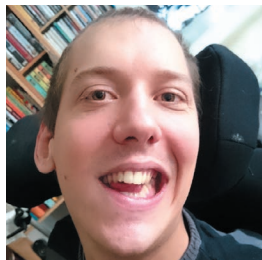


AARON SCHAAL



Science must rise up to support people like me

Institutions could do more to support researchers who have disabilities, says Aaron Schaal.

The topic I study happens to be similar to one that occupied physicist Stephen Hawking for much of his life. And like he did, I need technology to communicate, as well as round-the-clock personal assistance to live independently; I can control only the movements of my eyes reliably. My family, supervisors and the German health-care system provide essential support. Hawking's death last month renewed focus on accessibility in science. In my experience, there are too many obstacles in academia for people who have physical or mental-health conditions — and who have much to offer to science.

As a 27-year-old doctoral student in mathematical physics, I study why time moves in only one direction. I rely on a very simplistic mathematical model consisting of classical particles that interact through gravity. This should yield ideas for explaining the 'arrow' of time.

Since I was two years old, I have had generalized dystonia — abnormal muscle tone caused by a rare metabolic disease called glutaric aciduria type 1. To communicate and write, I use an eyetracker on my computer or a colour-coded, plexiglass board that I designed myself, which has Latin and Greek letters, as well as numbers and mathematical symbols. Many of my colleagues have learnt to 'listen' to me by tracking which symbols on the board I look at. At first, it can take nearly half an hour to understand a sentence. With practice, the process becomes relatively fast, especially if my conversation partner knows the context. With my PhD adviser, for example, this form of communication takes about three times as long as regular speech.

When interacting with people who can't use the board, I communicate using my eyetracking device, which can produce synthesized voices in different languages, or with the help of personal assistants. The eyetracker allows me to type about two characters per second, assuming that I know exactly what I want to write, that my eyetracker is optimally positioned and calibrated and that the word-prediction software is working well. To give a talk, I formulate the whole thing in full sentences first, so my assistant or laptop can then read it aloud.

During my undergraduate studies, I had to request accommodations, such as extra time for exams. Professors rarely knew what to do: most had had no contact with anyone with a disability. Some couldn't imagine how I would be able to write exams at all.

Things improved as more professors came to know me. The supervisors of both my bachelor's-degree thesis and my master's-degree and PhD work have strongly supported me, which has included dealing with bureaucracy. In my work as a teaching assistant, I have been treated extremely well. I create exercise worksheets, organize tutorials and maintain the website for the course lecture series. These are all things I can do from home, especially if I am unable to go outside. All this shows that individual solutions do exist — if a university is willing to find them.

In 2015, I co-founded Chronically Academic, a global network that connects academics who have disabilities or chronic conditions. Our

website, which I set up and maintain, hosts resources for individuals and institutions (see <https://chronicallyacademic.org>). Last year, we published a series of articles on chronic illness in academia in *The Sociological Review*. Last month, some of us co-organized a conference at University College London called Ableism in Academia. Today, we have some 150 active members offering peer support and raising awareness.

Our experiences show that a research career is possible if you really want it and have support from your family, supervisors and colleagues. But it could be a bit easier. Academics are often expected to move across countries or continents, which can be difficult for some people with certain disabilities, given large variations in health-care systems. Even those who remain in one place must attend conferences. Flying is impossible for me; no commercial aeroplane will transport me in my own wheelchair. To travel, I need at least two personal assistants and a host of technical and medical equipment. A week-long trip to Tübingen (a 3- to 4-hour car ride from my home in Munich) costs US\$3,000–5,000, including food and lodging for my assistants. I can apply to several German health-care authorities or my university to cover the costs, but that is time-consuming and far from straightforward, and success is not guaranteed.

Once there, events are not always accessible. I have slept on the floor when only bunk beds were available. My colleagues have similar stories. At a conference on inclusion, restrooms were accessible only by stairs, and event planners put planks over the entrance steps for wheelchair access only after an invited scientist refused to be carried in.

One person changed universities after continuous teasing from supervisors and colleagues about involuntary facial movements. Another left when departments refused to even discuss making accommodations.

Needs vary. For me, it's mainly wheelchair access; others need sign-language interpreters. Event planning should include inviting attendees to state any special needs, and working to accommodate them. Institutions should offer and promote training on how to support students and staff. More-flexible contracts — working reduced hours or from a home office — would be a huge improvement. Scholarships and administrative help to cover extra costs of travel and assistance would expand opportunities. And events should be made truly accessible to all participants.

Without these moves, disabilities such as mine will remain out of sight and out of mind in science, making it more homogeneous and less compassionate. That is a severe loss. There are many times when I cannot do anything but think, which lends itself to coming up with new scientific ideas. As Stephen Hawking showed so dramatically, research benefits from a more diverse workforce. ■

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