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Making disability conferences more actively inclusive

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ABSTRACT

In this article I explore how generic disability conferences can become more inclusive of participants with intellectual disability. Increased inclusivity entails adapting to the support needs of people with intellectual disability, in line with the principles and practice of inclusive research. In the article I consider three specific areas where there can be more inclusion – access to information related to the conference, access to knowledge imparted during the conference, and financial issues. While many good practices have been developed in these areas, it is important to ensure that inclusion is catered for in a systematic and pro-active manner, so that people with intellectual disability have increasingly more meaningful and active roles within disability studies and disability research.

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Introduction

Things have come a long way since 1981 when, during the International Year of Disabled People, disabled people took exception to the way that year's Rehabilitation International conference was dominated by the voice of health professionals, and walked out to subsequently set up Disabled People's International (Driedger 1989). Conferences about disability and disabled people the world over nowadays regularly present research as well as reflective work that is focused on socially constructed disabling barriers. More importantly, disabled people themselves present papers and posters, deliver keynote speeches, and participate in symposia and panels. If the presenters, like me, are non-disabled, then it is quite likely that their presentation includes, and sometimes is entirely based on, the opinions and life experiences of disabled people. Many access requirements are of course also taken into consideration.

Ensuring that disabled people have access to conferences and can make their voice heard is of course in line with the ethos of disability studies, rooted as it is in the emergence of the disabled people's movement. But, in the same way that there needs to be greater inclusion of people with intellectual disability within

disability studies, there is also much that can be done to make generic conferences on disability more easily accessible for people with intellectual disability, so as to ensure that they do not only participate in conferences which are specific to intellectual disability. They can and do participate in these conferences, both as presenters and as audience members, and there has in fact been progress in this regard over the past two decades. But that participation is limited. It can be said that it is still very much the case that they (with the help of their assistants) have to adapt to the way conferences are organized. Perhaps it is time to consider how to be actively more inclusive of conference participants with intellectual disability.

In this article, I briefly explore the context in which the need for this increased inclusivity is felt and the ways we can make it happen. Most, if not all, suggestions refer to practices that have already been adopted by some conference organizers, in some or all of their conferences. The suggestions presented are also partly based on my own experience of accompanying people with intellectual disability to participate in such conferences. My aim here is to highlight practices that make disability conferences more actively inclusive for people with intellectual disability.

Inclusive research and inclusive conferences

Many people with intellectual disability are actively involved in research thanks to the principles and practices of inclusive research (Nind 2014; Walmsley and Johnson 2003). If people with intellectual disability are being more actively involved in conducting research, then it follows that they should also be actively involved in participating in disability conferences. By 'inclusion' here I am referring to taking concrete and concerted steps in a systematic manner to actively promote inclusion, rather than the current way in which adaptations tend to be made in an ad-hoc manner, mostly by the people supporting them directly. As in inclusive education, we need to distinguish between integration (where the individual is slotted into a mainstream system with supports) and a deeper level of inclusion where the whole system is differentiated for greater access. Three aspects of inclusion are considered here: access to information, access to knowledge, and financial issues.

Access to information

For active participation in any conference, access to information is vital. The first piece of information one needs is the call for papers, from which one gets to know that there is going to be a conference in the first place, the themes of the conference, the deadlines, and the process for submitting abstracts. Next, and a close second, comes practical information about the conference: the venue, the dates, and arrangements for registration, accommodation, and travel.

How much of this information is accessible for people with intellectual disability in an easy-to-read version? How much of it is delivered automatically to their mailboxes? I think it is more likely for an academic working in disability studies or

a professional working in the disability sector to inform co-researchers with intellectual disability about an upcoming conference they could participate in together, rather than the other way round. Providing easy-to-read information is a vital step towards enabling people with intellectual disability to exercise their agency more actively in deciding whether or not to participate, and if yes, in what manner.

Once the decision is taken to participate, people with intellectual disability also need to choose which panels to attend during the parallel sessions, a decision that is usually taken on the basis of the presentation titles and the abstracts. Access to the information held in the abstracts is therefore also key to the active participation of people with intellectual disability in conferences. Rather than depending entirely on simplified explanations provided by the assistants accompanying them, people with intellectual disability should be provided with an easy-to-read version of the abstract, for example by providing three to four easy-to-read points. This practice has already been adopted for articles published by some academic journals in the field of disability studies, and has been used in some international intellectual disability conferences.

Access to knowledge

Information and its sister, knowledge, are of course the life and blood of conferences. The question here is how much of the information and knowledge that is shared and discussed in conferences is accessible for the people with intellectual disability participating in them. Presentations by people with intellectual disability are accessible if they are presented in an easy-to-understand format. There may need to be translations if the presentation is delivered in a language not spoken by the people with intellectual disability. But it is one thing for accompanying persons to do word-for-word translations and quite another for them to provide simultaneous interpretation of abstract concepts or complex arguments to the person with intellectual disability they are supporting. How does one whisper a simplified explanation of complex notions such as 'epistemic injustice' while the presenter is speaking, without having the chance to discuss? The whispered explanations are another issue of course. They may cause an inconvenience to nearby members of the audience, but are a vital tool in ensuring simultaneous access to information and knowledge for people with intellectual disability.

Some presentations (whether in parallel sessions or keynotes) are, by their very nature, more accessible than others. Presentations which are accompanied by slides with key words and little if any jargon words make it easier for persons with intellectual disability to follow. This is not to say that all presentations have to be in easy-to-read formats and that theoretical and abstract discussion should be banned. Ideally, in each of the parallel sessions there would be at least one panel that is accessible to people with intellectual disability. This would give space for a diversity of modalities in which presentations are made.

Posters are by their very nature more accessible. The information provided is concise and one can read it at leisure. However, there are styles that fit more with the guidelines of producing easy-to-read documents than others. Once again, I am not suggesting that all posters need to be in this format, but having a section with easy-to-read key points would certainly help make the knowledge more accessible.

Discussions of epistemic injustice and other concepts in relation to disability are important and have a very valid contribution to make to disability studies. But conference participants can be encouraged to consider ways of making their presentations as accessible as possible, precisely to address epistemic injustice, especially, but not only, if the subject of their paper is the life experiences of people with intellectual disability themselves. Furthermore, knowledge in conferences is not presented, discussed, and generated in formal presentations only of course but also in lunch and coffee breaks and the other different opportunities that conference participants have to meet up informally. Likewise, for people with intellectual disability, being physically present during conferences enables them to network with other researchers which, as any website on academic conferences will tell you, is one of the main benefits of conference participation.

Financial issues

Finally, I come to financial issues. Having the money to participate in a conference is as essential as having access to the information related to it. While many academics can apply for funding from their university to participate in conferences in their own countries and abroad, many people with intellectual disability who are involved in inclusive research are not directly employed by a university and do not have access to automatic funding for conferences. Furthermore, many people with intellectual disability are in low-paid, part-time jobs if they are in employment at all (Emerson et al. 2011; KNPD 2011) and are unlikely to be able to afford to self-fund all of the expenses related to conference participation, especially when the conference is in a foreign country. The extra costs of having a personal assistant also need to be considered.

Consequently, another way of making conferences on disability more accessible for people with intellectual disability is by offering reduced fees. There are already conferences where disabled activists pay such a fee. Where this reduction is not the rule, I feel that a case can be made for people with intellectual disability in particular. After all, even if all efforts are made to make these conferences as inclusive as possible, there will still be a significant amount of presentations and speeches whose formats and content is not readily accessible for many people with intellectual disability. This results in a reduced range of options for conference participants with intellectual disability, and even in their opting out of certain sessions altogether.

Conclusion

As I said earlier, the suggestions put forward in this article draw from already existing practices. But these practices have not necessarily become the established way of doing things in generic disability conferences in the same way that providing a physically accessible venue, sign language interpreting, and so on has become. Nor has there been a traceable linear progression of increased inclusivity in generic disability conferences. What is needed is a concerted effort to ensure that inclusive practices are adopted in a systematic manner so that they too become part of the way things are done. As things stand, while people with intellectual disability can and do participate in conferences about disability, their presence still tends to be an exception and remains on the margins of the conference. The adoption of more inclusive practices should encourage and enable them to participate more frequently, more actively, and more fully.

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