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**Abstract**

Disability is as much a factor in interactional dynamics as ethnicity, age, gender or sexuality, and therefore its impact on the processes around qualitative research warrants much more systematic attention. Disabled researchers are not confined to disability studies research, although most accounts of the impact of disability on the research process have, thus far, been undertaken within this field. This paper moves beyond this narrow focus to consider the impact of disabled identities and the embodied experiences of impairment on studies involving, primarily, non-disabled people. By reflecting on our experiences as visibly disabled researchers, we highlight some of the practical, ethical and conceptual dilemmas we encountered. Impairments may assist rapport building with participants, but also introduce complex dilemmas concerning whether, when and how to disclose them, and the consequences of doing so. We highlight the centrality of the visibility of the disabled body in mediating these

dilemmas, and its part in constraining our responses to them. While we value our commitment to positive readings of disability, we demonstrate that disabled researchers nevertheless undertake research in contexts where disability is assigned meanings disabled people may not share. We argue that *all* researchers should attend to their own 'body signifiers' (whether in relation to ethnicity, wealth, gender, age etc.) and embodied experiences of research processes, as these are integral to research outcomes, the ethics of research, and are a means by which to address power differentials between researcher and participant. This paper addresses a gap in the literature, using our experiences of research to highlight the negotiations and dilemmas faced by visibly disabled researchers. Negotiations of identity prompted by the disabled body in the research process require consideration and should not be ignored.

### *Introduction*

Disability is as much a factor in interactional dynamics as ethnicity, gender or sexuality, and therefore how disability is constructed and negotiated in qualitative research warrants much more systematic attention. There has been considerable academic debate about the appropriate methods to research disability: emancipatory research (the perceived necessity to have a disability in order to carry out meaningful disability research) (Barnes and Mercer 1997) and participatory research (which aim to fully involve disabled people in the research process) (Zarb 1992). While these literatures have been instrumental in rethinking how research is carried out with disabled people, there has been little analysis around disabled researchers researching outside disability, or the impact of the disabled body on the research process. This paper contributes to this discussion by reflecting on our experiences as disabled researchers conducting qualitative research and highlights some practical, ethical and conceptual dilemmas we encountered, particularly around recruitment, disclosure and rapport building.

Researchers must account for their role in the development of a research project and identify factors that shape the work they do (Seymour 2007). Reflexivity is an important tool to analyse such researcher effects and address concerns around “the disembodied researcher,” that is, the exclusion of embodiment from our analysis of research practises (Ellingson 2006). Examining reciprocity can address issues of power in the researcher-researched relationship, and the co-constituted nature of qualitative research (e.g. Lather 1988; Stanley and Wise 1993; St Pierre 1997). The personal identities of researchers have long been acknowledged as having a profound impact on the research process- researchers all respond differently to the research, ask different questions, and prompt different replies (Finlay 2002). Researchers’ social and personal identities are consequently particularly significant during interviews: their presumptions, values, experiences and abilities inform the unfolding research throughout its entire course, from its initial conception to analysis, writing up and dissemination.

Some dismiss reflexivity as egocentric or self-indulgent (Patai 1994), however others believe failure to acknowledge and interrogate the ‘invisible factors that influence and constitute a research project’ (Seymour, 2001: 121) is negligent and leads to ‘deceptively tidy’ accounts of research (Ellingson 2006: 299). Engaging in truly reflexive work can be uncomfortable, as researchers develop a tendency to write themselves out of the research process to focus fully on participants (Ryan-Flood and Gill 2009). Failing to consider and highlight the impact researchers have on fieldwork, analysis and publication, however, may produce an illusion of objectivity that is potentially deceptive. Disability impacts on the research process, just as gender, ethnicity or sexuality might. Consequently, reflections on the mediating effects of impairments and disabilities should be incorporated into research.

It is important to explain the terminology and approach taken within this article. Within disability studies there is much about the appropriate terminology around disability and

impairment (Barnes and Mercer 1996). Social model of disability theorists suggest that someone is disabled not by their impairments, but by society as a result of barriers (attitudinal, structural, physical). We refer to our impairments as epilepsy (for Lindsey) and a neuromuscular condition (for Felicity) and will refer to ourselves as disabled in line with social model of disability definitions. We believe that people's reactions to our disabilities (attitudinal barriers) together with environmental barriers disable us, and the visible presence of an assistance dog (Lindsey) and a wheelchair (Felicity) serve as prompts for the negotiation of such barriers in the context of social interaction. While positive readings of disabled identities have been suggested in the literature (Swain and French 2000), and we embrace such positive understandings of disability, identities cannot be understood as fixed and unchangeable, determined by those who bear the markers of them, but are rather *negotiated and co-constructed* in the context of social interaction. Through the processes of carrying out research as visibly disabled researchers, we experienced this aspect of our identities as requiring *particular* forms of negotiation. Indeed, our disabilities were not always attributed the same meanings by the participants in our respective research projects as we assigned them ourselves. As Corker (1999) has highlighted, the cultural construction of disability as a site of oppression has been underplayed by social model of disability theorists, and yet such cultural notions of disability and their influence on communication and identity negotiation within research relations is an important consideration for disabled researchers. These identity negotiations demanded conscious effort and action on our part, and, as will be discussed within this paper, were associated with very specific ethical, social and political dilemmas. It is our belief that these negotiations cannot be overlooked as they are an integral part of the research process for disabled researchers, who, regardless of their own perceptions of their disability, must take on the work of managing physical barriers, impairment effects as well as the personal reactions and responses to disability of others within their own research projects.

### *Background*

Felicity has a neuromuscular condition necessitating the use of a wheelchair. Lindsey has epilepsy and is supported by an assistance dog, 'Wilf' (trained to anticipate and warn of seizures by barking). It is the presence of our assistive devices (a wheelchair and an assistance dog) that identify us as disabled. Without them, people would not know immediately about our impairments unless we disclosed them, although they become visible in particular contexts. Despite both identifying as disabled researchers, our impairments are different, resulting in sometimes similar, but often contrasting, experiences of disablement. Felicity has been disabled since childhood whereas Lindsey became disabled at eighteen; a difference that affects perceptions and perspectives (Shakespeare 2008). Our contrasting impairments and assistive aids also have an impact on our experiences of disablement. The wheelchair is the national symbol for disability in the UK and as such is a well recognised marker of disability. The use of a dog to help with epilepsy however is far less recognised. Most people are familiar with guide dogs that assist people with visual impairments, yet despite the growing use of assistance dogs by people with a range of impairments, Lindsey's experiences reveal there is little awareness of assistance dogs for epilepsy.

Felicity's fieldwork explored the role of experiential knowledge in reproductive decision making for families affected by Spinal Muscular Atrophy (SMA). In total, 61 in-depth interviews were conducted; 25 with individuals affected by SMA, and 36 with individuals with SMA in their family. Interviews were also conducted through a variety of methods; by telephone (44), email (10) and face-to-face (7). Twenty-three participants with SMA were full or part-time wheelchair users. All the remaining 36 participants, except for 2 (1 of whom had a visual impairment and the other amobility impairment) described themselves as non-disabled. Lindsey's fieldwork explored the ethical implications of epidemiological research using patient records. This involved qualitative interviews with medical researchers (26), health professionals (22) and patients (28). This research was approved of by Oxfordshire Research Ethics Committee A (07/Q1604/14). All patient

and two health professional interviews were carried out face-to-face. All researchers and the remaining health professionals were interviewed by telephone. The studies used similar methods, yet it is important to highlight that Felicity's research touched on participants' perceptions of disability and impairment and disabled people participated in the research whereas Lindsey's research was not about disability issues and unfortunately no disabled people (identified by demographic questions) volunteered to participate.

Reflexive diaries kept before, during and after the fieldwork will be referenced throughout this paper. No findings from these studies are presented, instead we focus on the impact of researcher disability in the processes of recruitment, negotiation and carrying out interviews. There may be similar discussions to be had around the processes of data collection, analysis and dissemination, however there is insufficient space to discuss all aspects here. By focusing specifically on emergent considerations from our experiences of research; we will draw attention to the benefits and disadvantages of 'identity matching' of researcher and participants in relation to disability before analysing the impact of visibly disabled bodies, and any implications for our respective research.

The few reflexive accounts by disabled researchers highlight points at which the experience of disability intersects with the experience of the research, inevitably altering its shape and outcome. Highlighting disability in this way does not imply it is a problem or a negative experience, but rather a characteristic that should not be neglected or denied as it often impacts on the research process. Such accounts have included discussions of access issues (Barnes 1992; Andrews 2007), impairment effects (Seymour 2007), the visibility of disability during fieldwork (Ellingson 2006), the sensitivity of funding bodies to the needs of disabled researchers (Mercer 2002) and the confidence and self-perception of disabled researchers vis-à-vis their non-disabled counterparts (Tregaskis and Goodley 2005). However, few focus primarily on how these

various effects are negotiated, nor the dilemmas contained within negotiations. Within reflexive literature more broadly, discussion of negotiations centre around how far characteristics of researchers influence the responses of participants, and thus how far they should be 'matched' in order to reduce inequalities of power and status thereby facilitating trust, empathy and rapport. Feminist writers have drawn attention to the heightened degree of empathy and rapport between women by virtue of their shared gender (Hesse-Biber et al. 1999; Oakley 1981). This debate also relates to ethnicity (Edwards 1990; Song and Parker 1995), sexuality (Platzer and James 1997) and disability (Barnes 1992; Oliver 1996).

'Matching' the identities of researcher and participant is based on an assumption that there are underlying commonalities of experience which define certain social groups and which can thus only be teased out by researchers with privileged access to this knowledge. This assumption overlooks ways in which experiences within any social group are cut across by sexual, ethnic, class and impairment differentials. Disability, like nationality, sexuality or age, involves divergent experiences, identities, and representations (Seymour 2007). Edwards' experience as a white woman interviewing black women, highlighted that while women may identify with one another *as women*, there may be cultural, educational, employment and general life experience differentials which transcend essentialised notions of womanhood and can lead to a 'gulf' between researcher and participant. Although women interviewed related to Edwards as a woman, there remained areas of their lives that were not openly discussed (Edwards 1990). Such 'matching' therefore may not always be productive in terms of facilitating a research relationship. We may not know which social characteristic to privilege as certain identities may serve to 'trump' others. Murphy argues that disability can be regarded as the master category of identity, displacing all other characteristics in the eyes of others (Murphy 1987).

While this literature is useful for understanding possible interpretations of researchers' identities and subjectivities within research, the rigidity of the concept of identity that it supports should be questioned. Notions of 'self' and 'identity' may be more open to construction and negotiation than 'matching' proponents suggest (Giddens 1991). Empirical studies with disabled people have to an extent queried the 'visual materialism' (Hughes 2002) inherent in approaches to identity involving a straightforward 'reading off' of physical characteristics to arrive at 'truths' about identities and subjectivities. Such empirical work suggests that a 'disabled identity' might be more malleable than previously supposed (Deal 2003), and suggesting the possibility for multiple subjectivities.

### *Empirical Work*

Identities are shifting and ambiguous, and despite having visible markers of disability, we experienced an inter-changeability of various aspects of our identities at different points. We identified within ourselves professional identities, such as student or 'postdoc'; identities within our subject disciplines, as social scientist, lawyer, and ethicist; identities as intellectuals and as women. Mark Priestley identified considerable potential for conflicts of interest between his 'academic' and his 'political' self (Priestley 1997). Mirroring Priestly's (1997) and Edwards' (1990) reflections, we found our different identifications could conflict during the research process. While Lindsey acknowledged that talking about her disability was important in establishing rapport, her 'political self' rejected this expectation to disclose. As Morris (1991) has argued through the presentation of an anecdotal account, disabled people are expected to make public the stories of their disablement, their very differentness overriding their right to privacy.

I remember reading something by Mark Priestley when he described the conflicts of interest between his 'academic' and his 'political' self" I wonder if that is what I am experiencing. My political self does not want to disclose information about my disability

when it is nobody's business. My academic self wants to get good data so will! Then again my political self also recognises the importance of getting good data to prove a disabled person can succeed, can do this work. Perhaps even that my disability helps rather than hinders (Lindsey, reflexive diary).

For Lindsey, when being asked about Wilf and her impairment, her disabled identity and impaired body came to the fore, yet when male participants asked her out they were responding to Lindsey's identity as a woman and female body. Lindsey thus negotiated various aspects of her identity and felt that in different contexts, her identity was perceived differently.

Felicity's identity as a disabled person operated differently depending on whether she was interviewing non-disabled or disabled people. At times a 'disabled identity' appeared to signal shared experiences, the 'right' to research, and take on board the concerns and issues of disabled populations, providing her with 'insider status' (Seymour 2007). Seymour maintains when interviewing disabled people, disability can serve as a 'badge of authenticity' and a marker of shared identity:

....it was clear that this [visible disability] was my passport into the world of disability. It gave me legitimacy: I had earned the right to conduct research and to engage with participants as 'one of them'. We shared understandings and common experiences of stigma, oppression and bodily revolt associated with our disabilities (Seymour, 2007: 1193).

Similarly, Andrews describes her participants' visible knowledge of her disability (as a wheelchair user) as a rapport-building experience when conducting interviews with other users (Andrews 2005). Through sharing experiences as a wheelchair user, Andrews felt that she was able to break down unseen barriers of communication which

encouraged participants to share more. When interviewing disabled people, Felicity's disability seemed to be interpreted in this way:

....I'm so glad that it's a disabled person doing this research, it makes it a lot easier to talk about things. I thought you were going to be able bodied [Participant 016: 4].

Participants must feel comfortable to talk about issues often considered taboo or difficult to talk about, for example attitudes towards selective termination for the condition participants had themselves or in their family. A disabled identity can help bridge the gulf between the worlds of the researcher and participant, offering a point of connection. Thus, while being attributed a disabled identity can sometimes be experienced as invalidating, during interviews it can unify, facilitate rapport and challenge traditional barriers of power and status. This is not to say that having a visible disability removed discrepancies of power in all interview situations with other disabled people nor was it always perceived as a common identity. Felicity was frequently asked questions about the nature and origin of her impairment, suggesting the *type* of impairment may impact on the extent of a perceived common identity (Deal 2003). When conducting interviews with disabled participants, it is also likely that there were different dynamics due to complex inter-subjectivities (i.e. the mutual communication of their responses to an experience), after all, two people's experiences and their exchanges lead to the collaborative effort of the interview (Fontana and Frey 2005).

Discussions around the role and experiences of visibly disabled researchers have largely been confined to the context of disability research, whereby the disabled body is regarded as having symbolic value establishing authenticity, insider status, commitment to emancipatory research and the 'right' to research disability issues (Seymour 2007; Tregaskis and Goodley 2005). However, as Barnes highlights, '[h]aving an impairment does not automatically give someone an affinity with disabled people, nor an inclination

to do disability research' (Barnes 1992:121). There is a frustrating assumption that disabled researchers are exclusively interested in, and are solely capable of completing, disability research. Such a limited perspective of disabled researchers can have a negative impact on opportunities for disabled researchers. Disabled researchers work beyond the realms of disability research and to write our own bodily experiences and identities out of this obscures this fact.

*Negotiating the (Visibly) Disabled Self: Disclosure, Methods and Technologies*

Our experiences demonstrate that while disability can assist rapport building it can create dilemmas around when and how to disclose to participants. While the negotiation of a 'disabled self' may be experienced by all disabled researchers, for those with *visible* disabilities, this negotiation may take on new dimensions. All impairments may be more or less visible in different contexts, however for those individuals whose impairments cannot easily be concealed, the process of negotiation may be experienced differently. As Hughes describes, it is on the physical body that markers of difference (sex, age, ethnicity, impairment) are inscribed, and it is on the basis of these markers that bodies, identities and subjectivities are 'read' and assumptions made (Hughes 2002). French's work around the experiences of disabled health care professionals describes the importance of being seen as professional irrespective of disability, pointing to the importance of cultural constructions of disability on the negotiation of professional identities (French 1988). As does Ellingson, who identifying herself as a cancer survivor, conducted an ethnography of a geriatric oncology team, noticed that her 'body signifiers' were read in sometimes unwelcome ways by oncology patients:

In my research, my misshapen leg and knee brace both proved a point of connection with oncology patients and, at times, drew unwanted attention that affected my participant observation. I am marked physically as a patient, even when I want to be

perceived as a researcher, demonstrating the slipperiness of the categories (Ellingson 2006: 306).

Impairments can be read not only from the visibility of impaired bodies and their mannerisms, but they can also be made visible by the use of assistive devices.

Visible impairment is an important aspect of researcher identity. While individuals with hidden impairments may be able to 'pass' (Goffman 1963) as non-disabled to avoid negative assumptions attributed to a 'disabled identity', for individuals with visible impairments, such an option may not be available. Epilepsy is usually described as a hidden disability however Lindsey being accompanied by a dog wearing a bright yellow jacket transforms her impairment into a visible one, a sign that there is "something different." Goffman's (1963) groundbreaking work on stigma suggested that the visibility of a potentially stigmatising aspect of identity is an important aspect of the mechanism by which individuals with stigmatising traits come to be reclassified as 'discredited'. Those able to conceal this potentially stigmatising aspect of their identity, Goffman argues, will do so in an attempt to manage the way in which their identities are perceived by others, in order to 'pass' as 'normal' and 'credible'. For Lindsey, the presence of Wilf in his jacket ensures that she cannot 'pass' and she is unable to remain 'credible' in face-to-face interviews (Goffman 1963). Although people tend to recognise a dog in a yellow jacket as a working dog they are not clear what his role would be once they have established that Lindsey is not blind or D/deaf. So, while Wilf provided a visible clue that there was 'something different', people were still unsure what that 'something' was.

Lindsey developed a strategy of discussing her impairment and form of assistance while it was useful to do so. In this context, it was useful to do so as the dialogue helped build rapport and provided a sense of reciprocity. As Lindsey shared information, her participants seemed more willing to talk openly and share information in return.

Lindsey encountered difficult decisions about disclosure of her impairment – if to disclose at all, and if so, the form, content and timing of disclosure. In order to negotiate access to participants' homes, Lindsey felt disclosing was unavoidable to ensure participants were aware of Wilf and so information was provided in the participant information sheet (PIS).

Most of the interviews in this study will be conducted by Lindsey, but if Lindsey is not available another researcher may come to talk to you. Lindsey has an assistance dog with her at all times. He is called Wilf and is very friendly! Wilf looks after Lindsey because she has epilepsy so we hope you will feel comfortable having him there. When Lindsey rings you to make arrangements for your interview she will make sure that you are happy for Wilf to be there. You will not need to make any special arrangements for Wilf or Lindsey. Lindsey is happy to answer questions about Wilf, once the interview is over (Lindsey PIS).

For telephone interviews when this was not a consideration, she did not disclose. During one telephone interview Wilf barked and Lindsey explained why she had a dog at work, the participant replied “oh dear, I’m so sorry to hear that, that must be awful for you.” Lindsey found it strange that sympathy would be expressed just because she found out Lindsey had epilepsy. This demonstrates that participants may attribute different meanings to our disabilities (e.g. tragic) than we do.

It is impossible to evaluate the impact disclosure had on recruitment rates. Some participants may have been deterred from taking part if they did not like dogs but others volunteered to meet Wilf. On arrival, all participants were keen to meet Wilf and to ask questions. Before the first interview, Lindsey was anxious about answering lots of questions about Wilf.

Having said in the PIS that I was happy to answer any questions about Wilf after the interview I now feel under pressure to answer all those questions that really annoy me

on a day-to-day basis. What does he do? How does he do it? How was he trained? What breed of dog is he? How long have I had him? ... I suppose I'll smile and politely answer all the questions, listen to all the stories and keep my frustrations deep inside. I guess this is the trade off for them letting me come into their homes and ask them lots of questions. But how will I restrict the discussions about Wilf to the end of the interview? (Lindsey reflexive diary).

Despite Wilf's role being disclosed in PIS, it became clear that the information was not sufficient to answer everyone's questions and it was impossible to restrict the 'dog chat' to the end of the interview. As soon as people answered the door Wilf's presence was obvious and having introduced herself and Wilf the questions began. By discussing Wilf and her disability before the interview, Lindsey felt in control, it served as an ice-breaker and got "the purple elephant (or large tan crossbreed) out of the room" (Lindsey reflexive diary), which meant that she could focus on the interview. In this way, Lindsey found her disability to be useful and have a positive impact on the research process. The questions commonly asked were those Lindsey anticipated: the 'want to know' questions rather than the 'need to know'. Lindsey gets frustrated when people only see, are only interested in only and respond to Wilf making her feel invisible, as if one identity trumps all others. Some questions were unexpected, for example one male interviewee asked her if Wilf would kill someone who attacked her. This made Lindsey feel uncomfortable as she was in his home and at that point it was a relief to know that Wilf was there. Four interviewees asked Lindsey specifically about epilepsy rather than about Wilf. Questions about Wilf are tiresome to Lindsey who has that conversation with every person she meets, yet she was more comfortable to disclose this information in the interview context than in other contexts. Lots of people have dogs (particularly in the UK) and so participants felt dogs were an interest they shared with Lindsey. These discussions happened before the interview started, before consent was obtained and the digital recorder switched on, so it is not possible to illustrate the points made here with quotes.

Throughout this analysis of embodiment, Wilf is key as the visual marker that signifies difference to an onlooker. Lindsey was frequently told that people would not know she was disabled if not for the presence of Wilf, a statement people meant as a compliment. Since initially submitting this article Wilf has retired and has not been replaced. In more recent fieldwork, Lindsey has noticed a difference in the way participants regard her. There are obvious differences, such as an absence of conversations about dogs and/or epilepsy, instead new ways of breaking the ice and building rapport have been found. Lindsey's epilepsy is now a 'hidden disability'. Whether or not to tell participants she has epilepsy is now a different issue as rather than a dog being present there is a possibility Lindsey might have a seizure, so considerations are now around the safety of carrying out fieldwork alone with epilepsy.

Felicity found telephone and email interviews avoided problems she encounters in daily life such as inaccessible buildings and physical strain caused by travelling long distances. By conducting interviews by telephone or email many identity negotiations that emerge around the visibly disabled body in the research process were circumvented, although it was participants' preferences that largely determined the method of interview. Technology, particularly the internet, can facilitate the transcendence of the body for some disabled people, allowing them to adopt an identity that is not dominated by their visible impairment and the associated work of identity management (Seymour 2001).

People with physical disabilities use technologies to augment, strengthen or bypass aspects of the body that may impede their participation in everyday life.....the body is to all intents 'eliminated' (Seymour 2001: 161).

While Seymour acknowledges that the body may still enter into research conducted online (the very choice of methods may be linked with the effects of a physical impairment) for many disabled people, online communication may a way to remove the body from social interaction, thus eliminating some of the difficulties associated with social interaction in the presence of a visible physical impairment, in particular

attitudinal barriers (Campling 1981). For others, new technologies can break down barriers and allow disabled identities to surface (Roulstone 1998). While attention has been paid to the consequences of this for research participants, there is very little written by disabled researchers who have 'bypassed' the body or broken down barriers in this way.

Andrews (2005), who researched a group of wheelchair users undertaking volunteering work, reported the negative attitudes to disability that a conversation on the telephone with a gatekeeper prompted, around the perceived 'usefulness' of volunteers who are wheelchair users (Andrews 2005). As a wheelchair user herself, Andrews (2005) challenged the gatekeeper on these presumptions, by stating that she was a wheelchair user. While Andrews (2005) highlights the pre-conceptions others may have had of her and the importance of identity perceptions to research outcomes, she does not directly discuss this as an issue of the (in)visibility of her disability, nor the role of technology in mediating the sorts of identity negotiations she encountered. Our research contrasts with Andrews' as all her interviews were conducted face-to-face, meaning participants had visible knowledge of her disability. Many of our interviews were not conducted face-to-face and so the 'visual cues' that others use to define us as disabled people were absent. If we had not met the participants before, there was no way they would have known we were disabled. This raised ethical issues around if, how and when to identify ourselves as disabled people.

Telephone interviewing proved to be liberating for us both. While being disabled is not an inherently negative experience, it is often the case that people's reactions to disability can be difficult to manage, and attitudinal barriers are frequent. For Lindsey, every social encounter is dominated by discussions about Wilf and her impairment, so to be talking to someone for 90 minutes without Wilf's presence being known was rare. Nondisclosure meant that many of Felicity's participants appeared to presume a non-disabled status, as some of her participants commented:

You know my sister can't just walk down the street when she goes shopping like you or I could, you know, we just take that for granted, don't we? (Participant 061: 20).

I mean, disabled people, like people in wheelchairs, you don't really think of them *as* people, do you? Like having brains and personalities do you....and you just wouldn't want that for your child (Participant 013: 11).

Felicity's experience suggests that the use of technology had an impact on perceptions of her identity; in this context of telephone interviewing, she was not marked as a disabled person. She recruited through a support organisation and some participants had met her in person when she attended their conference (and so had visual cues about her disability), others however, were recruited through responding to an e-mail bulletin which did not reference her disability. Felicity did not know if participants recruited through snowball sampling knew she was disabled, so it was impossible to know for certain whether participant 013 quoted above was aware of Felicity's disability. Unlike Andrews (2005), Felicity did not confront this comment as she worried about alienating or offending the participant and preventing co-operation. These situations could be unsettling as Felicity was concerned that participants would feel betrayed or embarrassed by her decision not to disclose her disability, should they discover this later, as it could potentially have informed the perspectives on disability they were willing to disclose to her. However, it also suggested that a disabled researcher could effectively by-pass many of the identity negotiations cued by a visible disability and which can place a considerable demand on disabled people (Seymour 2007), as Felicity reflected following interviews with non-disabled parents:

I began to wonder how far these accounts would ordinarily be accessible to me as a wheelchair user; would comments such as these be made to my face? After the initial hurt had passed, however, I began to feel strangely liberated

by the experience of this interview, by removing my body from the interview situation, I began to wonder, was this what it was like to be responded to as a non-disabled researcher? Was I free to pass between identities depending on the means of communication with participants? What does this mean for the data? (Felicity Reflexive Diary).

This fluidity of identity was significant in relation to the subject of Felicity's research. When talking to people about their reproductive decisions with a known genetic condition in their family, Felicity felt her identity as a visibly disabled woman could inhibit discussions about how they would feel having a disabled child themselves. The visible presence of a wheelchair was the primary marker that signalled a disabled identity to participants, however Felicity's impairment also became visible at points during interviews; muscle spasms and needing to frequently shift position in the wheelchair due to pain may also have been visible signals, but it is not clear whether participants' noticed or responded to these visible signs of impairment. However, the significance of a disabled identity to the way in which Felicity was perceived was communicated in various different ways. One woman, who had met Felicity at the conference before being interviewed and thus was aware of her disability, appeared conscious of this during the interview and it affected the interview and the data collected:

It's hard for me to talk about how I would feel about having a disabled baby because I think that could be....quite offensive to disabled people really. I just don't want to offend anyone (Participant 056:47).

Haraway (2008) has rejected the conceptualisation of straightforward division between human bodies, and what she terms 'companion species', a term used to encompass both technologies and animals. According to Haraway's vision, animals, technology and humans, are co-constituted, created through an interdependent relationship with one another, altering the way in which we may view the use of a wheelchair or assistance

dog. Indeed, while we often experienced our forms of assistance as extensions of our own bodies, nevertheless it was through the cultural meanings imbued in those means of assistance that assumptions about our identities were derived, and thus a conceptual separation forged. While our respective disabilities may increase when separated from our assistive devices (when Lindsey is without her assistance dog or Felicity is sitting in a chair), our perceived identities as disabled people, may, paradoxically, disappear.

### *Discussion*

#### *The impact of disability on power relationships in the research process*

Our experiences highlight some issues around our identities as disabled people, negotiations around disclosure and the impact of the visibly disabled body on the research process. We will now consider how these issues affected the power relationships in the research projects we carried out. As Arendell highlights, relationships between participants and the researcher are inevitably complex, multifaceted, and dynamic (Arendell 1997). Power relations within the interview context have been well researched and described. Feminist writers in particular draw attention to the discrepancy of power in interview situations, with power presumed to be lying predominantly with researchers, leaving participants vulnerable to exploitation (Oakley 1981). In order to address this imbalance, Oakley (1981) proposes a reciprocal relationship, a mutual sharing of information, rather than situating participants as sources of data. Such discussions, however, assume that only the participant can experience the interview as disempowering or exploitative. Researchers, however, can also experience vulnerability in the interview context (Cotterill 1992). For visibly disabled researchers, such negotiations of power and identity have particular dimensions.

Relationships of power can be observed as they are played out through identity categories. Identities are imbued with relative social power and translate into relationships of power in everyday life. Relationships of power serve to privilege some positions and marginalize others: men over women, non-disabled people over disabled people. In a research context, the identity 'researcher' may have more power accorded to it than that of the 'participant' although the research relationship is not a simple matter of dominance of the researcher over the participant. Foucault (1978) suggests where there is power there is always resistance to that power. Through judicious use of self-disclosure it may be possible to transform the research relationship. Gurney described how:

[f]emale researchers must work especially hard to achieve an impression combining the attribute of being nonthreatening with that of being a credible, competent professional (Gurney 1985: 43).

McDowell asserts that because male participants perceive women as unthreatening or unofficial, access may be granted to confidential documents or difficult issues are discussed relatively freely (MacDowell 1988). Lindsey discovered that discussing Wilf and her disability seemed to change the power differentials of the interview. Identifying herself as disabled signalled to some that she was non-threatening, a "low-status stranger" (Daniels 1967), given the cultural constructions of disability that posit disabled people as particularly vulnerable. It therefore served as a way to break down the researcher-researched hierarchy. Similarly for Felicity, the presence of a personal assistant or the various practical barriers presented by partially accessible houses served to break down some of the presumed hierarchies between researcher and participants. Being pulled ungracefully over steps or unable to pass through gaps between pieces of furniture in a wheelchair, while perhaps detracting from the anticipated image of the 'professional' researcher, nevertheless relaxed the (often) socially awkward situation of

the interview. While other markers of our identities, including those of class and ethnicity intersected with our identities as disabled people and altered the way in which we were perceived by participants, we have focused primarily on disability as this aspect has been overlooked in the literature, and, as has been noted is frequently perceived by disabled people as the 'master category' of identities in the eyes of others (Murphy 1987; Watson 2002).

Inequalities of power in most researcher-participant relationships are exacerbated by the imbalance of disclosure, such that the researcher remains remote and unknown to the participant (Butler, Ford et al. 2007). Ellingson believes that the 'writing out of bodies' upholds researcher's power over their participants, it is a mark of privilege to 'have one's positionality obscured' (Ellingson 2006: 301). Both Lindsey and Felicity found the power relations between a disabled researcher and non-disabled participant were complicated and appeared to affect this traditional dynamic. The power relations depended on the way we were perceived; at times we were seen as academics, and therefore accorded high-status, but at the same time visibly disabled and we chose to disclose information when asked, which altered the nature of this status. In face-to-face interview situations, 'perception management' (Goffman 1963) becomes more complex. Using technologies in interview situations suggests new ways in which we could manage this aspect of our identities.

The presence of a visible disability had a marked impact on the practical, ethical and conceptual dynamics of the interview situation which simultaneously provided new challenges and considerations. The tension between our identities as researchers and that of visibly disabled women, for example, impacted on the negotiation of power in the context of interviews. Certainly, we found that a combination of our biographies and our tendency towards reciprocity gained us access to information that might not be given so willingly to a different researcher.

## *Conclusions*

Negotiating the disabled body into the research process requires consideration and should not be ignored. In this article we considered the impact our visibly disabled bodies have had on the research process. While reflexivity is often seen as contentious, we have found it a useful means to highlight some of the particular issues we encountered as visibly disabled researchers carrying out qualitative research. We have discussed the effectiveness of 'matching' characteristics of researcher with participant, and suggested that people may have many different identities or selves, and thus it may be impossible to know which to 'prioritise' in the research context. We resist attempts to limit us, as disabled researchers, to only researching disabled people, indeed perhaps only people with the same impairment. We recognise that being a disabled researcher can provide an 'insider' status when interviewing other disabled people and as such, the presence of a visibly disabled body in the research process can be beneficial. However the visibly disabled body can simultaneously be attributed stigma, and assumptions can be made about the researcher. Through reflecting on our own experiences, we highlight that decisions relating to disclosure of disabilities raise many issues that have been underexplored in literature, despite them representing a significant negotiation in our research experiences. In some instances we chose to control disclosure through methods and technology, at other times, disclosure was not an actively made decision but occurred simply through the visible markers of disability. By highlighting disclosure, and non disclosure, as a key site in which this identity negotiation occurs, we have also acknowledged the potential of our identities to affect relationships with participants, and therefore the research process. While in some instances there was explicit acknowledgement that being interviewed by a disabled person had an impact on what participants were willing to discuss in an interview, there were also more subtle assumptions and forms of identification offered by participants that highlighted that disability (much like gender, age, ethnicity and other 'body signifiers' of identity), can inform the research relationship.

This paper has highlighted that the presence of a visible disability in the context of research, can also introduce social, ethical and personal dilemmas for disabled researchers. For example, the question of if, when, how and to whom a disclosure of a researcher's (visible) impairment takes place can be regarded as decisions which carry ethical implications that disabled researchers need to consider. While some visibly disabled researchers may choose to sideline their impairments as irrelevant to their practice as researchers, an analysis of the way in which identities are read in the research process, and the impact they have on the data produced means that these questions cannot be dismissed as entirely irrelevant. It is important to reflect on our disabilities and not to deny our disabled identities, which begs the question, is there an ethical imperative to disclose our disabilities to participants? There is potential for participants to feel betrayed if the interviewer is exposed as being not who they imagined them to be, and questions directed at disabled researchers about their impairments, together with responses given, can have serious implications for the dynamics of the interview situation. If we believe that it is unethical to keep information about ourselves confidential, how much should we disclose? Do researchers not have a 'right' to privacy? What entitlement do participants have to know about us? How do we balance disclosure of personal information with the importance of remaining professional? Attending to questions around disability, disclosure and methods are thus also relevant to non-disabled researchers and broader political issues. Addressing such questions acknowledges the presence of disabled researchers working in fields beyond disability research. Through highlighting our own experiences of conducting research as disabled researchers, we have drawn attention to some of the dilemmas we encountered. As Ellingson (2006) has noted, writing our bodily experiences into the research

...points to the expanding (albeit still not broad enough) group of people whose perspectives are and/or should be represented

within the interdisciplinary health fields. Marking our ethnicity, nationality, gender, sexuality, health status, and other aspects of our identities draws attention to the plurality of bodies who are both researchers and researched (Ellingson 2006).

While this paper has specifically addressed disability, our findings also suggest that *all* researchers should attend to their own 'body signifiers' (whether in relation to ethnicity, wealth, gender, age etc) and embodied experiences of research processes, as these are integral to research outcomes and the ethics of research, as well as a means by which to address power differentials between researcher and participant. This process may be especially important when considering identity matching of researcher and participants and the (un)desirability or (un)importance of this. The discussions in this paper will also be relevant when considering bodies in other types of research contexts such as participatory action research, collaborative research, and arts-based research. Negotiations of identity prompted by the disabled body in the research process requires consideration and should not be ignored.

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