

Being an inclusive researcher: seeking questions raising answers

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## **Abstract**

In this article, I reflect on three incidents that occurred in my inclusive research work. As a conceptual framework, I use Bourdieu's call for a reflexive sociology. My reflection is informed by the principles of the disabled people's movement, especially giving primacy to the experiences and voice of disabled people. It is also informed by the strong link between the disabled people's movement and disability studies, which requires academics (including non-disabled ones like myself) to be attentive to their activist role. Making sure that this role is carried out effectively, I argue, entails considering the various factors that make our work possible, and being attentive to the impact of our work. It also entails asking questions, of ourselves and others, and being especially attentive to questions that would go unasked unless we stop to reflect about our work, and the possible answers that these reflections can lead to.

## **Points of Interest**

- In this article, I reflect on three incidents that happened when I was doing inclusive research. Listening to what disabled people have to say about their experiences is very important.
- As a non-disabled academic, I am also aware that my work in disability studies is like that of an activist working for disabled people's rights. Therefore, to do my inclusive research work well, I needed to reflect on how I did it and whether my work with a co-researcher with intellectual disability was done well.
- I conclude that it is very important for someone like me to ask questions and reflect about my work, and look for ways in which I can do it better.

## Introduction

The link between activism and the academy and disability, the subject of this special issue of *Disability & Society*, is embedded in the history of the disabled people's movement, which has been extensively chronicled (see, for example, Campbell and Oliver 1996; Shapiro 1994). Two significant characteristics emerge from these histories. The first is the realization by disabled people that their disability is not equivalent to impairment but is 'something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society' (UPIAS 1976, 3). The second characteristic involves a move away from assuming that it is only professionals – medical, educational, or otherwise – who are qualified to speak about disability, but that in fact what disabled people have to say about the experience of living with a disability and in a disabling society is of foundational importance. These two characteristics have underpinned the formation and development of disability studies as an academic discipline that emerged from the disabled people's movement (Barnes and Mercer 2010; Goodley 2011; Linton 1998).

Given the centrality of disabled people's perspectives and actions in matters concerning them, the role of the non-disabled person in activism and academia has been much debated. I myself am a non-disabled academic, and my main area of interest is means of empowerment for people with intellectual disability, including through self-advocacy and inclusive research. I have been involved in supporting people with intellectual disability in self-advocacy settings for over 15 years, including being a support member of a self-advocacy group and conducting inclusive research with a co-researcher with intellectual disability. In this article, I reflect on my work in the latter arena, and associated work, at university. I first present an overview of the motivations for developing emancipatory disability research, which is following by a brief history of the evolving roles of people with intellectual disability in research. I then explain the research method that I have used for this article – discussing three incidents that arose from my work and which gave me much pause for reflection. The conceptual framework in which I carry out the discussions in this article is Bourdieu's call for a reflexive sociology, of which I also provide an overview. I then present and discuss the three incidents, and finish with concluding reflections about the need to be attentive to opportunities to raise questions about the role of the inclusive

research as both activist and academic and to seek potential answers for these questions.

### **Academic-activist disability research**

As the call for papers for this special issue states, when *Disability & Society* was founded in 1986 the editors stated that 'we do not wish the journal to be viewed as a vehicle for merely representing professional perspectives' (*Disability & Society* 2018). That 'merely' is telling. Traditional hierarchies of voice are overturned in disability studies. Professional perspectives are not the most important, but the perspectives of those who live with a disability on a daily basis are.

Because disability studies is so intimately connected with the disabled people's movement, how to do research about disability has always been an important subject for consideration. Indeed, the first special issue of *Disability, Handicap & Society* (as this journal was then known), in 1992, was about disability research. Barton's 'Introduction' provides the context within which these and the other articles were written, recognizing:

an increasing disenchantment with many research projects ... their misunderstanding of the nature of disability, their distortion of the experience of disability, their failure to involve disabled people and the lack of real improvements in the quality of life of disabled people ...

...

These papers raise fundamental questions about the nature and purpose of research and in what ways such activities can be underpinned by effective empowerment. Thus, this whole issue is set within the broader context of emancipation, choice and social justice. (1992, 99)

These articles, together with the contributions to *Doing Disability Research* (edited by Barnes and Mercer 1997), can be considered as laying the foundations of emancipatory disability research. The principles of this research approach, set out by Stone and Priestley (1996) as well as Barnes (2001), refer to the adoption of the social model of disability, being politically committed to the rights of disabled people, holding oneself accountable to them, choosing appropriate methods for conducting research, giving primacy to the voice of disabled people and their experiences, and seeking practical outcomes for the research. The role of the non-disabled researcher, the main focus of my article, is consistently part of the discussion. Among the earliest discussions,

one finds the reflections of Priestley (1997) and Drake (1997) on their position as non-disabled persons working with disabled people in favour of the latter's rights. The issues raised in these reflections have featured in many subsequent discussions, including those by Bricher (2000), Humphrey (2000), and Kitchin (2000). Similarly, the role of support members in self-advocacy and of the academic in inclusive research has been extensively discussed (Bigby, Frawley, and Ramcharan 2014; Chapman 2014; Williams 2011).

### **Subjects, participants, researchers**

The negative associations of the label 'intellectual disability' and the connotations of incompetence and inability – and even the notion of not being fully human – that it gives rise to have been debated by many authors (see, for example, Kittay and Carlson 2010; Rogers 2016). The ability for people with intellectual disability to flourish when provided with support, and their resilience in the face of adversity (as chronicled, for instance, by Bogdan and Taylor 1982; Goodley 2000), have shown that intellectual disability is not the equivalent of cognitive impairment, and that people with intellectual disability are significantly affected by the socially created barriers they face in their lives. Indeed, in the first issue of *Disability, Handicap & Society*, St Claire challenges medical definitions of 'mental retardation' and argues that it is 'a social psychological phenomenon' (1986, 233). Significantly, 12 years later, Chappell (1998) wrote about intellectual disability being left out of the social model, an issue taken up again by Chappell, Goodley, and Lawthom (2001), by Goodley (2001), and by Goodley and Van Hove (2005).

Broadly speaking, applying the social model to intellectual disability leads to research that focuses on disabling barriers, while research that simply equates disability with impairment focuses on the incapacities of people with intellectual disability, thus reinforcing the idea that the restrictions experienced by people with intellectual disability arise from their own innate cognitive limitations, rather than predominantly from externally imposed and socially constructed barriers. For a long time, it was a focus on incapacity that informed research in the area of intellectual disability. There is the work carried out around a century ago, where people

with intellectual disability were the subject of studies by eugenicists whose pseudo-scientific research sought to depict the social problems posed by those whom they called 'feebleminded', such as the people with intellectual disability whose photographs feature in books by Martin Barr (as quoted in Bogdan, Elks, and Knoll 2012).

Researchers' preconceptions tend to creep into how they see people with intellectual disability going about living their lives. This can be seen in the contrasting portrayals of people with intellectual disability in similar situations which emerge in Robert Edgerton's (1967) *Cloak of Competence* and Robert Bogdan and Stephen Taylor's (1982) *Inside Out*. Both books deal with the life stories of people with intellectual disability who moved out of long-term residential institutions into community-based homes in the United States. Edgerton's book presupposes the incompetence of people with intellectual disability, whom he depicts as finding strategies to hide this incompetence. On the other hand, Bogdan and Taylor portray the two people with intellectual disability involved in their study as skilfully finding ways of coping in a society that treats them as inferior citizens. Their study leads them to conclude that 'mental retardation', as it was then called, 'is a crude metaphor' (1982, 7) and 'is relative not absolute' (1982, 8). The lived experience of people with intellectual disability is contingent on the environment they live in and the socio-cultural context in which they are situated. Edgerton himself later acknowledged that the people he interviewed turned out to be far more adept at adjusting to life in the community than he had previously thought (Edgerton and Bercovici 1976). Research, then, does not merely describe the lives of people with intellectual disability. It also interprets their behaviour and actions, and what they say.

Those interpretations can serve to reinforce or challenge perceptions of intellectual disability. In the 1980s, Carol Sigelman and her colleagues conducted a series of interviews with people with intellectual disability. Their main conclusion was that responses given by people with intellectual disability cannot be relied upon. Sigelman et al. write that 'the present analyses suggest that the validity of answers given by mentally retarded individuals can never be assumed: it must be demonstrated' (1982, 518). The solution that they present is to check responses given with

another adult taking care of the person being interviewed. The fact that other adults can also be biased in their responses and provide inaccurate information themselves is not flagged as an issue, and their ability to provide reliable information is not questioned. But when it comes to speaking to people who have an intellectual disability, the burden of proving capacity to respond is here shifted onto them.

Rapley (2004) argues that the effect of the work carried out by Sigelman et al. was to establish what they termed 'acquiescence bias' in people with intellectual disability and the idea that their responses in interviews tend to be unreliable. He takes to task the methodology employed by Sigelman et al. His main criticism is that they did not consider the context in which the interviews took place, especially the relationship between the interviewer and the interviewee. This relationship, Rapley argues, is very much that of a professional quizzing a client. The people with intellectual disability who were interviewed were being tested and they were aware of it, and so they tailored their responses according to what they felt would be the 'right' answers.

Sigelman et al. hoped that the use of multiple-choice questions would be explored further to give people with intellectual disability 'meaningful opportunities to speak for themselves' (1982, 518). These opportunities did eventually come about, especially through inclusive research and in different ways to those envisaged by Sigelman et al., and to a greater extent than they could perhaps have imagined.

Inclusive research entails close collaboration between people with intellectual disability and academics (who are usually non-disabled) seeking to shape the research agenda in ways that promote the involvement and empowerment of people with intellectual disability (Walmsley and Johnson 2003). Inclusive research is a way of extending self-advocacy and activism in academia, by supporting people with intellectual disability to engage in academic activities, including teaching and researching. It presupposes that people with intellectual disability can engage meaningfully in research not only as respondents but also as researchers in their own right (Walmsley and Johnson 2003; Nind 2014).

Among the challenges faced by the academic researcher who is trying to be inclusive are the control exerted by non-disabled adults on the lives of people with intellectual disability and the provision of support for people with intellectual disability to engage with research. Planning and undertaking research calls for a certain level of intellectual skills, and some people's cognitive limitations may prevent them from engaging in it unsupported. The role of non-disabled people in emancipatory and inclusive disability research is contentious, especially because of a long history of non-disabled researchers whose primary loyalty was not to disabled people, but to their own discipline and the 'scientific' quality of their studies. Williams (2011) contends that, without support, people with intellectual disability would not be able to carry out their own research. Consequently, as Goodley states:

[p]eople with the label of intellectual disabilities ... set disability studies a number of challenges, including making research more inclusive, theoretical ideas more accessible and fully representing their activism as it is enacted in the international self-advocacy movement. (2011, 30)

While inclusive research and self-advocacy are about people with intellectual disability having control over their lives, and over research carried out about their lives, they are also about persons who do not have intellectual disability providing them with the necessary support for them to conduct these activities. The type of support needed entails direct intervention, for example to simplify complicated texts, to 'demystify' the research process (Barnes 1992), and to enable people to reflect about their lives, identify their wishes and aspirations, and request support on their own terms.

The necessity of these interventions means that a discussion of the role of persons providing support in self-advocacy and in inclusive research is an important one. Although these persons are mostly ones who do not have a disability, they may of course be disabled themselves. If, for example, an academic with physical or sensory impairments is working inclusively with a co-researcher with intellectual disability, they would still need to consider the issues that are raised in this and other articles about providing support for people with intellectual disability in research. However, as mentioned earlier, my focus in this article is on my own role as a non-



disabled person.

### **A method for reflection**

If one sets oneself up as being an inclusive researcher, reflecting on one's practice every step of the way is very important. It is within the context already outlined that I have chosen to reflect on my role of 'being' an inclusive researcher. Both Chang (2008) and Wacquant (1992) warn that turning the research spotlight onto oneself can become narcissistically indulgent. It is as if I was saying 'Here I am. I do inclusive research. And my work is worthy of note.' I kept this warning in mind as I wrote about my experiences and reflected on them.

In my writing, I have sought to heed Bourdieu's call for a reflexive sociology, which I return to in the next section. Therefore, the focus is not on myself but on my work within inclusive research, methods I have employed, decisions I have taken, choices I have made, practices I have engaged in, and the wider socio-cultural context in which all this has happened. This approach is also in line with how Chang describes autoethnography as 'a research method that utilizes the researchers' autobiographical data to analyze and interpret their cultural assumptions' (2008, 9). Culture here is being used in its widest sense, and assumed to include cultural constructions and perceptions of intellectual disability. The research I present takes cues from autoethnography through recording and reflecting on some of my own experiences in doing inclusive research. My approach entails presenting three incidents from my work and then analysing them. These were incidents I had recorded in a research diary in which I take note of events that attract my attention.

This approach is related to anecdotal research which, as Van Manen (1989) states, can be dismissed as non-scientific but can actually have great value. Anecdotes can be used to complement abstract concepts by providing examples of what these concepts mean in actual lived experience. Van Manen further argues that the act of writing anecdotes down is valuable in itself since it allows the writer to distance themselves from these stories and to reflect on

them. Anecdotes also allow the researcher to focus on micro interactions. The value of analysing such interactions between non-disabled academics and people with intellectual disability has been shown clearly by, among others, Williams (2011) and Ellis (2017), who use conversational analysis. Likewise, Chapman's (2014) observation that people with intellectual disability are more likely to be involved in meetings if they are sitting next to a support person shows how important it is to be attentive even to minute and seemingly irrelevant details.

As seen in the following, Bourdieu also calls for researchers to reflect on their work and their discipline together, rather than on their own. However, I am all too aware that this article presents a lone reflection by me about my work. The reason for this is that I have not yet had the opportunity to conduct an inclusive research project in a team of academics and co-researchers with intellectual disability. As I explain, my work has thus far mostly involved me and one person with intellectual disability, and it is on this work that I reflect. I have also chosen to reflect mostly on my own role and my development. While, as I argue in this article, the partners involved in inclusive research are co-equals, the academic and the person with intellectual disability do have different roles to play, not least because the former does not bring with them the lived experiences of the latter, experiences that, as already discussed, are so central to disability studies. Nor, to speak in Bourdieusian terms, do they tend to have the same economic, cultural, and social capital.

I have also kept in mind the biases that Bourdieu warns about: those arising from my personal background and from my academic position, and the risk of engaging in a purely intellectual discussion without offering possibilities for practical outcomes. Accordingly, in the next section I present myself and my background briefly, providing information that is relevant to my reflection without indulging in sharing irrelevant aspects of my personal history. The focus on my experiences in doing inclusive research, I hope, can serve as a prompt for broader reflections on issues related to inclusive research.

As Chang (2008) observes, the autoethnographic method involves writing not only about the

researcher's life but also about that of people who have come into contact with the researcher, in the aspect of life they are writing about. In my case, my writing inevitably involves me primarily discussing my experiences of working with one person with intellectual disability. I have therefore obtained her go-ahead as well as ethical approval from my university's Research Ethics Committee to talk about these experiences. The person has given her approval in the knowledge that, although I am using a pseudonym to talk about her, people who know us may identify her. I have shown her a draft of this article, including the incidents that I present which directly involve her, and have obtained her permission to use them.

The pseudonym I have chosen for this person is Lucia, a name which derives from the Latin for light, as a reflection of the insight and knowledge I have gained – on a personal and an academic level – from working with her. Following a description of the conceptual framework within which I have conducted my research in the next section, I present three anecdotes and discuss them, before concluding with some final reflections on the link between activism and academia in inclusive research.

### **A framework for reflection**

The foregoing overview of the development of the disabled people's movement, self-advocacy, and emancipatory disability and inclusive research has shown how the roles played by non-disabled people have been, and remain, an important issue. It is within this context that I have set out to reflect on my own role as an academic who 'does' inclusive research. Guiding me in this reflection are the work of those writing within the fields of disability studies and inclusive research, including of course those cited earlier. Along with these writers, I have also turned to Bourdieu's work on reflexive sociology.

In his sociology, Bourdieu moves away from dichotomizing quantitative and qualitative methods, from separating theory from research, and from having to choose whether to study the individual or society. This move is reflective of Bourdieu's conception of society which, Wacquant (1992)

writes, he ‘explodes’:

and replaces it with those of field and social space. For him, a differentiated society is ... an ensemble of relatively autonomous spheres of ‘play’ that cannot be collapsed under an overall societal logic. (1992, 16–17)

Using Bourdieu’s concept of field, Thomson (2012, 67) explains, enables the researcher not to be ‘bogged down in aimless debates about the primacy of either social structures or human agency’. Individuals work within and with structures, rather than despite or outside of them. Consequently, one investigates the interconnectedness of the various factors in any given field, or social space, which comprises people and institutions as agents and the actions undertaken by them. These actions are shaped by habitus, the way we are predisposed to act in any given situation, and the principles and rules that we (often implicitly) follow (Bourdieu 1990).

Wacquant (1992) notes that the researcher needs to reflect on how their field informs how the object of research is conceived of, and of how habitus influences research practice. In parallel with the exponents of emancipatory disability research, Bourdieu writes:

One may ... ask whether a transformation of the social organization of scientific production and circulation and, in particular, of the forms of communication and exchange through which logical and empirical control is carried out, would not be capable of contributing to the progress of scientific reason in sociology, and this more powerfully than the refinement of new technologies of measurement or the endless warnings and ‘presuppositional’ discussions of epistemologists and methodologists. (Bourdieu 1987 as quoted in Wacquant 1992, 32–33, fn 56)

The researcher must also be aware of how theory informs practice, and vice versa, such that theory and practice (in this case of the practice of research) are recognized as being employed simultaneously in every aspect of research. Thus, research decisions, however small, are informed by theory, and theory can only become clear through ‘systematic engagement with empirical reality’ (Wacquant 1992, 35).

Bourdieu calls for a reflexivity that is focused on the research methodology being employed, rather than on the researcher; and one that is collective, rather than solitary. At the same time, Wacquant tells us, Bourdieu points out three types of biases that one needs to be aware of: the researcher's social origins, the position of the researcher in the academic field, and the tendency 'to construe the world as a spectacle, as a set of significations to be interpreted rather than as concrete problems to be solved practically' (Wacquant 1992, 1878; original emphasis). Here, we can note another similarity with emancipatory disability research – treating research not simply as an opportunity to engage in abstract discussions, but as a means of finding practical outcomes to real problems faced, in this case, by disabled people.

Bourdieu's focus on the researcher's individual position on the one hand, and his insistence on the reflexivity being directed towards the discipline (a 'sociology of sociology' as he refers to it time and again in Bourdieu and Wacquant 1992) on the other, may seem contradictory. However, within the context of Bourdieu's rejection of binary logic, the individual researcher is an inextricably embedded part of a whole, which is the discipline. Thus, the researcher working within disability studies is an individual with a particular social and personal background who is located within a specific place in academia. At the same time, the researcher is influenced by (and hopefully contributes to) their field of inquiry. Any reflexivity on the part of the inclusive researcher needs to take these different strands into account. Furthermore, Bourdieu insists that a reflexive sociology is one through which the researcher challenges unquestioned assumptions, identifies misrecognized mechanisms, and becomes aware of the power they may unwittingly exercise over others through their work (Bourdieu and Wacquant 1992). These are important and very relevant challenges for inclusive research, given that it is a means of promoting the empowerment of people with intellectual disability and redressing power imbalances between them and non-disabled people.

### **Some personal background**

In the context of the vexed issue of the role of non-disabled persons in the disabled people's

movement and in disability studies, noted earlier, my status as a non-disabled person needs to be part of the reflection. Barnes' (1992) vision of the emancipatory researcher implies a role of activist researchers for non-disabled people. It is also a vision that has caused many a non-disabled researcher to reflect on their contribution to disability studies, as seen earlier.

Recently, Kulick (2015) has discussed how many authors in disability studies reveal whether they have a personal experience of disability themselves or within their family. He writes of how he agonized about whether to mention his experience as the brother of Karen, his younger sister with Down syndrome, when he was researching the sexuality of disabled people (Kulick and Rydstrom 2015). As he argues, while his experience of growing up with Karen (who subsequently died) undoubtedly left an effect on him, he came to research the topic not because of that personal experience but through his work as an anthropologist. Kulick concludes that, while having such an experience is valuable and provides a lot of insight, it is not a guarantee that one's work will be faultlessly emancipatory. Likewise, not having a direct experience of disability does not preclude one from doing work that is attentive to the situation of disabled people, and that addresses their priorities and their needs. What is important, Kulick argues, is maintaining a high level of self-awareness, and connecting with the people with whom one is carrying out research and with their experiences. Furthermore, within the context of their personal experiences within the psychiatric system, Russo, Beresford, and O'Hagan write that:

we would like to see more efforts directed towards challenging structures that define all our places. We would like to learn more about our allies' own agendas rather than them validating how it is for 'consumers'. This could perhaps extend the limits of what we all can do together. (2018, 1878)

What I present here are those parts of my experiences which provide the context of my work with people with intellectual disability and my motivation for that work, and which are relevant to the discussions and reflections that follow.

Apart from not having a disability myself, neither do I have anyone in my family who has a disability. In fact, I did not get to know a disabled person closely until well into my adulthood.

The Malta I grew up in, in the 1970s and 1980s, shunned interaction with disabled people, unless you were one yourself, were closely related to one, or worked in service provision in the disability sector as it was then. Disabled people may have been taken out of the cellars they were often imprisoned in and moved to live in decent places (Bonnici 2005), but these were physically isolated and it was not until 1990 that the first community-based group home was opened (Bezzina, Callus and Camilleri 2017). Likewise, there were no disabled children in the mainstream schools I attended.

My interest in working with people with intellectual disability developed when I started teaching in the early 1990s. The education system at the time was highly selective and, from a young age, students were separated according to whether or not they were academically oriented. This was the education system that I had gone through myself and, while I was never a top-ranking student, I always managed to hover somewhere in the middle of the top class. My placement there, and the segregation of disabled people in Maltese society and in schools at the time, cut me off completely from becoming aware of the realities of life with a disability. It was when I started teaching, initially in a secondary school for students who had failed to get the right grades, that I became more aware of how many children struggled with formal learning and how many had been undone by the very system that was supposed to educate them.

I gradually developed an interest in becoming a special education teacher. This was the only possibility for teaching students with intellectual disability in Malta at the time. Ironically enough, I moved to Wales in 1994, the year Malta adopted an inclusive education policy (Kummissjoni Nazzjonali Handikappati 1993). That move led to me working with children and adults with intellectual disability. It also led me to postgraduate studies in the area, and to continuing to work in the disability sector on my return to Malta, including developing self-advocacy initiatives at the National Commission Persons with Disability (2005), a subject that I would later take up for my doctoral research and now lecture on at university. The work also led to my helping to set up an independent self-advocacy group and becoming one of its support members.

It was through my work on promoting self-advocacy that I first met Lucia in 2005. Since then, we have collaborated on self-advocacy work, as well as work at university, including co-lecturing and co-researching. In the next section, I present and reflect on three incidents from the work that Lucia and I have carried out together. These are incidents whose significance I kept reflecting on long after I had jotted them down in my research diary.

### **Reflections on three incidents**

Reflexivity is about seeking questions that need to be asked and exploring answers to them – with the probability that more questions will be generated in the process. My reflections are therefore based on three questions – a question that I should have asked Lucia, a question that she asked me, and a question that was asked of her by a bus driver.

*‘Can you do the lecture in English?’*

One of the first steps that I took in collaborating with Lucia within academia was to invite her to co-lecture with me on the topic of self-advocacy, and eventually about the research we carried out together. The involvement of people with intellectual disability in co-lecturing at university brings in an activist dimension to one’s academic work. Having Lucia (as well as other persons with intellectual disability) talk about their lives enable students to appreciate the ability of these persons to speak for themselves. Creating opportunities for them to present the results of inclusive research also serves to maximize its impact, a topic addressed by Williams and Tarleton (2015). Taking this step is also in line with supporting disabled people to be activists, rather than being activists on their behalf (Drake 1997).

The first incident I recount is something that happened after one of the lectures. It is important to take into account the fact that, although Malta is a bilingual country (with Maltese and English both being official languages), Maltese is the dominant language for the majority of the population. At the University of Malta, lectures are carried out in English. When I started co-lec-



turing with people with intellectual disability, I always assumed that they would not be able to speak in English at any length and so we do the lecture in Maltese, and if there are non-Maltese-speaking students, other students translate for them. In the case of Lucia, this went on for a couple of years until an encounter with one student, who was an Englishwoman who had lived in Malta for many years. As usual, the lecture was conducted in Maltese with someone translating. At the end of the lecture, this English student started chatting with Lucia – she recognized her because they live in the same town. They spent the best part of half an hour chatting on in English and to my shame I realized that I had never bothered to find out how fluent Lucia was in English. I had simply worked on the assumption that being bilingual is difficult for people with intellectual disability, and had mentally, and unquestioningly, placed Lucia in that category.

By co-lecturing with Lucia (and other people with intellectual disability), I was consciously heeding the call made by Goodley and Moore (2000), among others, to make efforts at removing the boundaries between academia and activism. This I did by supporting people with intellectual disability to co-lecture at university, thus bringing them into a social space that they do not normally inhabit. However, I was not being attentive enough to how I was doing it – because I was not pausing to reflect, to ask questions. At this point, I could say that I had come a long way since the day I embarked on my teaching career, still unaware of how ill served disabled students were at the time by the education system I was a part of. But I was unwittingly engaging in a disabling practice as far as Lucia was concerned. It had to be a chance encounter that I happened to witness which brought me to the realization that I was not as attuned to Lucia's support needs as I thought I was.

Not making a clear-cut distinction between the individual and the structure, but seeing oneself as an actor who is part of the structure (as Bourdieu invites us to do; Wacquant 1992), means that while we affirm our capacity as actors, we also acknowledge our roles within the structure. That way, when we challenge the structure and ask questions of it – as Russo, Beresford, and O'Hagan (2018), quoted earlier, ask us to do – we are aware that we also need to challenge and

ask questions of ourselves. In the case of the incident under scrutiny here, I had not even realized there was a question that I needed to ask in the first place, which involved me asking Lucia: 'Can you do the lecture in English?' A simple enough question but one that went unasked until circumstances showed me that I should have asked it. Had I not simply ploughed on, happily secure in my own assumptions about Lucia's abilities, I would have known to ask her that question much earlier.

The realization of Lucia's fluency in English led to another: that we could easily participate in conferences abroad. Lucia could present and engage in discussions in English. While it would of course also have been possible to do so in Maltese with me translating, her ability to converse directly in English meant that she would be able to participate more directly and independently. Participation in these conferences has given us the opportunity to discuss our work with other researchers using an inclusive approach, and to learn from their own research presentations. It really was a question of one development leading to another. And this development was based very much on stopping to ask a question that needed to be asked and then being open to new opportunities that present themselves.

### *'What's a literature review?'*

Because abilities and support needs vary, it is important neither to overestimate nor underestimate co-researchers' abilities. The incident that I have just described is a clear example of me underestimating Lucia's language skills. On other occasions, it was a question of my overestimating her ability to understand, and here I come to the second incident. When Lucia and I started working on a particular inclusive research project, I explained that we would need to look at what other people have written about their own research. I assumed that this explanation of doing a literature review would be enough. But she did not understand immediately and I had to take quite some time to explain to her how people who do research, like we were doing, write articles in journals to present their results so that others can learn from that research.

Challenging this assumption of mine was easy enough. Lucia made sure of that by immediately showing me that she had not understood my brief explanation. One of the issues that this incident raises is the importance of checking for understanding between inclusive research partners. This need goes both ways of course. I need to make sure that Lucia understands what I say – a less assertive co-researcher may not so forthcoming with stopping me where they do not understand. I also need to ensure that I understand what Lucia says.

Another issue raised by this incident that I continued to reflect on is whether the active participation of people with intellectual disability in every step of the research process entails involvement in the more academic aspects of research, including the literature review. Machi and McEvoy (2016) identify two main purposes of conducting a literature review: to synthesize and analyse existing literature on the topic being researched, and to explore topics that require to be researched. The extent to which this process is of direct use for people with intellectual disability is worth debating. Their lived experience of having an intellectual disability provides them with insights that non-disabled researchers do not have direct access to, as St John et al. (2018) state. Thus, in inclusive research, the choice of research topic is grounded in the experiences of the researchers with intellectual disability (see, among others, Tilly, Money, and Making Ends Meet Research Group 2015).

Significantly, making the literature review process accessible is rarely a topic of discussion in the literature on inclusive research. O'Brien, McConkey and Garcia-Iriarte mention that one of the strategies which can be used to identify a research topic is 'presenting the most relevant research reports in an accessible manner' (2014, 69). However, they do not refer to actually engaging in developing and writing the literature review for an academic article.

To some extent, I followed O'Brien, McConkey and Garcia-Iriarte's (2014) advice by presenting the findings of relevant research papers in an accessible manner to Lucia. I felt this was important for her to be aware of the wider context of doing research, of how other researchers in other countries have worked on the topic for our research (which she had chosen herself), and of how

once someone carries out research, they publish articles about their work for others to read. However, I cannot claim to have involved her in the literature review. In the end, the research report we wrote together, and the conference presentations that we made, focused on the findings, without referring to research papers published by other authors. When it came to writing an article for an academic journal, I did the literature review myself. I based it mostly on the papers for which I had made an accessible summary for Lucia. However, I worked on the published version of the papers, to which Lucia did not have direct access. There is a risk, therefore, that Lucia was involved in the literature review only in a tokenistic manner.

Having more accessible research formats, such as the video articles produced by the Norah Fry Research Centre at the University of Bristol for this journal, would help address this issue. After all, inclusive research means involving people with intellectual disability in all stages of the research process. Citing Brett et al. (2010), Di Lorito et al. write that:

the benefits that co-research can generate do not simply occur during the process. They require extensive work prior to and throughout the research process in order to create a solid 'architecture of involvement' which will maximize and optimize the input of co-researchers. (2018, 683)

The question then becomes whether or not the literature review is part of that process, part of the 'architecture' of doing inclusive research. It is easy to consider the literature review to be an academic exercise, with the pun being fully intended. But, if disability research is carried out and published to raise awareness, provide information, and increase knowledge about the situation of disabled people, people with intellectual disability have a right to access that information. Similarly, if conducting a literature review is an important way of exploring the context in which the chosen topic is being investigated, and of presenting that context when publishing the research, then involving people with intellectual disability in the process is important. Working on making the literature review process more inclusive would heed Bourdieu's call, in the excerpt quoted earlier, for 'a transformation of the social organization of scientific production [and] ... of the forms of communication and exchange' (Wacquant 1992), a call which runs parallel to Oliver's (1992, 101) entreaty to change 'the social relations of research production' in disability research.

Furthermore, as Bourdieu argues, theory and practice inform each other constantly and are closely intertwined (Wacquant 1992). Similarly, inclusive research combines academia very closely with activism, and making literature reviews more inclusive contributes to solidifying this combination.

*'What's research?'*

The third and final incident that I have reflected on is a conversation which Lucia reported to me when we were working on an inclusive research project. Lucia takes the bus to come to university, which is next door to the general hospital, with buses on the route serving both destinations. One day when she arrived at my office, she recounted the following exchange with the bus driver as she was boarding and paying her fare:

Bus driver: Are you going to the hospital?

Lucia: No, I am going to University.

Bus driver: What are you going to University for?

Lucia: To do research.

Bus driver: What's research?

The bus driver's assumption is based on an association between disability and illness – perhaps an easy enough assumption in a culture that still largely equates impairment and disability and views them both through a pathological lens. Lucia's reply certainly challenged the bus driver's assumptions, so much so that he ended up wondering what a person with intellectual disability would be going to university for.

This incident takes us outside the physical boundaries of the university campus into the wider Maltese society of which it forms a part. It speaks of a society that has made great strides in providing support for persons with intellectual disability while at the same time retaining misconceptions that remind me of the social context in which I grew up. It is important to con-

sider what enabled Lucia to be on that bus. Some years before, Lucia had received support to learn how to use the bus on her own through a scheme funded by Aġenzija Sapport (2018). Once she had mastered that skill, she could travel independently. Taking the bus that specifically went to university was occasioned by our inclusive research project being funded by the University of Malta. The funding we received enabled Lucia to be paid for her work and for the two of us to carry out the research.

The factors that led to Lucia's encounter with the bus driver also need to take into account, among others, the transformation in disability policy that occurred in Malta especially from the late 1980s onwards, which would eventually lead to the adoption of an inclusive education policy (of which, as it happens, Lucia was one of the first beneficiaries); and of the setting up of services that promoted community inclusion (Bezzina 2017). Account also needs to be taken of the achievements of the disabled people's movement on an international level that led governments, including Malta's, to actively promote and fund inclusion; and of the strides made in disability studies in general, and inclusive research in particular, to make academic activities such as research more accessible for persons with intellectual disability.

All of these factors are predicated on the recognition of the rights of persons with intellectual disability to being equal members of their community. Thus, change has happened, but it has not yet spread widely enough. Lucia, and other people with intellectual disability, may enjoy a recognition of their rights and their abilities in many of the social spaces which they regularly inhabit but that recognition is not necessarily spread across society. Inclusion can remain a special activity carried out on specific days of the week or in specific places, as Gates (2018) observes. On the other hand, one needs to be wary of making clear-cut distinctions between inclusionary social spaces and exclusionary ones. As Power and Bartlett (2018, 351) argue, it is much more appropriate to speak of 'moments of inclusion', times and places in which people with intellectual disability, with support from others, have negotiated the creation of environments that enable them to flourish and in which they find acceptance.

These moments, these social spaces, can create ripple effects that widen the scope for inclusion of people with intellectual disability in mainstream society. Thus, the factors that contributed to

Lucia taking the hospital–university bus route helped create the moment, in time and in space, when she could use her assertiveness and challenge the bus driver’s erroneous conclusion and show him that having an intellectual disability does not mean that she goes to hospital, and that she has a valid and meaningful role to play at university. Those factors arose from the work of disabled and non-disabled allies. As someone who identifies as a non-disabled ally, I am reminded by Lucia’s account of her encounter with the bus driver of how important it is to combine academia with activism, to see them as two roles that, rather than being juxtaposed, are complementary with each other.

### **Concluding reflections**

In my reflection on these three incidents, and on the questions that have arisen, I hope to have shown how important it is for activism to continue promoting disabled people’s voices and providing support to those who need it in order to make themselves heard. Activism within academia includes supporting people with intellectual disability to speak at university, to conduct research on areas that are of concern to them, and to present and discuss that research. It entails opening up to possibilities that make the research process more inclusive. It also entails being attentive to how academic activities can provide opportunities for activism at a societal level, keeping in mind the close link between academia and activism in disability studies, and the intimate connection of the latter with the disabled people’s movement. Keeping this link in view not only means furthering an activist agenda through one’s work, but also being attentive to how one-on-one interactions pan out.

In the case of inclusive research, this attentiveness extends to taking heed of the perspectives of co-researchers with intellectual disability and catering for their support needs, and being especially mindful of the fact that perspectives and support needs vary from one individual to another. The minutiae of inclusive research work are as important as the principles which inform its practice. Goodley (2000) affirms the connection between self-advocacy and inclusive research. For the non-disabled academic, maintaining this connection is about acting in ways that enable people with intellectual disability to advocate on their own behalf and that of others in public fora, and also to be in control of more private interactions.

In this regard, one of the most crucial actions is the asking of questions, and the opportunities for growth they bring with them. There are questions that seem straightforward enough – like Lucia asking me what a literature review is. Academics can use such questions as a means of checking where practices need to become more inclusive, and how to go about it. Other questions, like the bus driver's, may be motivated by received misconceptions, and can become an opportunity to challenge these misconceptions and the stereotypes associated with them. These misconceptions may be

carried by others, but also by ourselves. I may look back with satisfaction at how much I have learnt over the past two and a half decades but that does not free me from any lingering incorrect assumptions which predispose me to act in ways that are erroneous. In fact, the questions which we need to focus on most are, paradoxically, those that are at risk of remaining unasked, unless we give attention to the situations which give rise to them, as in the case of the first incident that I discuss. All of these questions tie into the fundamental question, identified by Barton and quoted earlier, 'about the nature and purpose of research and in what ways such activities can be under- pinned by effective empowerment' (1992, 99). These activities include day- to-day interactions between people with intellectual disability and non-dis- abled people, as well as research activities at a wider level.

Finally, following Bourdieu, we must be attentive to the various factors that play a role in inclusive research, as well as in disability studies more generally. Academics involved in inclusive research, including myself, need to be aware that our actions are one of those factors, and that these actions are informed by our predispositions. We must also be aware of how those actions in turn impact our work and on how the theory and practice of inclu- sive research develop. As mentioned earlier, Bourdieu tells us to keep in mind not only the focus on refining research methods and developing new ideas and concepts. Important as these things are, we must also be aware of how knowledge and information in research is communicated and exchanged (and even created) on both a micro and a macro level. In fact, our reflections on the questions that get asked should feed back into the development of ideas and concepts, and research methods – keeping in mind that we need to actively seek the questions that need to get asked, rather than



relying on happenstance to make us aware that there is an issue which needs to be dealt with (as I myself discovered when I had to question my own assumptions). The empirical reality we must deal with is not only the reality we find out about through research, which inevitably changes as a result of various cultural, economic, and political developments – that reality we reflect on as we analyse and write about the data generated from our research – but also the realities of the micro interactions that arise from conducting research. The issues associated with these interactions are, to a considerable extent, ones which have long been debated within disability studies, as seen in this article. Renewing the debate on these issues that has always been part of the development of the disabled people’s movement and of disability studies – including through reflexivity – is of crucial importance because, if we want our academic work to stay true to the ethos of the disabled people’s movement, how can we be sure we are doing that unless we raise the questions that we need to ask ourselves and seek answers to them?

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