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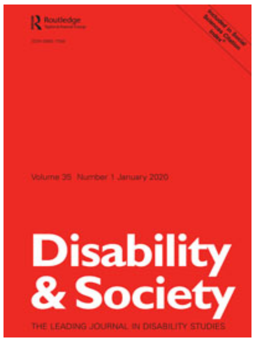

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Rethinking inclusion and disability activism at academic conferences: strategies proposed by a PhD student with a physical disability

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ABSTRACT
Conferences are central to academia, providing opportunities for scholars to exchange ideas, socialise and build networks and extend their scholarship. Therefore, inclusive research in universities must extend to including activists and disabled academics in conference settings. Unfortunately, conferences pose particular accessibility problems for participants with physical disabilities, long-term illness or chronic pain. In this article I will explore my own experience and insights about how conferences might be better organised; on the one hand to avoid losing the voices of disabled activists and scholars which Disability Studies needs to have practical impact, and on the other to create a new set of inclusive conference practices, going beyond accessibility attempts to 'fit' disabled attendees into traditional lecture halls which are fundamentally not inclusive.

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I am a Belgian PhD student in my late twenties and follow a part-time PhD trajectory. I have cerebral palsy (CP). From head to toe, my muscles are spastic and weakened, causing daily difficulties, tiredness and pain. While CP typically causes visible symptoms, in my case it is as much an invisible illness, making it difficult for me to comfortably fit into disability categories and to be a disabled person in academia, as the few policies designed to include disabled researchers focus on visible issues, such as mobility. Sociologist James Overboe (1999), who has CP too, shared a similar personal experience in his article 'Difference in Itself'. It stimulated him to look for an alternative way of being, beyond classification. He wrote that he felt a sense of freedom when he tried to accept being of no category to anchor his existence or no place to belong, because then he was released from the restrictions of the ability/disability categories.

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In my view, we could also attempt to break the tension between the preconceived categories of (dis)ability by rethinking how attention for reasonable accommodation, organised assistance, accessibility[1] and individual needs could be valuable for the conference experience of a larger group than persons with specific physical disabilities for whom these are a necessity. I will demonstrate how this could be a useful starting point to create a new set of inclusive conference practices.

Firstly, I reflect on my conference presentation experiences. Since I wish to present in the best possible physical conditions, I always contact conference organisations long before the programme is finalised. These preparations are an extra workload, although it has almost become routine. In a previous Current Issue article, disabled PhD student Stephanie Hannam-Swain (2018) wrote that taking care of all the disability-related workload can sometimes feel like having another part-time job. I often feel similar during conference season. As I can breathe less deeply when speaking due to contractures in my chest, I need a clip-on microphone to help my voice carry further. Often this microphone type is not supported and then I have to bring my own sound system of 3.5 kg. Because I have contractures in my shoulders and neck too, which prevent me looking regularly behind myself, I request a low table and a laptop so that I can sit down and look at my slides and the audience simultaneously. In modern business meeting rooms this equipment is easy to arrange, but not in traditional university auditoria, which have been seldom designed with the needs of disabled teachers in mind. Many colleagues, however, have told me that a hands-free microphone and a front-view set-up could be more comfortable for all presenters.

I developed my own presentation method with mainly visuals, which can compensate my static posture. Visuals are also very suitable for video or livestream presentations. In the spring of 2018 I presented via video at three conferences, because it was medically impossible for me to be there in person. Overall, conference organisers showed much understanding and enthusiasm for my request. Only the Q&A sessions posed a technical challenge, since the Internet connection in the room was often unstable and Skype was not supported. I solved this problem through a light browser-based web-conferencing application which also allowed me to follow the entire session via webcam. While I was pleased that my presentations went quite smoothly, I also was astonished that video interaction is so little used at academic conferences compared to other educational settings or the business world. It is a missed opportunity to let persons participate for whom it is difficult to travel or attend an entire conference, for various reasons such as physical difficulties, but for example also sudden illness or family obligations, which are common reasons for a late cancellation at conferences.

Secondly, I discuss the practical issues of travelling to a conference and moving around on site. I always travel with a wheelchair, which makes it more challenging to use public transport. The journey is extra tiring and painful when the venue is far away from the airport or main station. Since this extra distance also comes with a financial, ecological and time costs for every participant, I hope that there will be more attention to accessibility when deciding on the location of a conference in the future.

As I need personal assistance during the entire stay, my parents take leave to accompany me. It is tough to get a budget for a personal assistant in Belgium, even if you have an important and recognised care need like I do. The waiting lists are so lengthy that it is not likely I will receive a budget as long as my parents are still physically able to take care of me. Unfortunately, I cannot change this challenging and frustrating fate, which takes much more courage to accept than my impairment or chronic pain. So, I try to raise awareness about the problematic and complex relation between disability benefits and bureaucracy in modern history. In the meantime, my university is examining how it could provide more financial support for disabled researchers.

Many traditional university lecture halls have not been designed with the needs of a physically disabled audience member in mind either. Too often there is no elevator access or space for a separate chair or wheelchair next to the fixed seating. If there is one, it is typically located in the front of the room near the door. I understand this is necessary for safety reasons, but it also makes it impossible for a wheelchair-user to sit close to the other participants. A ground-floor meeting room with moveable chairs, on the other hand, encourages both spatial and social inclusion.

During walking lunches, I have experienced similar problems. They are my social nightmare, because I cannot stand, hold my plate and eat at the same time. I usually end up at a special table with my parents, sometimes joined by a disabled colleague who has similar motor problems. Additionally, the lack of low tables makes it difficult for others to join us. So quick walking lunches create a social barrier for both participants with and without disabilities. Even at Disability Studies conferences, the lunch setting is often problematic. Apart from a seated setting, I believe that an organised assistance system could be a conversation opener too, especially at Disability Studies conferences. Inspired by lunch initiatives for early career researchers, arranged lunch or coffee break meetings could be held between scholars with a special interest for inclusive research and persons who wish assistance. During these moments, assistance would no longer be reasonable accommodation, but part of a collaborative commitment to bridge the gap between academics involved in disability research and disabled scholars or activists.

Lastly, I would like to shed light on my additional travel expenses for disability reasons. The hidden costs of having a disability at conferences have already been problematised in several articles, reports and blogs over the last few years (see, for example, Callus 2017; Dunstan 2017; Fullick 2016; Sang 2017). I often have to take a taxi to comfortably travel with a wheelchair and luggage. I also have to choose a hotel very close to the venue, if I wish to have the possibility to rest on a bed between sessions. As conferences are typically organised in the city centre, the hotels near the venue are much more expensive. My body cannot handle an exhausting conference schedule of several days, which is already a challenge for academics in good shape, hence it is also a pity that few conferences offer daily registration fees. If I am lucky, my university budget covers my own expenses for one conference. My colleagues without disabilities can often go to two conferences with this budget. I have to pay my parents' flight and room myself. So, I would say that the same rule applies for disabled academics as for all disabled persons: to get the things you want in life, it is best to have many savings. Consequently, disability activism at academic conferences is always going to be limited, if it is only a possibility for those who can pay. Universities should anticipate this issue in their diversity and inclusion policies and work out a financial support programme to help disabled scholars get out of this discriminatory and disadvantaged position.

Over the past two PhD years I have repeatedly applied for scholarships, but this has been tough. I have obtained funding once. Many conference funding programmes are specifically aimed at doctoral students from low-gross domestic product countries or scholars with a very limited university budget. I cannot help but notice, however, that persons with physical disabilities, who often cannot work full-time or have many additional costs, face quite similar budget problems to attend conferences. I would like to argue in favour of alternative funding procedures, based on both financial and diversity grounds. Broader funding guidelines would perfectly align with the growing awareness for diversity and equal opportunities in the planning policies of most conferences. In recent years, organisers have increasingly tried to reflect more diversity in their line-up of speakers; for example, by encouraging or including submissions of scholars belonging to groups who are historically underrepresented in their academic discipline due to gender identity, ethnicity or disability.

I am hoping that the inclusive potential of the strategies proposed in this article will be discovered by many more organisers in the future and that it can help them to spatially and conceptually redesign conferences into events without physical or social barriers for all, leading to further cracks in the tension between the categories of (dis)ability in academia and giving a louder voice to disability activists or disabled scholars. Only truly accessible conferences can become platforms where academic study and daily disability experience meet, merge and become each other's sounding board. This is an underestimated way of carrying out inclusive research and collaboration, through which Disability Studies can find new opportunities to make a 'real' difference at a collective and individual level to disabled persons lives and to policy and activism, and through which activists and disabled persons can have a pragmatic impact and constructive role in academic discussions.

Note

1. The United Nations pragmatically defines accessibility as flexibility to accommodate each user's needs and preferences. The measures that can be taken to ensure persons with disabilities access on an equal basis with others can be found in Article 9 of the United Nations Convention of the Rights of Persons with Disabilities. Accessed 20 October 2018. https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-9-accessibility.html.

Disclosure statement

No potential conflict of interest was reported by the author.

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