ABSTRACT

Disabled scientists face tremendous barriers to entry into, and progression within, a scientific career, remaining immensely under-represented at every career stage. Disability inclusivity drives in science are increasingly prevalent, but few data are available from the developmental biology community specifically. The Young Embryologist Network sought to draw attention to this by platforming disability inclusivity as a key theme at the 2022 conference. Here, I review literature exploring disabled scientists’ experiences in academia, report findings from the conference attendee survey and spotlight a new disability support grant from the British Society for Developmental Biology. I also highlight specific unmet needs and suggest educational resources and actionable measures in the hope of improving the experiences of disabled scientists in our community.

Disability

The Equality Act, 2010 (UK) (https://www.legislation.gov.uk/ukpga/2010/15), describes a person as disabled ‘if they have a physical or mental impairment, and the impairment has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities’. However, this definition fails to capture the great variety of experiences of disabled people. It de-emphasises lived experiences and disregards the human element of whether disabled people feel impaired, or if individuals self-identify as disabled (Box 1). Disabilities can be visible, invisible, physical, sensory, psychological and everything in between. They may be present from birth (congenital) or acquired later in life, and may be related to neurodiversity or chronic illness, be triggered, flare up periodically and/or progress over time.

When discussing disability, references are often made to the medical or social models, which state that people are disabled by their impairments or by barriers imposed in society, respectively. This too is a contested research topic; the social model is typically preferred in disability activism, although limitations are acknowledged in both models (https://plato.stanford.edu/archives/sum2022/entries/disability/). The experiences of disabled people (see Box 1) across all intersections are complex, nuanced and beyond the scope of this article to attempt to summarise. However, disabled people share common experiences in a society that is often exclusionary and poorly equipped to offer support, which persists in academia.

This article is written and researched from a UK perspective owing to geographical location and personal experience. Some of the data used reflect this, but the points raised are broadly applicable to disabled people’s experiences globally. There are 14.6 million disabled people in the UK, making up roughly one-fifth of the total population (https://commonslibrary.parliament.uk/research-briefings/cbp-9602/). Government research suggests that 52.6% of disabled people are in employment compared with 82.5% of non-disabled people (https://www.gov.uk/government/statistics/the-employment-of-disabled-people-2022), although the disability equality charity Scope notes that disabled people were twice as likely to be unemployed in a recent Family Resources Survey (https://www.scope.org.uk/media/disability-facts-figures/). Furthermore, the same government report found that disabled people are more likely to be in ‘lower-skilled occupations’ and part-time employment.

Disabled people face further adversities in society. Disability often incurs a variety of added expenses, with Scope also finding that life is, on average, £975 more expensive per month for disabled people (https://www.scope.org.uk/campaigns/extra-costs/disability-price-tag-2023/). Plus, the distinct lack of representation of disabled people permeates through institutions, and disabled people are marginalised and often left out of equality, diversity and inclusion discussions altogether (Dolmage, 2017; Brown and Ramlackhan, 2022). This is perhaps reflective of historic and general trends, in that disability-specific inclusion often follows the successful implementation of legislation specific to other protected characteristics, hence it may come at a perceptively delayed rate (Lawson, 2011).

Working in science with a disability

In recent years, increasing studies have investigated the experiences of disabled scientists in STEM (science, technology, engineering and mathematics) (https://royalsociety.org/topics-policy/diversity-in-science/disability-reports/). However, to date, there is no extant literature on the representation of disabled people in the developmental biology community. Generally, limitations in the existence or availability of these data may arise from low rates of disclosure or a lack of representation.

Disclosure is a topical issue and a deeply personal choice for disabled people. Reportedly, disability disclosure is lower in STEM than non-STEM subjects. Furthermore, disclosure becomes progressively lower further along the academic career path, with students studying undergraduate degrees disclosing disability at the highest rate. However, disclosure is lowest amongst early-career staff on research-only contracts. This is corroborated by data emerging from the UK Research and Innovation (UKRI) in which only 1% of applicants between 2014 and 2019 disclosed a disability. Moreover, principal investigator applicants disclosing disability had an award rate so low that statistical analysis could not be performed (https://www.crac.org.uk/portfolio/research/qualitative-research-on-barriers-to-progression-for-disabled-scientists; Sarju, 2021). Additional major barriers to disclosure include associated stigmatisation, fears of stereotyping, and workplace discrimination (https://www.crac.org.uk/portfolio/research/qualitative-research-on-barriers-to-progression-for-disabled-scientists; Brown and...
Box 1. Language and terminology

There are differing views on the language used around disability, with ongoing debates around the use of person-first (e.g. ‘person with a disability’) versus identity-first (e.g. ‘disabled person’) terms. Identity-first language is used here owing to its connection with disability activism and awareness work (Brown and Ramlackhan, 2022). Identity-first terminology is also generally my preferred mode of description in describing my own lived experience of disability. However, it should be noted that this distinction is up to individuals and there is no singular correct way (Mattison et al., 2022).

Both ‘ableism’ and ‘disabilism’ are used to refer to disability discrimination. Ableism describes discrimination in favour of non-disabled people, whereas disabilism describes discrimination or prejudice against disabled people. Language reinforcing this discrimination may be referred to as ‘ableist’ or ‘disabilist’ language. ‘Allyship’ refers to the support of marginalised people in social justice work and activism. An ally in this context of disability inclusivity in developmental biology is, therefore, somebody undergoing efforts to improve the experiences of disabled scientists. There is a vast literature on how to be an authentic ally and educational resources are available from disability inclusivity charities online (e.g. https://business.scope.org.uk/article/how-to-be-a-disability-ally).

Ramlackhan, 2022); it could be that the number of disabled applicants/appartrion of said benefits whereas disablism describes discrimination or prejudice against disabled people. Language reinforcing this discrimination may be referred to as ‘ableist’ or ‘disabilist’ language. ‘Allyship’ refers to the support of marginalised people in social justice work and activism. An ally in this context of disability inclusivity in developmental biology is, therefore, somebody undergoing efforts to improve the experiences of disabled scientists. There is a vast literature on how to be an authentic ally and educational resources are available from disability inclusivity charities online (e.g. https://business.scope.org.uk/article/how-to-be-a-disability-ally).

Disabled people face barriers to entry into a scientific career at least as early as undergraduate level. In 2019, 21.8% of disabled people had a degree, compared with 38.0% of non-disabled people. Furthermore, disabled people were almost three times as likely to have no qualifications whatsoever (https://www.gov.uk/government/statistics/the-employment-of-disabled-people-2022). The number of students disclosing disability at the undergraduate level has recently increased, driven by more students reporting mental health conditions or specific learning difficulties (https://royalsociety.org/topics-policy/diversity-in-science/disability-reports/).

The structural setup of academic career progression often uses the quantity of research output in a limited period as a metric of success. This disadvantages, amongst others, people with conditions affecting the ability to work full time or whose disabilities necessitate periods of rest, leave for medical treatment and/or recovery time (https://www.crac.org.uk/portfolio/research/qualitative-research-on-barriers-to-progression-for-disabled-scientists). Consequently, the system becomes discriminatory, with career progression metrics serving as a barrier to attaining representation in senior positions. Representation of protected characteristics in senior positions is a key component in enabling diverse accessibility to a profession, but the barriers to disclosure and career progression for disabled people restrict this.

The Equality Act, 2010 (UK), also states that employers must make ‘reasonable adjustments’ to ensure that disabled workers are not disadvantaged in the workplace. However, laboratory spaces are often particularly inaccessible for disabled people (Powell, 2021). For example, some research requires long hours at the bench and periods navigating between areas of restricted or awkward spaces, which can be restrictive for people with physical disabilities. Benches and fume hoods are typically inaccessible for wheelchair users, as is the storage of laboratory materials and tools. Labs could be fully accessible if accessibility was considered when designing and arranging the space. Despite the legislation, much lab space cannot be entered safely by disabled people independently, potentially resulting in exclusion from bench/lab work altogether (Shew, 2020).

Together, low disclosure rate; barriers to further education, career progression and retention; discriminative practices; and lack of representation clearly impact disability inclusivity in STEM. In response, efforts are increasingly being made to prevent the continued overlooking of disabled people’s experiences, typically involving disabled scientists discussing their lived experiences (Karniski, 2021; Powell, 2021; Anbuhl et al., 2023) or reviewing the landscape and documenting their own experiences (Yerbury and Yerbury, 2021). Learning from lived experiences is a powerful tool for delivering inclusivity education, enhancing visibility and spurring positive cultural change, and one which our own research community can employ.

The Young Embryologist Network

The Young Embryologist Network (YEN) is an early career developmental biology organisation run by PhD students and postdocs in the UK. Established with the aim of increasing communication between early-career developmental biologists, each year the committee hold a free, one-day conference on a general theme of developmental biology, supported by generous funding from our sponsors. Since 2008, YEN has built up a large platform and our conference has become a staple of the developmental biology community calendar. More information is available at: http://www.youngembryologists.org.

YEN 2022 and disability inclusivity

The 14th YEN conference (YEN22) was a hybrid event, which took place in person at the Francis Crick Institute on 16 May 2022. Our varied programme included invited talks by Kate McDole (MRC Laboratory of Molecular Biology, Cambridge, UK) and Andrew Gillis (Marine Biological Laboratory, Woods Hole, MA, USA) and Elly Tanaka (Research Institute of Molecular Pathology, Vienna) alongside the usual programme of selected short talks and poster presentations from postdocs and students (Fig. 1).

Previously, YEN conferences have included talks or panel discussions on science-adjacent topics, such as mentorship (2021) and alternative career paths (2019). Drawing on the research outlined above and my own experiences of working in science with a disability, I proposed a session on disability visibility and methods for inclusion for the 2022 conference. Thereafter, the committee developed our initial ideas of a featured speaker or panel discussion into adopting ‘Working in science with a disability’ as the major theme of YEN22.

We were fortunate to host talks from disabled scientists with different experiences, across the breadth of career stages, featuring John Hutchinson (Royal Veterinary College, London, UK); Elisabeth Kugler (University College London, UK) and Oscar Cazares (University of California San Francisco, CA, USA). The day was concluded with a thoughtful summary address by Cynthia Andoniadou (King’s College London, UK), before opening the floor to a productive, open discussion, and gathering feedback via a post-event survey, providing valuable insight into the experiences of disabled scientists.

Survey and group discussion findings

Given the clear lack of data on the experiences of disabled people in our community, we saw a valuable opportunity to survey our delegates. Alongside a means for gathering organisational feedback, these data give insight into disability in our field specifically.

Thirty delegates responded to the survey (just over 7.5% of all attendees). Interestingly, in line with the population statistics, just over
20% (n=7) of respondents declared that they have a disability. This is a higher proportion than expected, given the under-representation of disabled people in STEM. The sample size is too low to suggest that disabled people are proportionately represented in our field, and self-selection bias is possible. It was also remarked upon, in both the discussion and survey, that the space felt genuinely inclusive, which may have enabled some delegates to disclose and discuss their disabilities with peers despite previously having not done so.

All respondents found these sessions informative and 97% (n=29) felt they had learnt something new about disability inclusivity, reinforcing the value of learning through lived experiences. Furthermore, 94% (n=28) felt that more could be done to support themselves or disabled colleagues. When asked to elaborate, recurring themes arose around allyship (Box 1), accommodations and adjustments, limited representation, and experiences of ableism (Box 2).

The survey results bolster what has already been published in the wider context of disability in STEM, giving us a clear insight into areas that could readily be improved to promote disability inclusivity and improve the experiences of disabled people within the field.

Fig. 1. Photographs taken at the Young Embryologist Network Conference 2022. (A) Conference introduction by the author. (B) Delegate Dillan Saunders presenting at the first poster session. (C) Networking break. (D) Selected short talk by Eirini Maniou. (E) John Hutchinson delivering his 'Working in science with a disability' talk remotely. All photographs were taken by Timo Kohler.
our own community. However, it is duly noted that the sample size is small. Therefore, this work serves as a launchpad, and an expanded survey will be circulated via the Node in future.

**Discussion**

Overall, considering the findings from this survey in the context of the limited field-specific extant literature, it is evident that we are severely lacking in our support for the disabled community in developmental biology. This is in line with disabled people’s experiences in STEM more broadly, and ranges from the limited attractiveness and accessibility of the career ab initio, through to retention and career progression at higher levels.

A particularly striking point to emphasise is the negative impact of ableist language (Box 2). Whether used casually or related to our work, ableist language serves to further oppress and ‘other’ disabled people and should be called out and discouraged as a basic component of allyship. Furthermore, we should be particularly careful with the language we use in developmental biology, considering much of our work centres on investigating developmental differences. There is a plethora of work demonstrating the negative effects of scientific/medical descriptions of disability, and how it influences societal perceptions of disabled people. Language guides are available online that describe the etymology of offensive words and offer suggested replacements (https://www.autistichoya.com/p/ableist-words-and-terms-to-avoid.html).

The inaccessibility of lab spaces should also be flagged to estates management at universities and research institutes. Surveyed delegates experienced that suggestions of inaccessibility and the need for change are met with nonchalance or dismissal, and that the perceived lack of disabled people in the workplace means that no changes are necessary. Making workplaces accessible and inclusive would attract disabled people to the workplace (and is also a legal requirement in the UK as part of the Equality Act, 2010) regardless of the technicalities of implementation. The onus should not be on the individual to fight for these changes, which only further consumes time and energy and detracts from career progression. Inclusivity needs to be considered in the design of new lab spaces from the beginning and not added as an afterthought. These are the basic foundational principles of the concept of Universal Design, which serves to create equitable environments and spaces usable for all in the first instance (Burgstahler and Cory, 2010). The need to incorporate these principles in lab space design is increasingly being highlighted (Mattison et al., 2022).

As discussed, repeated requests were made for general guidelines on how students/staff can best support disabled colleagues. A recent paper exploring disability inclusivity in STEM could be a great starting point. The authors present guidelines to ensure the authentic, systematic inclusion of disabled people, modelled under the principles of flexibility, accommodations and modifications, with suggestions and advice tailored to both academic and managerial staff (Mattison et al., 2022).

Lived experiences continue to be a good way to learn about disability. The publication of interview series with disabled scientists is an excellent and informative way to maximise reach (Karniski, 2021; Powell, 2021; Anbuhl et al., 2023). There are several other mediums through which readers can engage with lived experiences of disability. For example, one speaker at YEN22, John Hutchinson, curates a blog detailing his experiences of disability living with an invisible disability (https://whatsinjohnsfreezer.com). Community events, such as workshops or conferences, are essential to maintain public discourse, which could be similar to YEN22 or the sole focus of a dedicated conference (Brown and Ramlakhan, 2022). Furthermore, the open-access book ‘Ableism in Academia’ gives a broad and detailed investigation into the eponymous topic and can be accessed for free online (Brown and Leigh, 2020). Universities and research institutes could expand on this by featuring disabled researchers and their experiences in disability inclusivity drives publicly celebrating the work of disabled individuals, as with the increasingly popular features during Disability History Month (mid-November to mid-December in the UK).

Funding bodies and recruitment panels could also interact with the disabled community to identify more inclusive ways of hiring/promoting, with non-discriminative metrics in mind. This was raised in discussion at YEN22, and similar lines of thought have recently gained traction with the recent petition to the European Research Council (ERC) to remove age limits on ERC Starting and Consolidator grants (https://www.change.org/p/remove-academic-age-limits-on-erc-grants). It is stated that age restrictions on grant applications select ‘against social, economic, gender, ethnic and scientific diversity’. It also selects against disabled scientists, and a successful outcome from this petition would be a significant boost towards disability inclusivity in academic career progression.

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**Box 2. Key topics emerging from the discussion and survey**

**Allyship**

Guidance was requested on how disabled colleagues could be supported in the lab, and in relation to allyship (Box 1). The importance of allyship was highlighted in the talks, discussion sessions and survey, with respondents requesting guidance on how to be an authentic ally.

**Accommodations and adjustments**

Respondents shared experiences with the lack of pre-existing infrastructure to support accommodations and adjustments. The process of obtaining accommodations was described as ‘disorganised’ and ‘time-consuming’ at the expense of the disabled individual. Similarly, a distinct lack of support grants and funding to help cover any additional costs incurred by disabled scientists was emphasised and could be valuable for funders to consider.

**Representation**

57% (n=17) of respondents felt that a diverse range of experiences of disability were represented at the conference, noting that the speakers primarily acquired disability later in life. This mirrors the experiences of the session organisers who found that scientists with congenital disabilities were particularly under-represented/less visible and/or unavailable to give talks. Representation was further explored in the final group discussion, with the suggestion that the barrier to entry into a scientific career is earlier in the education process if one’s disability is congenital, supported by the markedly lower proportion of disabled people entering further education. Therefore, improving inclusivity for people with congenital disabilities will likely require coordinated efforts across education providers, supplemented by outreach activities and improvements in visibility and the representation of disabled scientists from universities/research institutes.

**Experiences of ableism**

Survey respondents and discussion participants highlighted examples of ableist behaviour and/or practices. Notably, widespread ableist and offensive language was witnessed in the workplace and in wider society, ranging from unintentional and ignorant use of offensive phrases to outright slurs. In line with other studies, it is clear that our community is not devoid of the ableist culture prevalent in STEM.
Finally, this research drew attention to the lack of a grant in our field aimed at offsetting the additional costs incurred by disabled people in academia. Funding bodies could address this directly by interacting with the disabled community and researching where funding might best be served. I am pleased to share that, having consulted with the British Society for Developmental Biology (BSDB), a new fund has been established: the BSDB disability support grant – perhaps the first of its kind in our field (Box 3). Other funding bodies and research/learned societies could also work with disabled scientists/members of their own communities to see where further specific funding could be useful. This is a positive step for our field, highlighting the need for the extension of such funding to research fellowships aimed specifically at disabled BSDB members at conferences. More information, including how to apply, can be found here: http://bsdb.org/membership/.

**Box 3. A new disability support grant**

The British Society for Developmental Biology (BSDB) disability support grant is a new fund to help offset the additional costs incurred by disabled people participating in Spring or Autumn BSDB meetings in perpetuity. These costs may include, for example, travel costs for a support person/companion. A strength of the grant is its flexibility: all requests for financial support will be considered and a maximum of £250 can be awarded per applicant.

Similarly, disabled scientists might consider the Louie Hamilton Fund. Louie Hamilton was a distinguished disabled developmental biologist who bequeathed money to the BSDB with the aim of providing financial support for disabled BSDB members at conferences.

Funding bodies and research/learned societies could also work with disabled scientists/members of their own communities to see where further specific funding could be useful. This is a positive step for our field, highlighting the need for the extension of such funding to research fellowships aimed specifically at disabled researchers, at either the doctoral student or postdoctoral level, with the aim of broadening participation.

**Conclusion**

This article discusses a variety of important points highlighting disabled scientists’ experiences. It attempts to supply the reader with adequate references, further reading and educational resources in the hope that this might help spur our community towards authentic disability inclusivity in developmental biology.

These findings corroborate the published experiences of disabled scientists in STEM more widely, and much of this article re-emphasises points already made. Thus, it is intended to serve as a starting point of consideration for members of the broader developmental biology community, and perhaps as an introduction to the subject for some.

Readers are encouraged to consider where inclusive adjustments might be made in their own workspaces, and how they might get involved in widening participation for disabled people. Funding bodies and organisations will also benefit from engaging more with disabled people directly and playing a more active role in researching and publicising the experiences of disabled people in science.

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**Competing interests**

The author declares no competing or financial interests.

**Diversity and inclusion**

The author, J.D.M. (he/him), has lived experience with congenital physical disability (Anbuhl et al., 2023) and is currently navigating his final year PhD studies in developmental and mechanocellular biology. He firmly believes that ensuring equity, diversity and inclusion is not only a moral imperative, but a catalyst for success and enrichment. He is keen to spotlight the adversities faced by disabled people in society and draws on his own experiences as a disabled, first-generation student from a working-class background. J.D.M. is eager to learn more about the experiences of disabled people with different intersectional identities and is committed to contributing to both scientific research and disability advocacy in his future career.

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