutgers.edu



Returning to Egypt: acquired disability ... ox.ac.uk



Ensuring a Diverse Workf... duq.edu



Inclusive, Accessible, Ar... heacademy.ac.uk



Fieldwork Site List | Disability Stud... disability.uoregon.edu



PDF) Fieldwork and disab... researchgate.net



PDF) Disabled Students ... researchgate.net

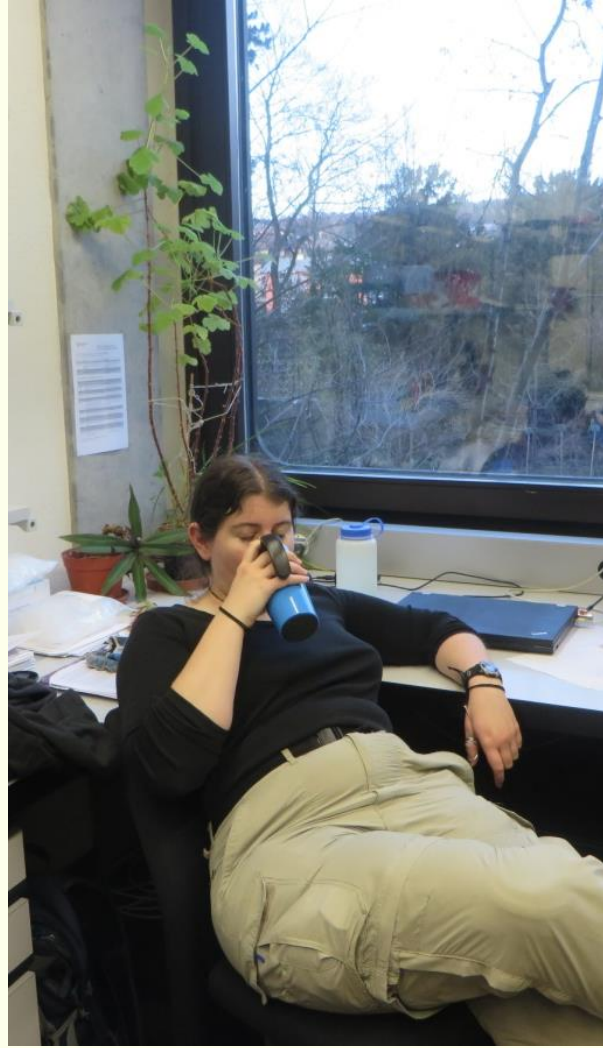


Fieldwork | Undergraduate Study ... exeter.ac.uk



Disability Accommodation and Access ... saic.edu

Which of these people is a field biologist?



Which of these people is a field biologist?

(me, no fieldwork yet)



(me, fieldwork-experienced)



Disability in the fieldwork setting

- Often treated as “optional” or a “special case” but may be a *fundamental* part of a person’s research – *or* a person is not hired because they are seen as “unable” to do the essential fieldwork for a job
- Assumption is usually made that a disabled person cannot do fieldwork, due to *inability* or *risk management/liability*
- Most fieldwork can actually be modified... with a little creativity and a great deal of communication and thinking ahead

What barriers and threats do disabled fieldworkers face?

- Environmental threats: inability to remove self from dangerous situations (wildlife, livestock), perhaps higher probability of injury, risks of lone working with some medical conditions (e.g. epilepsy, POTS)
- Communication threats: inability to communicate with the public **and authorities** if relevant disabilities present (e.g. person is d/Deaf/hard of hearing or nonspeaking/nonverbal, neurodivergence as well) – this also applies to language barriers in general!
- Assumptions about competence as a barrier: colleagues and fieldwork team leads assuming things about an individual's competence to perform fieldwork tasks

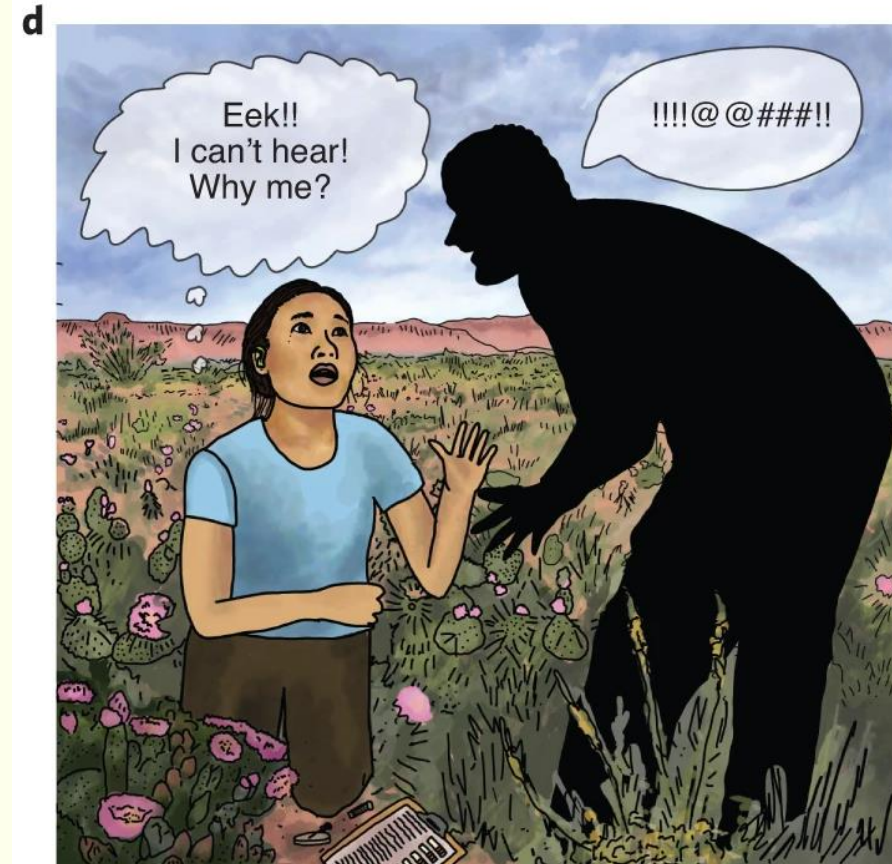


Figure: Demery & Pipkin (2021) *Nature Ecology and Evolution*

Questions when planning fieldwork

- What are the actual *fundamental tasks* involved?
- Does *every* individual need to perform *every* task?
- What *other extra factors* (accommodation, transport to the site) can be modified?
- How does *this particular individual's disability* affect their ability to do the fundamental tasks?
- What *accommodations can be made* to enable as much participation as possible?

Case study: Kelsey and the entomology class field trip: fatigue/chronic health conditions



Case study: Kelsey and the entomology class field trip: fatigue/chronic health conditions

Abled instructor's view

- *Fundamental tasks*: Explore many habitats on foot, catch lots of insects, pin and identify them all the same day
- *Every individual*: yes, all students must do it all together
- *Extra factors*: transportation involves hiking on forest roads and over rocky terrain, accommodation is in rickety bunks
- *Particular disability* not considered/assumptions made about ability to get by without sleep
- *Accommodations* not considered – it's every person for themselves

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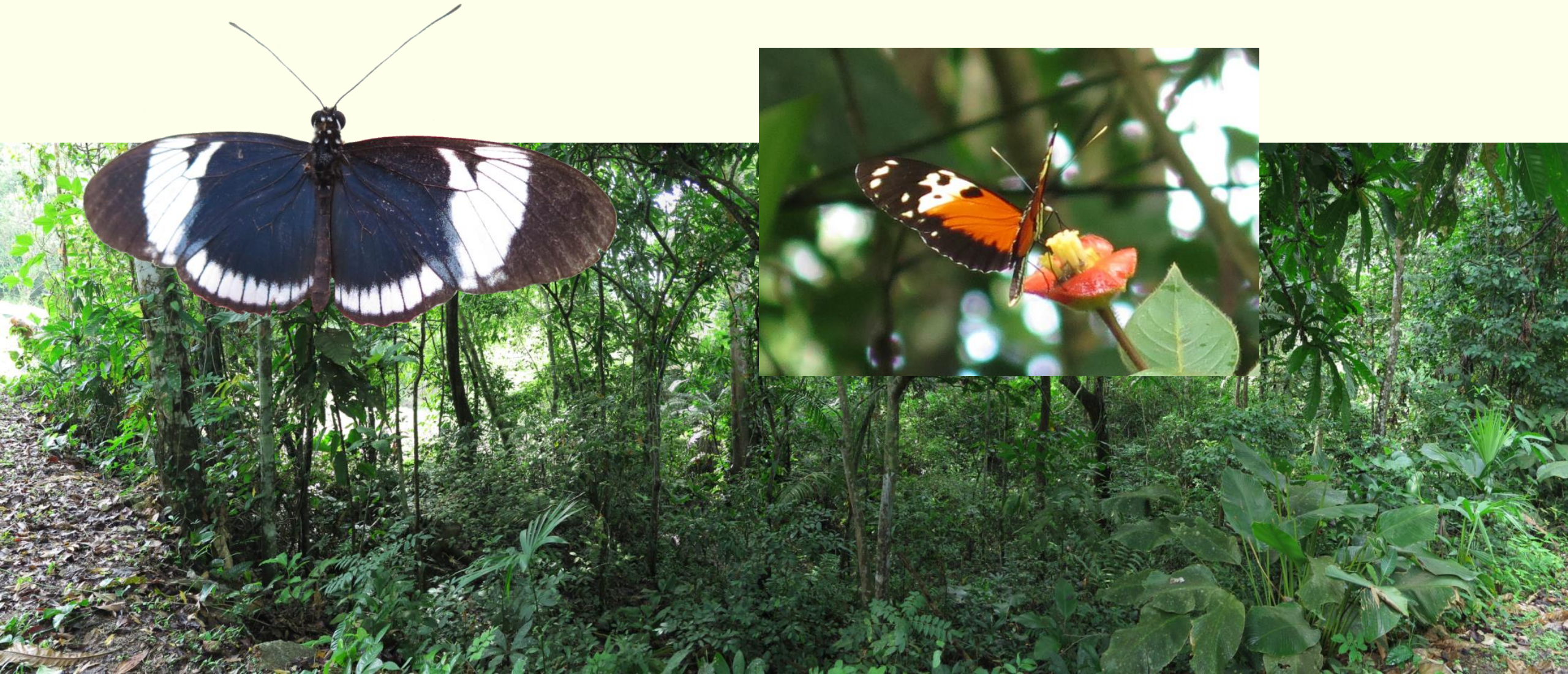
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Actual reality

- *Fundamental tasks*: catch, pin, ID insects in novel habitat
- *Every individual*: could put students in teams – some catch, some pin/ID
- *Extra factors*: consider better accommodations, sampling closer to field station vs hiking or split class in half (some hike, some stay close)
- *Particular disability*: move slow through terrain, communicate about the situation in advance & throughout, set a “stop work” time for sleep and dinner
- *Accommodations*: don't require students to sacrifice sleep for science

Case study: Kelsey and the butterflies in the rainforest of Panamá: mobility disability/fatigue



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Abled colleagues' view

- *Fundamental tasks*: hike into the deep forest, chase butterflies, catch butterflies, hike back to car
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Actual reality

- *Fundamental tasks*: catch butterflies
- *Every individual*: drop off Kelsey along drivable road, pick up later
- *Extra factors*: stay on drivable road
- *Particular disability*: butterflies come to focal plants so sitting in front of them works well
- *Accommodations*: pack a stool to sit on, plenty of water

Case study: Kelsey and fieldwork in Yosemite National Park: fatigue/chronic health/mobility disability

- Team got to the field site, need to carry ~100 plants in 8L/2 gallon pots up a hill (uneven footing) from the parking lot
- These plants are too heavy for me to carry safely (POTS, bad joints)
- Immediate change of plan: I designed the experimental layout while sitting in the parking lot on my laptop
- Colleagues took direction from me as to where to put each plant
- End result: field site was set up AND I was not exhausted or in extra pain!
- **This time was how it should be!**



Photo: H.D. "Toby" Bradshaw, Jr.

How do I work in the field?

- Think carefully about **what is actually needed** as outputs of fieldwork
- Where can we **save energy** (drive heavy equipment to site? sleep in good accommodation with separate rooms? set a “stop time” for evening analysis? cook or eat out?)? Do we need permits or extra funding for this?
- How can we **divide tasks** (e.g. Kelsey does sitting tasks, others do standing tasks, Kelsey doesn’t drive much, Kelsey plans experiments while others carry equipment to the plot)?
- What **equipment** should I bring extra (cane, stool, kneepads, braces, extra water and food, medications, emergency instructions)?
- If funding is available, can we bring an **extra set of hands** to lighten everyone’s workload?
- Are colleagues comfortable **dividing heavy equipment unevenly** when carrying?
- What is the **preferred hiking style** – would someone rather walk alone or with a companion if they are a slow hiker?
- Have an **honest chat** with field colleagues in advance about what accommodations might be needed
- Have a **debrief** if something happens, and also at the end of the field trip – what worked well/didn’t?
- Bring necessary **medical information in the local language**
- Make sure **travel insurance** covers pre-existing conditions!
- Most accommodations are **common-sense** or should already be in place (e.g. not working alone should already be a policy for everyone’s safety)

How have I seen other disabled scientists work in the field?

- Adapted wheelchairs (FreeWheel, Mountain Trike, Trekinetic, GRIT, etc)!
- Slates/tablets for communication (hearing/speech issues)
- Drones to observe areas one can't get to
- Note: all of these are existing technology!
- Self-advocacy around a person's individual abilities and limits



mountaintrike.com



Matt Lang/Smithsonian Institute



A. Romeo/ESA

Working in the field: physical disabilities

- Step 0: ASSUME IT'S POSSIBLE!
- Step 1: **communicate *bidirectionally*** – specify what is known about conditions, tasks, etc and solicit ideas about how to include disabled folks & accommodations that can be made, **check in** during fieldwork & after
- Ideas/things to consider: transportation to field site, terrain, housing, assistive devices like offroad wheelchairs, hiking poles, equipment distribution, fine motor tasks, redistribution of tasks in the field & at housing

Working in the field: sensory disabilities

- Step 0: ASSUME IT'S POSSIBLE!
- Step 1: **communicate *bidirectionally*** – specify what is known about conditions, tasks, etc and solicit ideas about how to include disabled folks & accommodations that can be made, **check in** during fieldwork & after
- Ideas/things to consider: communication methods (slate/tablet? verbal description of site?), redistribution of tasks in the field & at housing, whether sighted guides are needed for rough terrain, audio recording of field notes or Braille notetaker, how will urgent messages be passed?

Working in the field: chronic illnesses

- Step 0: ASSUME IT'S POSSIBLE!
- Step 1: **communicate *bidirectionally*** – specify what is known about conditions, tasks, etc and solicit ideas about how to include disabled folks & accommodations that can be made, **check in** during fieldwork & after
- Ideas/things to consider: very dependent on what the illness does. Many chronic illnesses can cause fatigue so consider similar accommodations to mobility disabilities, also having a “stop time” in the field or at night processing samples to ensure good sleep hygiene, regular rest breaks, availability of snacks/water/resting spot

Working in the field: mental health & neurodiversity

- Step 0: ASSUME IT'S POSSIBLE!
- Step 1: **communicate *bidirectionally*** – specify what is known about conditions, tasks, etc and solicit ideas about how to include disabled folks & accommodations that can be made, **check in** during fieldwork & after
- Ideas/things to consider: ensuring adequate sleep hygiene as above, allowing 'alone time' (even if just sitting with headphones in), confidentiality especially important due to stigma, avoid triggering stimuli, make sure medication is locally legal (true for all disabilities)

Privacy and stigma

- Realize that not all disabled/chronically ill folks want to Tell The World about their situation – this may include telling trip leaders too!
- Don't solicit based on "disability" (& remember that not all folks entitled to accommodations identify as disabled) but instead ask **everyone** if there are accommodations that can make the work more feasible or enjoyable
- Ensure privacy is available for e.g. taking medication, managing stomas, sensitive communications

Legal stuff

- Legal protections/accommodations for disability vary widely by country – the USA and UK are on the more accommodating end (yes, really)
- I would hope the Equality Act 2010 (UK) and the Americans with Disabilities Act (USA) apply to work-related tasks when a employee/student works for a USA/UK institution overseas, but I am not a lawyer so...
- Many medications may not be legal in many countries (e.g. ADHD meds, chronic pain meds) – v. important to check this in advance as it can vary from “you can bring enough for the trip” to “you must be a drug smuggler, we might execute you” – carry a copy of the prescription at all times
- Make sure health insurance covers pre-existing conditions

Fieldwork wellbeing plans/infosheets

- My group exchanges fieldwork wellbeing infosheets prior to fieldwork
- Items covered include:
 - Emergency contacts
 - Roles each person might take in the field
 - What each person needs during/after: driving days, field days, downtime
 - Preferred food, dietary constraints, opinion on alcohol
 - Physical and mental health conditions that might affect wellbeing
 - How best to address these if they come up
 - What support each person might need from field team leader
 - What worries each person the most about fieldwork
 - What is each person the most excited by about fieldwork
 - Any other comments

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Conferences can be a nightmare

- Conference environments are not designed with access in mind... can you think of some examples?

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 - Noisy, cramped poster sessions
 - Speakers/question askers who don't use a microphone
 - Raised stages with no ramp access
 - Fixed seating in sessions (no space for wheelchairs)
 - Limited dietary need accommodation
 - Raised tables at functions (hard if short/wheelchair user) or no place to sit at all
 - Full days (very difficult with fatigue)
 - No place to sit/lay down and rest at most meetings
 - Expectation to go out for lunches, dinners, after-hours bar visits, etc
 - Inaccessible accommodation and/or transport (shuttle buses)
 - Inaccessible venues!!!

Conferences can be a nightmare

Johnson apologises after minister who uses wheelchair denied entry to Cop26 venue

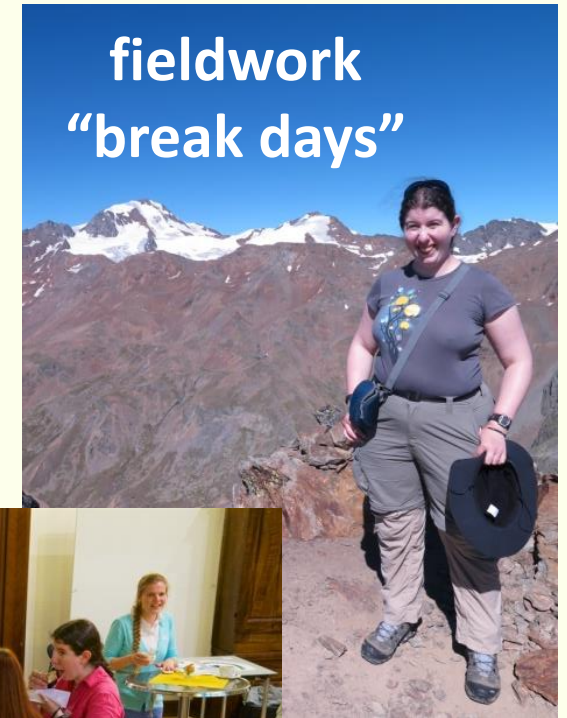
Israel's Karine Elharrar could not attend summit on Monday due to lack of accessibility



📷 Boris Johnson (right) is introduced to Israel's energy minister, Karine Elharrar (left), in Glasgow on Tuesday. Photograph: Reuters

(source: The Guardian)

Disability in informal work contexts



**diversity, equity,
& inclusion
advocacy**



What do all of these have in common?

- Considered “informal” or “extra” work and thus accommodations not considered at all, or considered not required due to their “optional” nature
- Yet... they are not “optional” in most cases & are an important part of career building, especially for early career researchers
- Again, communication is key!
- In (some) contrast to “official” things, one often has to ask about access every. single. time. ... which gets exhausting (but one usually has to ask about access for “official” things too most of the time so it’s a toss-up)

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- **Build access into your plans** for fieldwork, labwork, conferences, etc

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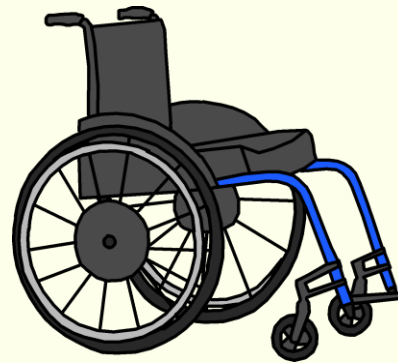
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- **The #1 thing you can do to improve any underrepresented minority colleague's experience and promote their success is to COMMUNICATE and RESPECT: be open and listen respectfully to their lived experiences (even if they are negative ones), treat them as the authorities on those experiences, respect when they don't want to share/talk, and engage in a dialogue about how you can work together to improve everyone's experiences and success.**
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Summary: disability in fieldwork

- **Many barriers exist** to disabled folks' success in fieldwork and academic research in general
- Most of these **barriers are due to the *perceptions and attitudes*** of abled colleagues, supervisors, and administrators, rather than due to the disability itself
- **Accommodations** exist for many if not all disabilities to enable success, though not all disabilities can be accommodated in all situations
- Particular issues exist around **invisible disabilities, disclosure, and privacy**
- Important to consider **intersectional** identities/multiple axes of oppression

Take-home messages

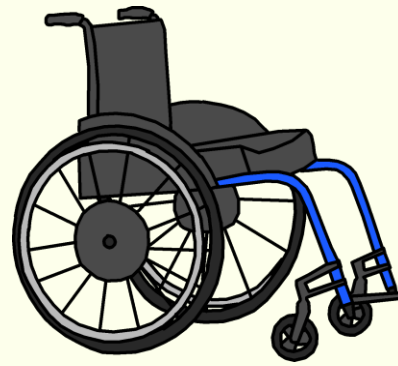


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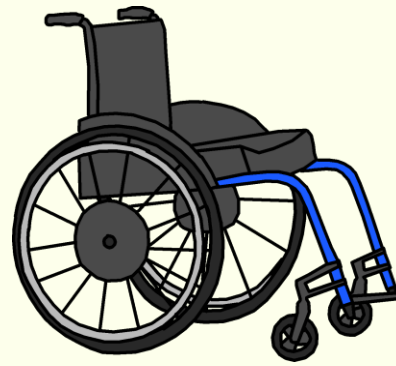
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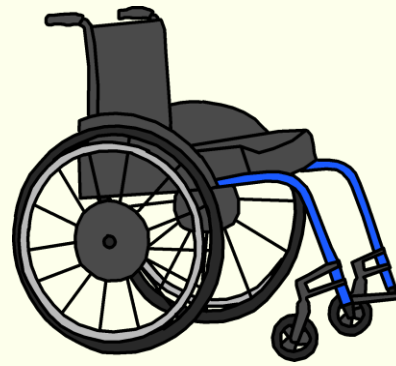
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Disabled in the field: navigating nature and academia as a disabled scientist



John Innes Centre

Unlocking Nature's Diversity

Kelsey J.R.P. Byers

John Innes Centre

Field Inclusive #FieldInclusiveWeek 2023

19 January 2023

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