

Day in the life of a disabled(?) scientist

Sightless in Science

By Robert Stevens (Manchester)

Within biochemistry and related disciplines, such as molecular biology, computers now play a central role. It is difficult to do wet work without computers and impossible to do biology with computers without involving laboratory scientists. This computational aspect of modern biology has given me a route by which I can remain within science, actually doing science, despite having lost my sight.

I finished a degree in biochemistry at the University of Bristol in the summer of 1986 and started a PhD at the University of Leicester in the following autumn. I lost my sight due to illness some six months into the PhD, so I retrained in computer programming at the Royal National Institute of the Blind (RNIB) Vocational Training College in Loughborough. This gave me the skills necessary to use computers through software known as screenreaders, which allow a standard computer, using standard software, with a standard keyboard to be used with synthetic voice output. Typing is echoed and as I move around the screen, the words, lines, button labels etc. are spoken. At the RNIB college, I learnt how to programme computers, to use general information technology and to function as a blind person in a work setting. Armed with these new skills I undertook an MSc at the University of York that was then called Biological Computation, which is now known as Bioinformatics. I then studied for a PhD in a sub-discipline of Computer Science known as Human Computer Interaction.

At my interview for a place on the MSc course, the biggest question was whether I would be able to do the mathematics — not necessarily from the mental point of view, but from the physically being able to do it point of view. My two interviewers, one of whom became my PhD supervisor, were right to ask this. Paper acts as an external memory; writing something down saves one the trouble of remembering it. Without paper one relies on memory. I used Braille algebra notation and got to the stage where, with Braille and my computer, I could do what was required for the course, but I soon realised that it was too much like hard work for me and that really my mathematics is poor. It did, however, give me the subject for my PhD research in Computer Science, and this reinforces my view that few things are a waste of time. I remain tremendously thankful that I undertook the MSc at York, as its hard work set me up for the rest of my career in bioinformatics.

At the point of finishing my PhD, there was the theoretical option of work in the commercial sector or in the university research path. Reflecting on the choice I made, as an inevitable consequence of writing this piece, I now realise that there was no

option at this point. I'd always wanted to do research and I didn't really think of trying to do anything else. So one early message is to follow one's desire. If that fails, then try the other routes.

Armed with skills and more qualifications than you can shake a stick at, I ended up, by serendipity as much as anything else, as a Research Associate (or postdoc) in the Department of Computer Science at the University of Manchester. It is at this point that I managed to take full advantage of my combined biochemistry and computer science background. One of the difficulties in the earlier days of bioinformatics was the mis-match of language and understanding of the two disciplines. As someone working at the interface of the two I could act as a communicator. I have taken full advantage of this and have moved from postdoc to lecturer and now senior lecturer.

What I actually do in research is by the bye, what I think is of interest here is how I do the work and my experience of doing so. In the university setting, the first thing to say is that, generally, my disability has not been seen as preventing me from doing the job. There are, of course, the usual misunderstandings common across society. It is, however, true that universities tend to be full of clever and, I suspect, largely liberal-minded people. This is, I think, one of the main advantages of a university career. As a student, my experience was that universities act well in support of people with disabilities. As a member of staff, the people in my department are the ones who know and care about me. The school here in Manchester has, over the past 10 years, been extremely good at not making a fuss in any direction.

I have met with some prejudice, but only a little. It is true is that as one rises up what passes for a career structure in



academia it becomes easier to handle a disability. This is largely because one starts making one's own rules — you work on the areas in which you want to work. Like most group leaders, my research is done vicariously; I have ideas, I look at results, I interpret, but the actual 'doing' is done by someone else, and that someone else has invariably been sighted. This doesn't mean I'd avoid a blind postdoc or student, although they might be warned that I'd know all the scams. Given the opportunity to employ a blind bioinformatician, my only criterion would be ability.

A general rule that I have made is to try not to use my blindness as an excuse to not do things. There are many things that one simply cannot do when blind, both generally and as a bioinformatician. Laboratory science was not really an option after losing my sight — a rapid death (probably electrocution or poisoning) would be the result. In my interview for my lectureship, I said that working as admissions tutor, dealing with potentially hundreds of hand-written forms was not within my capabilities. One reaction from those who know would be 'how lucky', and there have to be some benefits. There are, however, many jobs which I can do and my mode of work actually helps. I'm a good proofreader, I can interview, I can listen and I'm good at talking both informally and formally. I take advantage of these attributes and these are the ones, both inside and outside my strict research remit, which I exploit. So, do what it is possible to do.

A follow-on rule from this is fairness in offering help. Given the many things that I find it difficult to do, I find I have to rely on a lot of help for tasks such as drawing diagrams, checking the appearance of documents, finding things on awfully designed Web pages and so on. Given that I have a lot of help from a lot of people, I try not to refuse my help to others in return.

Moving from the general back to the science, bioinformatics is a mix of biology and informatics. It is no real coincidence that I'm at the informatics end of the discipline. Actually doing biology with bioinformatics would, I think, be rather difficult. Looking at sequence alignments, three-dimensional structure diagrams, systems networks, enzyme active-site mechanisms etc. are all forms of presentation that I would find difficult. The informatics end of the system — database design, knowledge representation (my own field), text-mining, distributed computing, software engineering, etc., all of which play large parts in bioinformatics, can all be done by someone with a visual disability. Designing a graphical user interface is tricky when blind, but then it seems to be beyond most sighted bioinformaticians too. It is, however, difficult to pull-apart potential confounding factors in this analysis. Do I work in my domain because my blindness allows it or because that's where my abilities lie anyway? It is possible that I might have been the most brilliant biochemist of my age (although those who taught and knew me as a young biochemist would disagree, as would I), but we will never know. What I do know is that I can work in my particular niche and that I enjoy doing so. One thing that can be certain that in the process of peer review, the fact of my blindness will count for nothing. So, my success in terms of publications is there for people to judge.

Much of this might appear rather rosy. There is, however, one hard truth within all of this — it is all very hard work. One thing that many disabled people will say is that all a disabled person's actions are attributed to their disability — especially failure. If I trip over or spill something it is because I'm blind; not because I'm careless, distracted, etc., which would probably be the case otherwise. Similarly, my fear is that if I fail as a researcher it will be due to my blindness, not because I'm not very good. Also, as one of the few disabled people in this sort of work, I am the exemplar — I am all of the blind people in bioinformatics. There are probably others, but I don't know them. Also, on a more mundane level, working with screenreaders to write papers, interpret results, working through other people to draw diagrams etc. is hard work; I feel as though I have no metrics, that I have to expend more effort to do a given task than would a sighted person.

You, the reader, might think this account rather mundane. I mean it to be that way. There are no heroics; there is no winning through against adversity. There is, however, getting on with it. One takes one's opportunities where one can. There will be fights, but I certainly don't seek them out. Others might, and I'm often grateful that fights have been fought. I am, however, not the first disabled scientist working in a university and I will not be the last. ■