

The hills are alive – studying orchid evolution as a disabled biologist

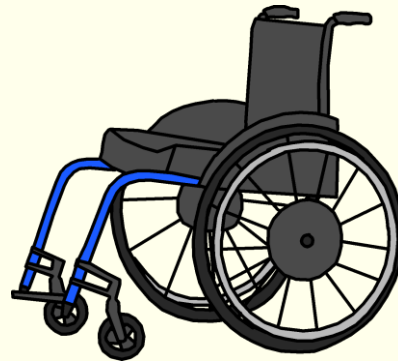


John Innes Centre

Unlocking Nature's Diversity

Kelsey J.R.P. Byers

John Innes Centre



University of Bristol International Day of Persons with Disabilities 2022

7 December 2022

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1. Who am I? How do I identify?
2. What do I study more broadly?
3. The *Gymnadenia* hybrid project
4. Life as a disabled biologist

- 1. Who am I? How do I identify?**
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I identify as:



- Multiply disabled

- Queer, specifically:

- Agender (any pronouns are fine!), assigned female at birth (“AFAB”)
- Asexual

- Otherwise carrying plenty of privilege (white, parents are scientists, socioeconomic status/class, first language English, from Global North, etc)



(Me rocking some asexual and disabled pride at London Pride)

- 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: 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 31: start continuous **crutch** use
- Age 32: start **mobility scooter** use ~half time
- Age 35: start using **wheelchair** most of the time

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- Age 23: diagnosed with **Joint Hypermobility Syndrome** (10 year delay post symptoms)
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- 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
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- 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)
- Age 37: “strong possibility” that I am **autistic**, awaiting final diagnosis (symptoms since childhood, ~30 year delay post symptoms)

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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.”*

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(*Gymnadenia* hybrid project slides have been removed from this publicly-posted slide deck as they are unpublished)

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Disability: invisibility

- Am I disabled?



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- How about now?



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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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- Statistics 1: 4.8% of HE 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*

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!

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 ...



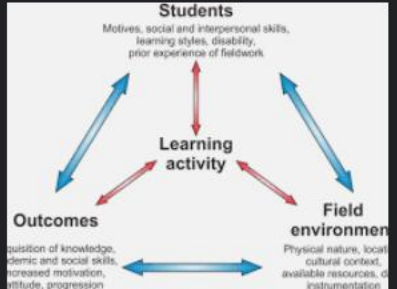
Geography Fieldwork - Notting Hill and ...



Year 12 Geography Fieldwork | All ...



Female researchers join forces to make ...



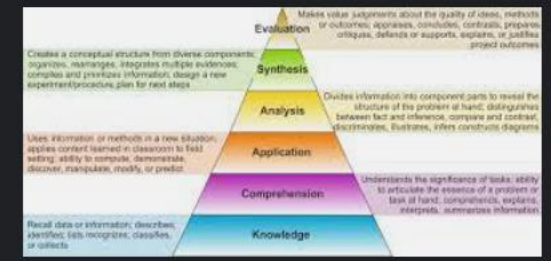
Fieldwork and disability: an overview ... cambridge.org



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



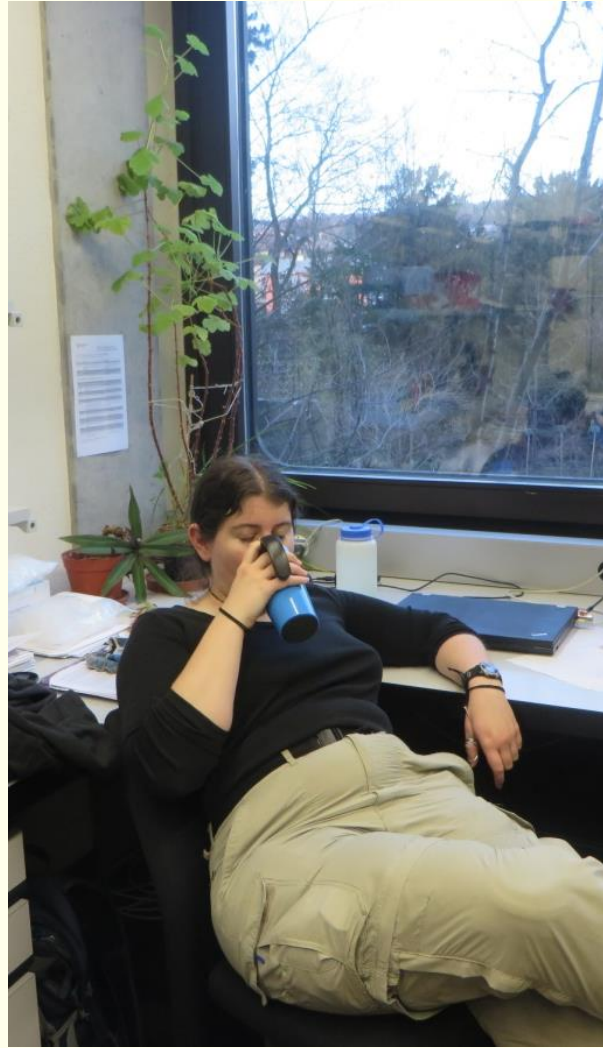
Disability Accommodation and Access ... saic.edu

Which of these people is a field biologist?

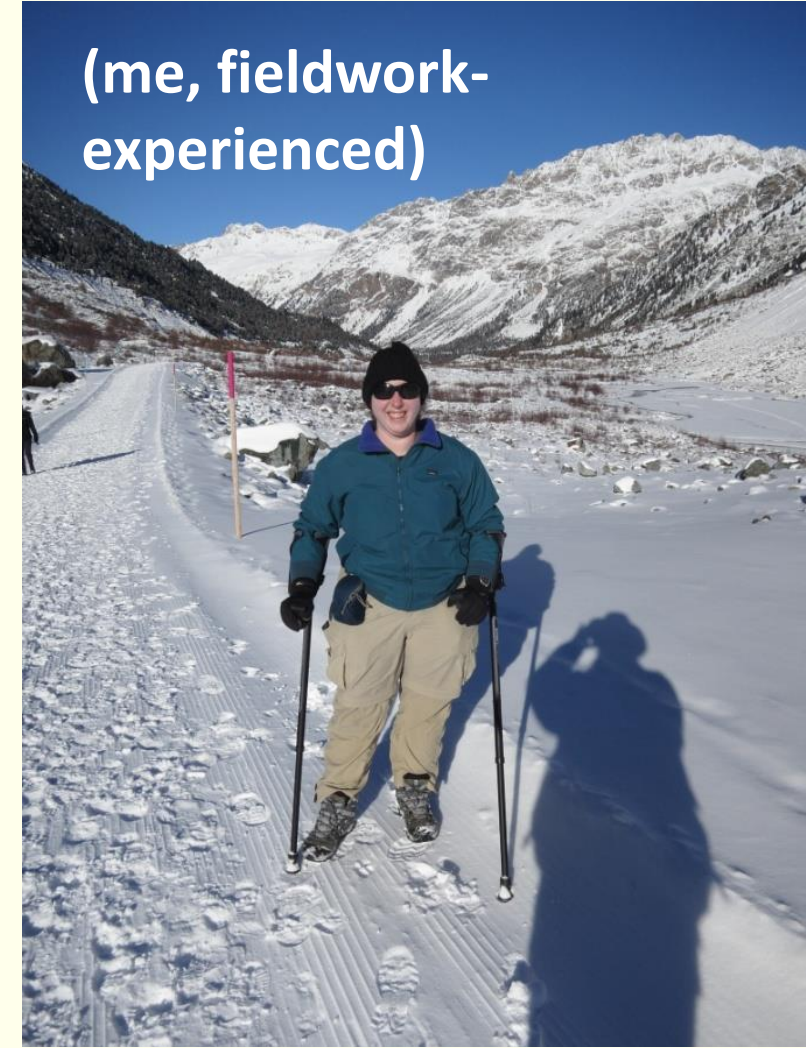


Which of these people is a field biologist?

(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

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
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Actual reality

- *Fundamental tasks*: catch 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

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- *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

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

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 UK is on the more accommodating end (yes, really)
- I would hope the Equality Act 2010 applies to work-related tasks when a employee/student works for a UK institution overseas, but I am not a solicitor 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

Conferences can be a nightmare

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

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

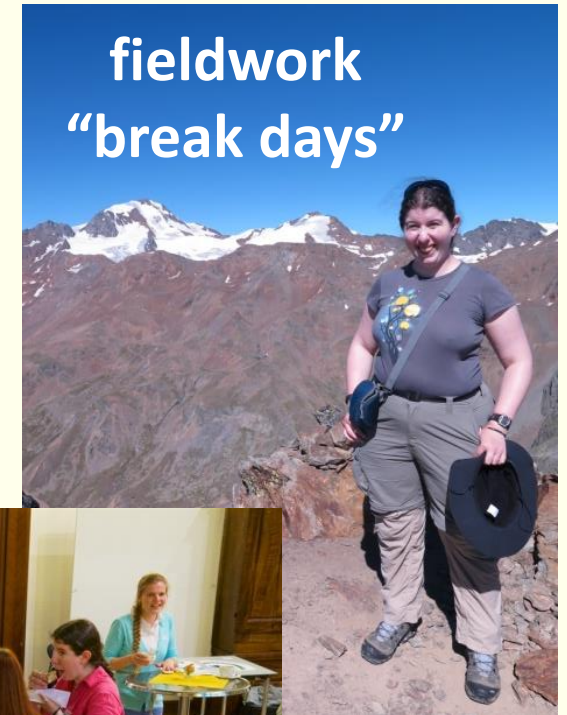
Israel's Karine Elharrar could not attend summit on Monday due to lack of accessibility



📷 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



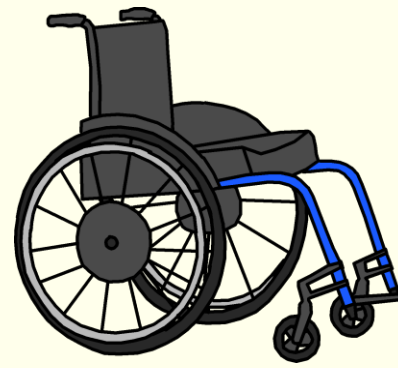
**diversity, equity,
& inclusion
advocacy**



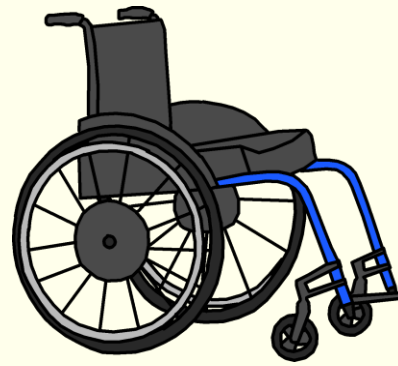
What do all of these have in common?

- 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 ECRs
- 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)

Take-home messages



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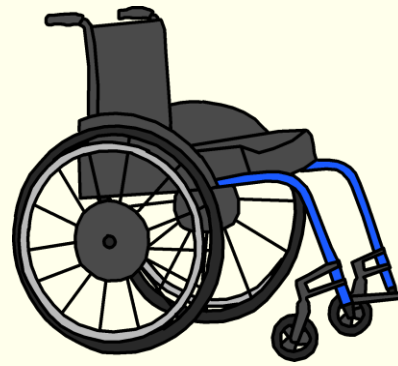
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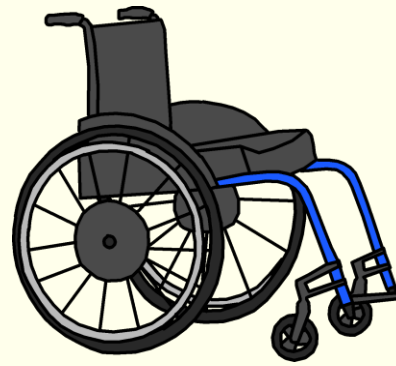
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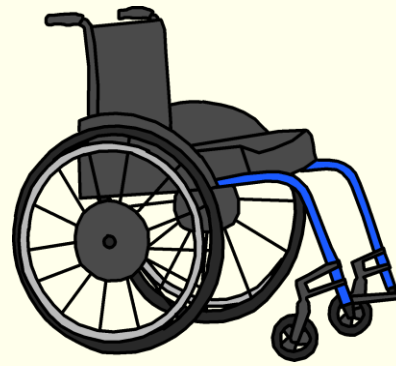
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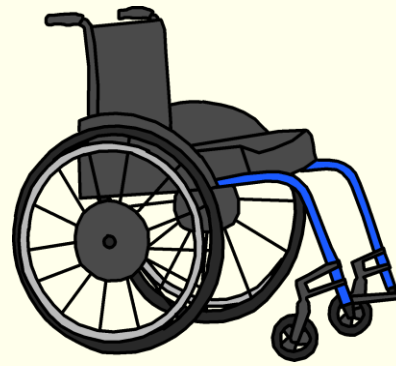
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6. Orchids are cool!

The hills are alive – studying orchid evolution as a disabled biologist

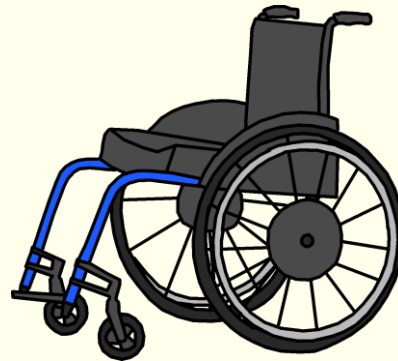


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