Disability and academic careers

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May, 2017.

Funded by the EPSRC (Career Acceleration Grant) and the School of Social Sciences, Heriot Watt University

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1 This report is written using Calibri which a sans serif font, recommended for accessibility. If a different a font
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Acknowledgements

It with gratitude that I acknowledge all those who took part in the study, sharing their time and experiences with such generosity. I hope to do justice to the stories shared with me. Thank you also to those who helped me recruit participants, by retweeting calls for interviewees, sharing my details and to the Herald for publicising my work. This research would not have been possible without the support of the EPSRC and the School of Social Sciences. Their support enabled the collection and transcription of the data. I would also like to thank the media services team at Heriot Watt University who helped to publicise the study, broadening the reach of the research.
Executive Summary

- Disabled people remain under-employed in the UK, although data suggests more disabled people are in employment than in previous years.
- Disabled employees experience a range of barriers including stigma and lack of career progression.
- Despite an increase in measures to support the inclusion of disabled students in higher education, less is known about the experiences of disabled academics.
- This research aimed to understand the experiences of disabled academics to develop a set of recommendations for universities, research funders and trade unions.
- Interviews were conducted with 25 academics, supplemented with 34 electronic responses to the interview questions.
- The key findings show that disabled academics report considerable barriers to their full participation in academic life including:
  - Fatigue
  - Lack of access to adjustments
  - Difficulty navigating institutional systems including Access to Work, adjustments and occupational health
  - A notion of an able-bodied ideal academic
  - The nature of impairment e.g. acquired/life long, hidden/visible impairment
  - Inaccessibility of buildings (for teaching, meetings, informal social interactions and conferences)
  - Difficult to access information on organizational policies and practices, including from employers and funders
  - Perceived rigidity of policies and practices including research funding, promotion requirements
  - Lack of awareness amongst line managers, trade union representatives, and employers
  - Incivility of colleagues
- Examples of facilitators to full participation included:
  - Staff networks for disabled staff (led by staff)
  - Comprehensive online information on the facilities and support available to disabled staff
  - Informed line managers and colleagues
  - Flexible working practices (both informal and formal)
  - Flexible and part time funding for research
  - More senior academics who are open about their own impairments/health issues/disability
  - Funding which provides allowances for carers to travel to conferences
  - Seniority and being white/male was seen as sources of relative privilege
- In conclusion, organisations including employers and funders, should consider short, medium and long-term approaches to change practices, policies and culture to ensure all academics are able to thrive.
Introduction

This report presents the findings from a qualitative study with current, former and retired academics working at PhD level through to Professor. Due to the sensitive nature of the research, this report summarises the findings anonymously, protecting the identities of both individual participants and employing organisations. Disability within employment, remains absent from much of the academic research. There is an assumption that disability is associated with unemployment rather than employment. Recent research from the UK Government shows that less than 50% of working age disabled people are in employment. However, the majority of those who are not in employment do want to be. The UK Government also acknowledge that an overlooked area of disability policy is the retention of disabled employees. Recent academic research has shown that disabled people can be supported in employment through work with trade unions. Although the changing nature of employment has effects for disabled employees, for example, difficulties securing employment due to difficulties with formalized recruitment procedures.

Within universities, the experiences of disabled staff have rarely been subject to empirical research. Evidence from Scotland suggests that the numbers of disabled students enrolled at universities is increasing, but with certain patterns emerging. For example, there has been an increase in middle class students with specific learning difficulties, with far less of an increase for working class or disadvantaged students with low incidence impairments. However, less is known about disability amongst staff within universities. There is evidence that disabled academics experience boundaries on their career choices and opportunities, which are linked to effects of impairments. There is also evidence that the working environment within academic departments in the UK is harmful to academics, and my result in mental health conditions. Working conditions with UK academia have been characterized by high pressure, long working hours and high demands for excellent teaching, research and administrative duties. There is a need to understand how working practices affect disabled academics and what strategies key stakeholders, such as universities, research funders and trade unions can do in order to create inclusive environments for all academics, including those who are disabled. The aim of this study was to understand the lived experiences of disabled academics across the career span, and co-develop with participants a set of recommendations for universities, research funders and the relevant trade unions.

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2 [https://www.publications.parliament.uk/pa/cm201617/cmselect/cmworpen/56/5602.htm](https://www.publications.parliament.uk/pa/cm201617/cmselect/cmworpen/56/5602.htm)
4 [https://www.publications.parliament.uk/pa/cm201617/cmselect/cmworpen/56/5602.htm](https://www.publications.parliament.uk/pa/cm201617/cmselect/cmworpen/56/5602.htm)
7 [https://eric.ed.gov/?id=EJ1117625](https://eric.ed.gov/?id=EJ1117625)
Defining disability
Disability is a contentious term, with varying theoretical definitions. This report adopts the definition provided by the UK Equality Act 2010:

‘A person has a disability 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.’

An impairment is considered long term if it is likely to last longer than 12 months, has already lasted for 12 months or is likely to be life-long.

This research is rooted in a social relational model of disability which views disability to emerge from the interaction between a person designated with an ‘impairment’ and the environment. Here, disability does not reside within the individual, but is a relationship rooted in power. Therefore, disability is an oppressive social relationship, and is distinct from the ‘impairment’11. The social relational model builds on previous work with the social model, which was developed to counter the stigmatizing narratives of the medical model of disability. Accordingly this report will use terms such ‘disabled people’ or ‘disabled academics’ rather than the person first approach of ‘people with disabilities’.

Research Methods

The study had two mains aims:

1. to understand the experiences of disabled academics and how it may vary by career stage, discipline, ‘impairment’, gender, ethnicity and age.
2. to develop a set of recommendations for employers, research funders and trade unions to better support disabled academics.

Sampling strategy

In order to gather information about disabled academics’ experiences, a qualitative approach was taken. This approach needed to be flexible enough to accommodate the varying requirements of participants. Interviews took two forms:

1. Telephone or Skype interviews
2. Electronic interviews via email, online shared documents e.g. google docs

Interviewees were recruited through a convenience sampling approach via social media and circulation by heads of schools and disability services in universities. The aim here is not to draw generalisations across the higher education sector, therefore such a convenience self-selecting sampling approach is appropriate. Each person who indicated interest in participating was provided with a consent form (Appendix A) which provided details of the study and the research ethics. In addition, all participants were provided with a copy of the interview questions (Appendix B). This allowed participants to see the range of questions to be covered, and for those with particular ‘impairments’ such as memory issues to prepare notes for the interview. Interviewees were also provided with the option to undertake the interview electronically via email or a google doc. 38 people took up this option. A further 26 people took part in a synchronous interview via Skype or telephone.

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total of 64 people participated in the research. The majority of participants identified as women, heterosexual and white British.

The resulting sample also included participants who identified as male, gender neutral or gender queer. In addition a minority of participants identified as asexual, bisexual, polyamorous or preferred not to define their sexual orientation. The participant sample also included academics who identified as migrants (EU and rest of World), Asian and Black British. With the exception of a very small number of participants, all academics were currently working (or most recent academic role) within the UK.

Participants were distributed across a full range of academic disciplines including engineering, physical sciences, medicine, social sciences, humanities and astrophysics. As such the sample includes perspectives from academics engaged in a diverse range of research and teaching roles including laboratory work, field work and desk based research. Participants ranged from early 20s to late 60s in age, from PhD students through to retired professors.

The ‘impairments’ reported by participants included neurodiversity (Autism Spectrum Disorders, dyslexia, dyscalculia, dyspraxia), mental health problems (depression, anxiety), mobility impairments, progressive neurological conditions, gynaecological conditions (e.g. endometriosis), traumatic brain injury and muscular conditions. A minority of respondents had multiple impairments and complex health needs. As such academics had both visible and hidden impairments as well as acquired or congenital health conditions or impairments. The sample is therefore diverse in terms of ‘impairments’

Interview procedure

Each interviewee was invited to select their own interview time using an anonymous online scheduling system. Once a slot was selected both the researcher and the interviewee received an electronic calendar invite. Each interview slot was 60 minutes long to allow for an interview of approximately 40 minutes following the initial interview discussion. Prior to the scheduled interview time each participant was contacted to confirm the date and time of the interview. Prior to the interview starting, the interviewer explained the true purpose of the study and how the data would be used. Participants were reminded of their right to withdraw from the interview without providing details, or to not answer specific questions. In addition, the researcher reassured participants that the interview could be stopped at any time and continued at a later date if necessary. Participants were also reassured that the transcripts and notes would be anonymized and asked if they consented to a digital recording of their answers. Of the 26 synchronous interviews, 25 were digitally recorded and professionally transcribed verbatim. A small number of participants asked to see their transcripts to ensure they were fully anonymized, and this request was honoured. For the electronic interviews, each participant returned their answers at a time which was convenient to them and follow up questions were also asked via email.

Analysis of the data

The resulting transcripts were read carefully to identify emerging themes, in order to address the two research aims. Key themes which emerged were visible/invisible disabilities, stigma, career progression, fatigue, networks, conferences, reasonable adjustments, accessibility, awareness and intersecting identities. It is important to note that while the research is rooted in the social relational model, where the term ‘disabled person’ is preferred, not all participants adhered to this approach and may have used person first language.
Findings

The findings presented here focus on two main areas – career experiences and suggestions for the inclusion of disabled people into academia.

Career progress to date

Participants who were working within academia were at various career stages, from PhD through to semi-retired Professor. Academics across the career span felt that being disabled had negatively affected their career progress or opportunities for development. Early career researchers, including PhD students, were skeptical of the availability of academic jobs especially lectureships. Participants explained that academia in the UK is competitive anyway, and they felt that their applications would lack credibility due to lower numbers of outputs relative to non-disabled academics. As such disabled academics felt that they were at a disadvantage in a very competitive labour market. More established academics felt that being disabled had slowed them down in their career progress to date. This may include difficulties undertaking or completing specific research related outputs, for example, time to write a career establishing book. For some participants the effects of their ‘impairments’ were severe enough to make working full time (or regular part time hours) very difficult, or impossible. These participants had found alternative routes to remaining in academia, for example, ad hoc hours on research projects, becoming an independent scholar or moving away from a science based discipline into social sciences, where it was perceived there was greater flexibility or requirements for physical work.

For participants with an ‘impairment’ acquired after establishing an academic career, the effect on career progress was more subtle, but also negative. One professor with a traumatic brain injury (TBI) stated that he was no longer allowed to take on new administrative roles, as this would take away time from his adjusted workload. This limited his opportunities to learn new skills and further develop within his current grade. More established participants also felt that career progression had been more difficult due to the increasing demands characterized by a promotion. For example, an ECR may see an increase in responsibilities from being research only, to being asked to undertake teaching, assessment and administrative duties in addition to research.

Future career progress and plans

A number of interviewees felt that their ‘impairment’ or disability would have a significant negative impact on their future careers. Participants referred to difficulties completing the required number of research outputs for promotion, or completing grant applications. This could relate to speed of writing or reading for interviewees with dyslexia, difficulties using technology e.g. those with muscular problems or fatigue associated with their condition or ‘impairment’. A small number of participants had either already left academia, or were planning to leave when their current contract/funding ended, as they felt it was not possible to secure another appointment. Such participants stated that they felt the effects of their ‘impairments’ were incompatible with current employment structures and practices within UK academia. Specifically, such participants felt that available funding was not flexible enough to accommodate their ‘impairments’, for example, while research councils provide part time funding, grants do not allow periods of reduced activity or disability leave.

A number of participants from engineering or physical science backgrounds, including computer sciences, had selected to move from those disciplines into social sciences. They felt that their physical ‘impairments’ prevented them from undertaking the physical labour required in research. Alternative disciplines included science education, where participants stated there was greater flexibility in managing data collection and other aspects of research careers. Further, some participants had changed the direction of their research to
accommodate their ‘impairment’, for example, field work in countries where disability is a taboo topic or choosing to engage in disability research and activism.

For those who were planning to stay in academia there was a concern that their ‘impairments’ were not compatible with career progression whether through promotion, moving employers or taking on developmental roles. Participants stated that they would not pursue promotion for example, to senior lecturer as they felt the promotion procedures were not accommodating to disability in similar ways to parental leave. In addition a number of participants felt strongly that their ‘impairment’ was incompatible with a more senior academic role. Through these conversations it became apparent that a number of participants had an idea of the ideal academic, which they were not able to match. This was despite currently engaged in academic work. Participants also felt that their ‘impairments’ interacted with academic norms to affect career prospects, including networking and conferences.

Working relationships
The importance of networking to professional careers, including academics, is well documented. This aspect of a career may be problematic for disabled academics. One area which participants discussed was attending conferences. While interviewees stated that they were able to attend conferences there were caveats to this. Academics with mobility issues, including those who use wheelchairs, reported difficulty ascertaining accurate information about the accessibility of conference venues, for example, steps leading into a main theatre rather than a ramp. There were clear examples in the data of the built environment of conference venues being inadequate for disabled delegates. One participant recalled not being able to access a venue to give her presentation. Her carer was able to attend and take notes, but this prevented the interviewee from taking part in informal discussions and networking. In addition, there may be inadequate toilet facilities which are close to the venue and accessible. The provision of facilities at conferences was also found to be problematic. Examples included inappropriate food (for example, contamination of gluten free food).

Beyond these tangible aspects of conference experiences, participants also reported difficulties with long days. For example, presentations running from the early morning to the late evening, with a conference dinner following. For those with fatigue issues, such long days are very difficult or impossible. One participant recalled falling asleep in sessions due to overwhelming fatigue. Other participants stated that they managed the fatigue and sensory overload of conferences by either returning to their accommodation or not attending the conference dinners. Academics stated this was problematic as they missed out on valuable networking and socializing opportunities. Participants felt this negatively affected their ability to develop their research careers. Attendance at conferences was at a price for participants, who reported they would need several days or a week to recover on their return, and this may require arranging teaching cover or taking time off.

Networking was also reported to be difficult during day-to-day working life. A participant diagnosed with Asperger Syndrome stated that she found it difficult to engage in ‘chatting’ to colleagues due to discomfort with this form of communication. A participant who uses a wheelchair shared examples of her colleague’s offices being inaccessible and as such she missed out on spontaneous meetings or informal get-togethers. Another participant who uses a wheelchair was unable to use her laboratory during the working day, and had special arrangements to work in the evenings. While this allowed her to conduct experiments, she felt she also missed out on the informal network and support system building which other researchers found useful. Similar experiences were reported by academics who work from home as part of reasonable adjustments. Another difficult aspect of working life was shared offices. Participants felt this affected their concentration due to noise levels, types of lighting and was associated with increased fatigue.
Respondents reported mixed experiences with colleagues. A number of interviewees stated that their colleagues were supportive and facilitated continued employment. Such working relationships included supportive supervisors who accommodate working from home, or flexi-time working. However, other participants reported far less positive experiences, which they often felt was the result of a lack of awareness amongst colleagues of disability. There were stark examples including one participant with cerebral palsy who told by a colleague that she should not become an academic as it was unfair to expect others to make adjustments. Another participant reported that a line manager had accessed their confidential occupational health file and threatened to disclose the contents. Such examples of aggressive behavior were not common amongst participants. More frequent were difficulties securing reasonable adjustments, which were seen in part due to ill-informed line managers.

Participants also reflected on their relationships with students. Many had not shared their disability with their students as they were concerned about negative teaching evaluations, or distracting students from studies. Others had felt their ‘impairment’ changed their relationships with students for the better. One participant with Asperger Syndrome felt she was able to relate better to students who struggle with social situations and provide a supportive environment to enhance the student experience.

‘Disclosure’ and Reasonable adjustments

The data revealed that participants were mixed in their level of disclosure in the workplace. Some with visible impairments said they had no choice but to disclose, as did others with acquired impairments such as traumatic brain injuries. Respondents who had experienced ill health while at work were also among those who had disclosed to their employer and line manager. In contrast, other participants had not disclosed, in part as they felt it was not their employer’s concern and they were unaware in what adjustments might be available to them.

Disclosure was not a binary state for participants. In part this was due to the nature of line management in academia, with rotating heads of department. Interviewees may have disclosed to one line manager and had adjustments agreed both informally or formally. A change of line manager resulted in a loss of that disclosure and adjustments, with the process starting again. An example of this came from a participant who had disclosed a vestibular impairment and had secured agreement to avoid teaching in a basement lecture hall. A new head of department was unaware of this agreement and was reportedly reluctant to honour the previous arrangement.

Often reasonable adjustments were informal, including working from home, arriving at work after 9 and leaving before 4 to avoid commuter traffic. However, the informality of these adjustments may make them vulnerable to being lost. While some academics did have formal adjustments, for example voice recognition software, accommodations were not reported in terms of managing workload, with the exception of a senior male professor. Where adjustments were in place, they were not always compatible with the demands placed on academics. An example included a participant who had access to voice recognition software but this was not compatible with the virtual learning environment the university used. Other formal adjustments included a carer to attend conference, financial support to pay for equipment and scheduling of lectures.

One recurring theme from participants was that being disabled was ‘like having a second job’. Navigating institutional procedures, structures and cultures to secure funding for reasonable adjustments was a time consuming and frustrating process. One participant applied for a disabled car parking space, which after considerable time was awarded. But the space was over 1km away from her office. As a wheelchair user this
was impossible. Eventually a suitable space was provided, but at considerable time and emotional cost to the participant.

Another side of disclosure was its effects on the recipient of that disclosure. Some younger and early career participants stated that an academic mentor had disclosed an ‘impairment’ or health problem, for example, depression or dyslexia, and this had made them aware of the potential for academia as a career path. One professor with depression reported that he disclosed to students as a way of opening space for a dialogue about mental health concerns within universities.

Suggestions for improving working life for disabled academics
The following section presents practical suggests for key stakeholders, as suggested by participants and including suggests developed based on participant response.

Suggestions for universities
The data suggests that universities have considerable scope to improve the working lives of disabled academics, potentially improving retention and enhancing the student experience. Suggestions include:

- Ensuring line managers and PhD supervisors are trained in disability awareness
- Including disability awareness in recruitment and promotion procedures and practices.
- Having a central source of disability information, for example, an intranet site
- Initiating disciplinary action against managers and supervisors who fail to implement adjustments.
- Enforcing smoke free zones
- Making buildings accessible
- Enforcing accessible parking
- Adjusting workloads for disabled staff
- Disability role models
- Establish disabled staff networks to provide support and inform university decision making

Suggestions for research funders
Participants were divided in the scope for research funders to support disabled applicants. There were suggestions that research funders could:

- Make their disability policies clear
- Streamline application forms
- Make funding more flexible, including more small grants for academics who are restricted in their working hours (e.g. one day per week)
- Have specific grants for disabled applicants

Suggestions for trade unions
Interviewees were skeptical of the role of trade unions, in part due to perceived lack of awareness of trade union case workers relating to disability issues. However, it was felt that trade unions could:

- Train their case workers on disability issues
- Facilitate reasonable adjustments and return to work procedures
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<tr>
<th>Short term</th>
<th>Collating of existing policies and practices onto a central intranet site</th>
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<tbody>
<tr>
<td></td>
<td>Detailing of existing policies relating to research funding</td>
</tr>
<tr>
<td>Medium term</td>
<td>Changes to policies e.g. disability inclusion in promotion procedures</td>
</tr>
<tr>
<td>Long term</td>
<td>Culture change e.g. disability champions, inclusive working practices</td>
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<td>New disability specific research funds</td>
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</tbody>
</table>

Table of short, medium and long term interventions.

Conclusions
The experiences of academics who participated in this research were varied, affected by nature of ‘impairments’, disciplines, career stages and nature of employment. Key themes did emerge in relation to fatigue, career progression, difficulties accessing networks and sometimes difficult interpersonal relationships. The data also suggest that disabled academics can shape universities and the student experience to be more inclusive, providing powerful visions of what is achievable for disabled employees. More work is required to undertake initiatives which put into action some of the suggestions proposed here, and assess their usefulness. In addition, future work should explore the experiences of disabled staff across staff groups within universities, to determine specific interventions to facilitate the inclusion of all disabled employees. Universities are in a position to create an inclusive working environment which allows all members of the university community to thrive.
Appendix A: Consent form

The experiences of disabled academics

Researcher: Dr Kate Sang (k.sang@hw.ac.uk) Associate Professor of Management, Heriot Watt University

Thank you for agreeing to participate in this research, designed to understand the experiences of disabled academics. For those interviews taking place face-to-face, Skype or by telephone, I would like to digitally record the interview for transcription purposes. This ensures an accurate record of the interviews. All interview transcripts will be anonymised to protect the identities of individuals and employing institutions. I anticipate interviews lasting between 40 and 60 minutes, covering career history, the impact of disability and recommendations for employers. Anonymised data from the interviews will be used to inform a report for Heriot-Watt University and resulting conference presentations and publications. The project has secured ethical approval from Heriot Watt University. Data will be securely stored, with raw data only available to me and the professional transcriber. Digital recordings will be destroyed once the project is complete.

Please note:

1. With your permission the interview will be recorded (if relevant)
2. You may withdraw from the interview at any time without providing an explanation
3. No questions are compulsory, please answer as many as possible. However, if any question causes discomfort, please feel free to move to the next question
4. Any data used in reports or publications will be anonymised to protect your identity and that of your employing institution (if relevant)
5. All data will be securely stored

I consent to participate in this study

Name

Date
Appendix B: Interview questions

Introduction

Thank you for agreeing to participate in this study on academic careers and disability. The research is jointly funded by an EPSRC career acceleration grant and an internal research grant from the School of Social Sciences at Heriot Watt University. Data from the interviews will be stored securely and, following anonymisation, used for resulting reports and publications. The interviewer subscribes to the social model of disability, hence the use of ‘disabled person’ rather than ‘person with a disability’.

Please answer as many questions as possible, passing over those which you do not wish to answer. You are free to stop the interview at any time, without providing any explanation. Details from the interviews or interviewees will not be passed on to any third party, although recorded interviews will be professionally transcribed.

If you are completing the interview via email, please feel free to use abbreviations, notes, bullet points, emojis or other forms of shorthand.

Questions:

1. Are you currently working as an academic (PhD through to Professor)? (if yes, please move to question 3).

2. If you have left academia, when did you leave and why? (If you have left academia, please answer the following questions with reference to your experiences in academia. Please also consider and discuss contrasts with any current employment).

3. Please tell me about your current job - what is your job title and your main responsibilities?

4. Do you work full-time or part-time?

5. Is your contract: temporary (how long), open ended or permanent?

6. Which disciplinary area are you based in? (e.g. engineering, sociology, etc.)

7. Could you please summarise your career history to date (an annotated CV would be fine here. It will not be used to identify participants).

8. Why did you decide to become an academic?

9. Can you please tell me about your ‘impairment’, disability or long term health problem?

10. Do you consider yourself to be disabled? What are your reasons for this answer?

11. Have you disclosed your disability at work to:
   a. Colleagues
   b. Line Manager
   c. Students
12. What were the reasons for disclosing or not disclosing?

13. How does your ‘impairment’ or disability affect your working life? (e.g. conferences, funding, teaching, relationships with students/colleagues/managers/supervisors, promotion access to networks, working hours and patterns of working)?

14. What adjustments (if any) have you negotiated with your employer? Are these adjustments formal or informal?

15. What, if any, effect do you think disability or ‘impairment’ has had on your career progress?

16. What, if any, effect do you anticipate disability or ‘impairment’ having on your future career?

17. How could universities better support disabled staff and PhD students?

18. How could research funders better support disabled staff and PhD students?

19. How could the trade unions or the students’ union better support disabled academics?

20. What other changes would you like to see in academia, to improve working life?

21. Is there anything else which has affected your academic career?

22. Demographic questions. Please provide details of your:

a. Age

b. Gender

c. Ethnicity

d. Nationality

e. Relationship status

f. Sexual orientation

g. Religious belief (if any)

h. Geographic region (This will be anonymised, but it’s useful to know broad areas e.g. Edinburgh, North East England, Wales etc).