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Who is “Us” in “Nothing About Us Without US”? Rethinking the Politics of Disability Research.

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Introduction: The Politics of Disability Research

Disability research (and disability studies) emerged from the activism of disabled people who not only challenged oppressive legal and social structures, but also the ways in which research was used to legitimate that oppression. At the forefront of this challenge in the UK was Paul Hunt (Stone and Priestly, 1996). Hunt (1981) discredited the work of formerly esteemed researchers Eric Miller and Geraldina Gwynne by highlighting the ableist and unethical basis of their work. Miller and Gwynne had been commissioned to research the experiences of disabled people who were confined to institutional living following agitation by The Union of Impaired People Against Segregation (UIPAS). However, Miller and Gwynne’s findings focused on improving the lot of practitioners rather than the quality of life and rights of disabled people. Hunt (1981) challenged Miller and Gwynne’s claim to objective findings by demonstrating that they had prioritised the perspective of practitioners over disabled people and reiterated wider social prejudices about disability. For example, Miller and Gwynne argued that in residential care, “the essential task to be carried out is to help the inmates to make their transition from a social death [e.g. being/becoming disabled] to physical death” (1981:10). Miller and Gwynne’s depiction of disabled people throughout their work was discriminatory and inflammatory, positioning disabled people as burdens and parasites. Hunt, however, subverted their discourse: “Miller and Gwynne make various references to residents as parasites and see us as essentially feeding off society not only economically but emotionally as well ... The real parasites are those like Miller and Gwynne who grow fat by feeding on others miseries” (1981: 11). Hunt’s analysis of the power and politics of research laid the foundations of disability research. He highlighted the politics of objectivity and accountability, exploitation and oppression and mandated that disability research should benefit disabled people.

The oppressive nature of research which purports to be about disabled people has remained a key concern within disability studies, and not just in terms of the research itself, but also in terms of “oppressive theoretical paradigm[s]” and “oppressive set[s] of social

relations” (Stone and Priestly, 1996: 699). According to Oliver “disabled people have come to see research as a violation of their experience, as irrelevant to their needs and as failing to improve their material circumstances and quality of life” (1992: 105). Nearly two decades after Hunt’s initial exposé, Kitchen (2000) found that disabled people still had negative experiences of participating in research and often felt exploited by it. In contrast, in disability studies research, political and ethical legitimacy is premised on avoiding exploitation and inequality and ensuring that outcomes directly improve the lives of disabled people. In this context, one of the most influential models is the “emancipatory” framework (Barnes, 2003; Stone and Priestly, 1996). This framework is comprised of a set of principles and practices which include: the researcher surrendering claims to objectivity in favour of an overt political orientation towards improving the lives of disabled people; the use of the social model of disability as the underpinning theoretical foundation; and control and accountability being deferred to disabled people (Stone and Priestly, 1996)¹. Underpinning this framework is the principle of “no participation without representation” (Kitchen, 2000; Oliver, 1992) or, “nothing about us without us”. Disabled people’s refusal to participate in research which is not representative of their experiences and interests draws further attention to the inherently political nature of research. All of these principles continue to underpin contemporary disability studies research.

This glance at the emergence of disability studies research highlights a number of issues which are relevant for our paper. Historically, research purporting to be about disabled people has been dominated by ablebodied researchers (Kitchen, 2000). Research has been experienced as exploitative, oppressive and unrepresentative, and many disabled people are suspicious of ablebodied researchers (Barnes, 2003; Kitchen, 2000; Oliver, 1992). As such, the ethics and politics of disability research are “heightened for non-disabled researchers” (Stone and Priestly, 1996: 699). Moreover, these concerns are not solely about the *politics* of ablebodied people researching those with disabilities, but they also give rise to *practical* questions about the role of identity and identification in the production of knowledge and shared understanding. For example, in addition to concerns about the ethos and intended outcomes of research, Kitchen’s participants also highlighted problems in terms of shared understandings: “non-disabled researchers can potentially misrepresent and misinterpret disabled people’s experiences and knowledge because they themselves have never experienced what it is like to be disabled” (2000: 33). Furthermore, people with disabilities may “only tell partial stories to a non-disabled researcher” due to

fears around stigma, misunderstanding or embarrassment (Kitchen, 2000: 34). Overall then, within disability studies, researchers with disabilities are often assumed to be both politically and practically best equipped to undertake disability research.

As researchers, whether working in collaboration or individually, we have all been influenced by the politics of disability research and have shaped our practices accordingly. Nonetheless, only author 1, Kay Inckle, currently identifies as a disabled person; author 3, Andrew Sparkes, has predominantly identified as able-bodied but has wondered at several points in his life whether or not he should identify as disabled, whilst author 2, James Birghton, identifies as able-bodied. However, these positions and their implications for the politics and practices of our research are not as straightforward as they might first appear (see also, Barnes, 2003; Shakespeare, 1996). Reflecting on our experiences we draw out three key themes for the politics and practices of disability research. These relate to: assumptions about identity and its implications for disability research, the experiential and political differences within categories of identity, and the problems of static binary positioning. We attempt to resolve these in a politics of *dys*-identification as an alternative to either normative identity politics or the wholesale dismissal of them. *Dys*-identification emphasises the complexity of disability identification while at the same time maintaining the political and ethical principles upon which disability research is founded. We begin our analysis by reflecting on how we, as three differently identified disability researchers, met and initiated our collaboration. We then explore the politics of identity and *dys*-identification and reflect on our research experiences in this context.

Us: Bodies, Selves & Research

I, Kay, first met Andrew at my PhD viva. I had come across Andrew's work during my research. Despite some significant differences in our focus – mine was on gendered embodiment and women's experiences of body marking practices (Inckle, 2007), and his on men's experiences of disability acquired through sports injuries (Smith and Sparkes, 2004, 2005; Sparkes and Smith, 2002, 2003, 2005, 2008) – there were important underlying resonances between us. Significant among these was our shared interest in non-traditional research methods. Andrew had written about the dilemmas and vulnerabilities that emerged from his own bodily experiences (Sparkes, 1996, 2002, 2003, 2004,) and I had been experimenting with creative research methods and self-exploration (Inckle, 2005; 2007). I was acutely aware that by drawing attention to the minoritised aspects of my own identity

within my research I was making myself vulnerable to a wide spectrum of attacks ranging from the positivistic critiques of my “lack of objectivity” to accusations of narcissistic self-indulgence. As such, it was important to me that my PhD was examined by someone who felt safe. That is not to say that I did not want – or get – a thorough intellectual grilling during my viva, but I wanted it to be from a position of methodological solidarity rather than from the thinly disguised ableist and misogynistic ire which is often directed at “non-traditional” researchers.

During my PhD research I had begun to actively identify as a disabled person. Much of this was out of necessity in that while I still cycled a bicycle (something else that Andrew and I shared) it had become impossible for me to walk without the use of mobility aids.

Notwithstanding that academic environments are largely hostile to disabled people (Brown & Leigh, 2018; Hannam-Swain, 2018; Inckle, 2018; Olsen et al, 2020), intellectually, social science can be a useful location in which to experience disability. Given that I was already very politicised about gender and sexuality, and mental health and illness, it was easy to submerge myself in the politics of disability studies and begin to figure out my identity and rights claims from there. As such, a few years later, when Andrew requested my input with one of his PhD students, James, who was researching the experiences of athletes with spinal cord injuries (SCI) I felt excited and validated. This was not only a validation of my own disability identity, but also an affirmation of the politics of disability research which recognises that expertise and insight emerges from lived experience and challenges the legitimacy of outsider researchers.

Andrew: my first encounter with Kay was at the cognitive level when, in my official role as external examiner, I read her PhD thesis. The first meeting of our physical bodies at the viva began with a sharp moment of contrast, not just in terms of gender and age (I was then 51 and Kay was 32), but also in relation to the surfaces of our flesh on display. Kay was heavily tattooed (in my eyes); I had no tattoos. When I was a boy, if you had tattoos and were not in the military you were classified as “deviant.” I remember my parents speaking negatively about tattoos and warning me never to make the “mistake” of getting one. My daughter was born in 1990 and my son in 1994, and I can recall giving similar warnings even though this body practice was becoming more popular and acceptable. Kay also had multiple piercings to her ears and nose; I had a solitary earring in one ear and nothing in the other even though it was pierced. She was clothed in layered shades of purple; I was in

black. I felt overwhelmingly “under-dressed” and corporeally boring in comparison to her. Recently, I learned that she had actually dressed-down for the viva, so it could have been worse!

In so many ways, Kay and I inhabited very different worlds. But, as she entered the viva room, I noticed she used a crutch. I did not need a crutch that day, but I had needed a walking stick to enable me to move, in great pain, at three earlier periods in my life prior to surgery on my lumbar spine in 1988, 1994, and 2000. I have also used a walking stick at other times when I have been in acute pain with my spine prior to steroid injections easing the situation. The use of a mobility aid was, therefore, a valuable point of recognition for me. Since then, I have watched with interest and learned from Kay’s experiences from using crutches to assist her mobility and her movement towards the use of wheelchair in recent years. Another point of recognition that we have shared since her viva is an interest in how people inhabit different bodies differently over time and in various circumstances.

The tribulations of my own body fueled a growing academic interest in how people occupied different kinds of bodies and I developed a module entitled Body, Identity and Culture, for the undergraduate degree in Sport and Exercise Sciences. I first met James when he opted to take this module, and again later when he undertook my module in Qualitative Research Methods. We met some years later when he requested that I supervise his PhD. As James sat opposite me describing his proposed research I read his body. The rickety chair just about managed to hold his tall and muscular frame. He clearly, worked out in the gym and it showed in the size of his arms encased in a tight T-shirt. At this point, it would have been easy to define him as a typical “jock” but as our conversation developed he began to touch on a number of ideas about sporting bodies that were based on his own experiences of the self as vulnerable and fragile. He described how his own sports career had been impacted by a serious, ongoing knee problem that had already led to 4 bouts of major surgery with more to come. As James spoke articulately about his body an emotional space opened up in our conversation that enabled me to share empathetic connections with him. I recognized that, like me, James was a “wounded storyteller” (Frank, 2013) and he was raising a lot of important and difficult questions about himself and others, including me.

I, James, vividly remember the first time I encountered Andrew in a lecture during my undergraduate degree in Sport and Exercise Sciences. Having recently undergone back surgery, he slowly made his way to the front of the cloistered theatre with the use of a walking stick. Hunched over and clearly still in pain, he began to tell stories about bodies and identities and experiences of injury, impairment and disablement. Having previously undertaken modules in anatomy, physiology and biomechanics, all firmly rooted in positivism, his words struck me. He asked us to think about *how* we construct knowledge and come to understand alternative forms of embodiment. In doing so, he destabilised the normative, essentialist and ableist knowledge that we, as sport scientists had previously assumed to be the “truth”. These revelations resonated particularly deeply with me as they coincided with a time in my life when I was trying to come to terms with a career ending sports injury and to repair a broken body-self-culture relationship. Andrew’s lecture helped me reflect on my own body and its place in the world and ignited my critical “sociological imagination” (Mills, 1959) in relation to understanding peoples’ experiences of disability.

Some years after this “epiphinal moment” (Denzin, 1989) I contacted Andrew in order to undertake a PhD that sought to ethnographically explore the experiences of people who acquired SCI and subsequently constructed and reconstructed embodied identities in disability sport (Brighton, 2015). One theme that emerged in this research was the body modificatory practices that disabled athletes engaged in. Given her expertise in this area, Andrew put me in touch with Kay who freely gave her time to provide guidance. However, before she approached the observations I had begun to explore, she asked to me to consider myself in relation to my participants and the phenomena:

Ok my first question would be (and you don’t have to answer this to me, but it might be helpful to reflect on this for yourself especially in light of some of the points you raise below): Why are you interested in this? What draws you to these topics? Do you share any of the experiences you are investigating? Why does it matter to you? What questions do you want to answer (in a more existential way) about embodiment, living with ‘difference’ and being both subject to, and the author of, physical difference? What questions do you have about your own embodiment and how is this influencing your relationship with and perspective on your work?
(Personal Communication)

I began to reflect on my positionality and intersectionality as an able-bodied, white, male, heterosexual researcher researching with disabled research participants and the importance of empathy and reflexivity in the construction of knowledge (Brighton, 2015; Brighton and Williams, 2018). As Kay (Inckle, 2007: 18) acknowledges, these reflections are “not so much about whether researcher and participants (and reader) *share* experiences, but rather the assumptions and processes through which we formulate the knowledge of shared experience and its implications” (italics in original). Kay therefore helped me understand how issues of identification, reciprocity and acknowledgement could be used to situate and problematise a reflexive approach to research as an able-bodied researcher researching disabled people’s lives. Since these early meetings Andrew, Kay and I have developed an “epistemic community” (Haas, 1992) and coproduced knowledge about how disability might be theorised, how ableism is culturally constructed and socially experienced, and how emancipatory and ethical research should be undertaken with disabled research participants (Sparkes, Brighton & Inckle, 2014; 2018a; 2018b; 2021).

At the outset of our collaborations, our positions in this epistemic community seemed straightforward: Andrew and James were able-bodied researchers and Kay was the disabled researcher who added political legitimacy via her lived experience. However, identity and identity politics, especially as they map out in research relationships, are much more complex than our initial positioning suggested. As such, we turn to a brief analysis of the politics of identity and *dys*-identification in order to deepen our exploration of the politics of disability research.

Disability, Identity Politics & *Dys*-identification

I, Kay, have a strong affinity with the politics of disability research. The principle of “noting about us without us” feels essential in challenging oppressive practices whereby “experts”, be they researchers, practitioners or policy-makers, assume authority over the lives of disabled people, most often to our detriment. This principle also resonates with the ethos and practice of feminist research which has also sought to challenge the hierarchies of power and knowledge in research (e.g. Ribbens and Edwards, 1998; Roberts, 1990). Therefore, both of the methodological traditions which resonate with me, e.g. disability and feminist research, are primarily identity-based. As such, I am often defensive and angry about the encroachment of able-bodied people, especially from the fields of medicine and psychology, into disability research. At the same time, I have never doubted the integrity of

and authenticity of Andrew and James's research and I have been enriched by it. I am also aware that identity and identification is much more complex than a simple essentialist binary of ablebodied and disabled (or female and male), and that identity politics themselves can be politically problematic and exclusionary.

For example, although I have been disabled all of my life, I have not always used that term to describe myself. For many years, and for a variety of reasons, I would pass as an injured ablebodied person. In recent years I have become a full-time wheelchair-user and this has both closed down and opened up multiple possibilities for me as my wheelchair-user identity exists within multiple paradoxes. For example, my pain levels have improved since I have become en-wheeled and I can now more easily take part in the physical activities that I love: swimming, (hand)cycling, dancing, Pilates and core work-outs and I thoroughly enjoy my body capacities. I have recently qualified as a Pilates Instructor and an exercise instructor for disabled people and I am much more physically mobile and active than I have ever been². At the same time, within the wider social context my wheelchair signifies immobility, weakness, vulnerability, dependency as well as endless encounters with environmental barriers.

In addition, because the wheelchair has been co-opted to universally symbolise disability, I am now positioned as "genuinely disabled" – something which I never achieved whilst using crutches. At the same time, being "genuinely disabled" and therefore entitled to legal protections, has not decreased the level of disability discrimination I encounter. Indeed, it has worsened. In 2019 disability discrimination finally destroyed my academic career, after years of discrimination, harassment and victimisation which resulted in two payoffs (with corresponding non-disclosure agreements) in the space of four years³. In contrast, however, in some contexts, such as disability and/or equality fora, my wheelchair affords me a political legitimacy which I, and other non-wheeled disabled people, otherwise lack. I would be dishonest if I did not admit that after a lifetime of invalidation that I do sometimes enjoy the easy legitimacy that my wheelchair affords me in these situations, in much the same way that I felt validated and empowered by Andrew's initial invitation to work with James and him on a disability research project. At the same time, I am not entirely comfortable with this positioning, it does not reflect my lived experience and I do not wish to reinforce any kind of hierarchy or exclusion around disability or any other identity. Andrew also grapples with disability identity and his position in relation to it.

As a child born in the mid-50s to a working-class family my (Andrew) developing sense of masculinity was framed by what Connell (1995) later defined as hegemonic masculinity. Like most boys in this period I was socialised within the family, school and sport to understand and relate to my own body, and the bodies of others, in very specific and limited ways. This was epitomised in the aggressive sport of rugby union that I excelled in. Rugby union valorized and celebrated the masculine virtues of physical strength, power, courage, risk-taking, dominance over others, and emotional detachment, all of which separated “real” heterosexual men from negative others, such as, gay men, and “the disabled”. I remember being told on numerous occasions, that if you don’t get the tackle technique correct you will break your neck and end up *disabled in a wheelchair*.

Against this backdrop, my relationship to the term disability has remained ambiguous and confused despite the often debilitating pain and immobility I experience. This ambiguity and confusion are accentuated in relation to issues of visibility and permanence, and not feeling worthy of claiming the term for myself. Thus, I saw “the back problem” that terminated my rugby career in my teens and led me having to take a year out of college to “repair” myself, along with along with regular episodes of pain and immobility and three operations as part of an *interrupted body project* (Sparkes, 2003). That is, something temporary that could be fixed and put right by therapeutic regimes, not something permanent. So despite, for example, having to use a walking stick and not being able to walk more than 20 metres due to intense pain, not being able to drive, needing assistance to get out of a car, and not being able to open the stiff doors to the building where I worked, I did not feel it appropriate to use the term disabled to describe myself. Recall the image presented to me of disability during my sports training which was of visible disability evidenced by the symbol of the wheelchair; whereas my back pain, and the things that caused it, were invisible. As Drew Leder (1990: 74) points out, “pain strikes one alone. Unlike the feel of the cool wind, pain is marked by an interiority that another cannot share”. Because of this invisibility, Elaine Scarry (1985) notes that for the person in pain there is *certainty*, while for the person hearing about the pain there is always the possibility of *doubt*. Thus, invisible pain and invisible injury or illness always face the dilemma of legitimation.

I encountered these dilemmas again in recent years, attacked once more by pain and immobility, but this time not limited to my back. Sleeping had become difficult because my

joints ached so much and I needed help putting my shirt on in the morning. Walking to the bus stop to get to work was extremely slow and painful, I could not make it up the stairs to my office and had to use the lift, sitting caused me pain as did trying to get up from a chair. Pain and fatigue enveloped me and I lost a lot of weight. Eventually, I was diagnosed with PMR (Polymyalgia Rheumatica, an inflammatory disorder that causes muscle pain, aching and stiffness, especially in the neck, shoulders and hips) and I was placed on a regime of corticosteroids (prednisolone) to manage this condition. Still, I saw PMR as a pretty awful but temporary condition⁴, plus given its invisibility, I was not sure how to define myself in relation to it. Given the limitations imposed on my body by PMR, I was told by a friend who as an occupational therapist that I was eligible for a “disabled sticker” for my car. On some days (PMR is a variable condition), getting in and out of my car was very painful, especially given the limited amount of space provide in standard car parking spaces. It would have made sense for me to use the larger space provided in the disabled parking bays. This was confirmed by the occupational therapist at my university who said they could give me a badge so that I could use the disabled bays on campus. But I could not bring myself to apply for either of these. I felt I would be cheating if I did, as I actually could get in and out of the car, and so my illness did not make me “disabled enough” to warrant a badge.

Given the invisibility of PMR, I also imagined what people might think of me parking in a disabled parking bay and seeing me on a “good day” walking as if nothing was wrong with me. They would perceive me as a fraud taking up space from somebody who really deserved it. Clearly, I held a notion of some hierarchy of disability on which I was ranked lower rather than higher. This problem remains, I continually grapple with the notion of not being disabled “enough” when compared to others who have “proper” disabilities. This is even though I do not know what constitutes “enough” and “proper” when it comes to my own body and where I might place “it” in my imagined hierarchy of disability. This confusion and unwillingness, to ascribe a specific label to myself, leaves me with a constant sense of illegitimacy regarding issues surrounding disability and my ability to engage with them in authentic ways in both my academic work and in my life in general.

Kay and Andrew’s experiences highlight the complexity of identity, even in relation something as apparently straightforward as a physical disability category. The problem of

identity has also been taken up theoretically, albeit in relation to gender rather than disability. The academic critique of identity and identity politics was spearheaded by Judith Butler in the nineteen nineties (e.g. Butler, 1991; 1993) with reference to the feminist and gay rights movements which preceded her. Butler argued that the identity politics at the heart of these movements' rights-claims were based on and reinforced essentialist binary categories (e.g. woman) which inevitably necessitated exclusions (e.g. trans women and intersexed people). As such Butler argued that any claim to an identity, or any invocation of identity politics, will only ever reinforce hierarchies of legitimacy rather than engender equality. Identity categories must therefore be interrogated and challenged rather than adopted and utilised because they can never create political transformation. To some degree, this challenge has also occurred within disability studies where the homogenous identity category of disability, particularly as it is presented in the social model, has been critiqued in terms of exclusions of gender (Inahara, 2006), sexuality (Kafer, 2013), diversity (Clare, 2017), madness (Spandler et.al. 2015) and its privileging of white (Frederick & Shifrer, 2019) and global-north perspectives (Nguyen, 2018).

Butler's critique led her and her followers to eschew the notion of identity altogether, and to vociferously argue against any politics or movements which were founded upon collective identification because of the inequalities and exclusions they created. However, the rejection of identity as the basis for a rights claim, and the dismissal of collective movements built upon shared identity, were alarming to many activists (e.g. Kirsh, 2000). For them, Butler's anti-identity position shored up the neo-liberal, individualist premise of an increasingly powerful shift to the right which was occurring just at the time when minoritized groups around the world were finally beginning to achieve political legitimacy (Kirsh, 2000). The right-wing co-option of anti-identity politics which Butler's work foreshadowed is even more entrenched today when label of "identity politics" is used to dismiss collective movements such as Black Lives Matter (Malik, 2020). Similarly, in disability politics, individualised rather than collective approaches risk re-enforcing a right-wing medico-charity model (Stone & Priestly, 1996).

Overall then identity politics can be problematic because their simplistic, essentialist categories create hierarchy and exclusion and do not map onto lived experience. At the same time, to do away with identity and identity politics all together is to forgo the possibility of collective action and solidarity which are essential to rights-based movements. As such

we need a more complex and dynamic approach which facilitates collective rights claims and political action without falling into the trap of limited essentialist identity. In this vein, we turn to Drew Leder (1990) and his work on the *dys*-appearing body, to begin to construct a politics of *dys*-identification.

Leder (1990) argues that in normative contexts the [normative] body is absent from consciousness⁵. He suggests that on the whole we take our bodies for granted and it is only at “at times of disturbance” (1990: 70), such as pain or illness, that our bodies draw our attention and our actions towards them: “aversive states bring corporeality to explicit awareness of the sufferer” (1990: 84). Leder refers to this attention and awareness as “*dys*-appearance”. Here, *dys* has negative connotations meaning “hard, bad or ill” as is illustrated by its use as a prefix in “dysfunction” (1990: 84). Thus, the body “appears” or becomes present to us only in the context of negative experiences. *Dys*-appearance is then a negative awareness or visibility.

However, Leder also makes reference to *dys* in a second way where it indicates being “doubled, away, asunder” (1990: 89), a process which demands our attention in ways which call us to question our usual self-interpretation (1990: 92). Both of these accounts of *dys*-appearance are useful in terms of rethinking a politics of disability research in which identification and identity politics are nuanced beyond simplistic bodily categories, and yet which at the same time remain faithful to the founding politics and ethics of disability research. We consider this a politics of *dys*-identification which incorporates both meanings of *dys*: it is a self-questioning, political identification which emerges in a negative context.

In the first instance, if *dys* in *dys*-appearance refers to the way in which “aversive states bring corporeality to explicit awareness of the sufferer” (1990: 84), then the *dys* in *dys*-identification emerges with reference to the aversive state of ableism. In this context, identification with disability has heightened intensity, and *dys*-identification functions in direct opposition to ableist norms. In this way, it is not a simple claim to legitimacy based on a set of bodily features or capacities, but a critical relation to the ableist structures and practices which make disability appear in an aversive state. It is a context in which the “the intervention of the conscious ‘I’ becomes a requirement” (1990: 87). This consciousness resists disabling practices and foregrounds non-disabling ways of being. Thus, legitimacy

rests not on an assumption of disability status but rather in evidence of non-disabling ways of being in the context of conscious self-reflection and awareness in opposition to ableism.

The second use of *dys*, which suggests being “doubled, away, asunder” (1990: 89), deepens this critical relationship with the structures of ableism and disability rather than reinforcing it as a simplistic identity category. Leder suggests that the experience of *dys*-appearance “radically diverges from the habitual” (1990: 89), signalling a critical and disruptive mode of being. It is a “demand” to question our usual self-interpretation (1990: 92). This demand reinforces the notion of identity as a politicised position rather than relying on essentialist characteristics which risk reiterating the medical model and undermining the foundational politics of disability research. This also accounts for the ways in which disability politics do not automatically ensue disability experience. For example, the Paralympic movement has received extensive criticism from disability activists for failing to support the rights of regular disabled people, particularly at the 2012 event in the UK which was sponsored by Atos, the company responsible for stripping benefits and causing significant harm to thousands of disabled people in the UK (Braye et al, 2013). Moreover, many Paralympians do not identify as disabled people (Purdue and Howe, 2012) and/or actively distance themselves from regular “gimpy” disabled people (Peers, 2012).

As such, this understanding of *dys*-identification moves us towards a more complex, but still inherently political, means of identification within disability research. It demands self-interrogation regardless of our habitual/imposed identifications in a political orientation which pulls asunder the normative paradigm of ableism.

***Dys*-identification in Research**

James’ experiences iterate both dynamics of *dys*-identification at work: Having been born and experienced my developmental years as able-bodied I, James, have often positioned myself as “different” to my disabled research participants and have to some extent felt like an imposter researching their lives. In an attempt to alleviate these anxieties, I have become acutely aware of the history of exploitative research practices in both positivistic and interpretivist paradigms and I have sought to research within emancipatory framework (Oliver, 1992). This has involved engaging in reciprocal, collaborative, empathetic and reflexive research methods, adopting openly ideological research positions which highlight

structural inequality and challenge oppression, and attempting to make a material difference to disabled people's lives in sport (2015a).

This is not to say that I have not been, and still am, guilty of reproducing ableist assumptions in the field. For example, I have presumed that participants would be able to greet me in a normative, able-bodied manner. This mistake is demonstrated when I first met a research participant called Anna who was an ex-Paralympic swimmer:

...in my nervousness [I] hastily stood up and held my hand out to greet her. Anna stood still and smiled at me as my mistake dawned on me. I had assumed her to inhabit a 'normal' body like my own, but Anna had no arms or hands to shake. (Brighton, 2015a: 165)

Although embarrassed of the implicit reproduction of my normative masculine embodiment, critical reflection of this encounter enabled me to develop a sensitivity towards the dynamics of bodily interaction between my body and the bodies of others in field relationships. Subsequently, in future research with wheelchair rugby players who have acquired spinal cord injury (SCI) and had impairment in their hands, I asked participants how *they* would like to be greeted and used this ritual in subsequent meetings⁶.

My ableist understandings were not only exposed through my body in research, but also in interviews in which the disabled body was talked about. This is perhaps most strikingly revealed in this interaction with Matthew, a wheelchair basketball player, when he expressed his desire for amputating his impaired limbs following SCI:

James: Would you say that you have accepted being in a chair?

Matthew: Yeah, I am used to it being in a chair. This is who I am. I wanted my Doctor to cut my legs off at the hip – so I could walk on my hands, but he wouldn't do it! I was like, oh, what!

James: Were you being genuine? (*shocked*)

Matthew: Yeah! I really wanted my legs off – I want them cut off so I can walk on my hands. 'Now', he said, 'if there is a medical reason we can get your legs working again then we can and will'. But I don't really want to... it would be easier [to move

around] on my hands. My hands would be longer than my body so I would be able to walk. (Brighton, 2015a: 167).

Like the doctor, I tacitly reproduced ableist and bio-medical knowledge in doubting Matthew's desire to amputate parts of his body for purposes of functionality and manoeuvrability in favour of finding a medical cure and retaining limbs to promulgate aesthetic normalcy (Brighton, 2015a). Reflecting on this interview "shock" (Sands & Krumer-Nevo, 2006) I subsequently developed corporeal disability knowledge and an approach to research in which participant agency was central. This was essential in "cripping" normative hegemonic restrictions placed on disabled bodies and illuminating how disabled people may offer resistance against them in "unruly" ways (McRuer, 2006).

These "revelatory moments" (Trigger, Forsey & Meurk, 2012) in the field have exposed my entrapment in ableist epistemic framework (Svendby, Romsland & Moen, 2018). It made me appreciate the view point of some disability scholars such as Branfield (1998) who suggest that able-bodied researchers are unable to ideologically engage in emancipatory disability research. At the same time, by reflecting on these ableist "naturalised" understandings and developing a critical disability epistemology, I hope that my journey as a researcher might aid other able-bodied researchers who engage in disability studies research⁷. Central to this process is returning to [name]'s initial query in asking "What am I doing here?" A question reiterated by disabled participants who were curious as to my interest in them. Telling stories of growing up with a disabled father and experiencing my own bodily interruption, albeit a minor one (a chronically degenerative knee) revealed embodied vulnerabilities and enabled shared identifications with participants. These "confessions" of experiencing impairment along with my developing "disability consciousness" (Berger, 2008; 2016) eased participants' scepticism around my ideological positioning, fostered a mutual sense of compassion and empathy, and facilitated dyadic relationships. Once my personal relationship to disability was clear, and as our relationships became more reciprocal as my fieldwork progressed, bodily "difference" between my disabled participants and I became less conscious.

My initial struggles around identity and identification became replaced with a more nuanced dynamic that we have framed as *dys*-identification. There were, for example, specific conditions where there was very little difference between my participants' and my

consciousness such as when I trained in a wheelchair alongside disabled athletes. Initially, having not developed the skills to use a wheelchair or much of a “feel for the game” (Bourdieu, 1990) of wheelchair basketball, my unskilled, cumbersome and awkward body “dys-appeared” into consciousness as Leder initially (1990) suggests. However, when I remained in a wheelchair in the public space of the foyer of the practice facility, I experienced the ableist gaze which rendered me an alterity, a product of abledbodied people “seeing” the world they “claim to have discovered” (Hughes, 1999). This illustrates that bodily *dys*-appearance is not only biological but also materialises through social processes. Thus, *dys*-appearance is not solely an “intracorporeal phenomenon”, where pain brings the body back into consciousness, but can take the form of an “intercorporeal phenomenon” where bodies become social by “virtue of the fact that they share the same space or field of perception” (Hughes and Paterson, 1999: 336). Within this understandings, my body *dys*-appeared due to the aversive context of ableism, not simply as a result of embodied experience of disability.

I, Kay, have also found the politics of *dys*-identification more useful than traditional ideas of identity and insider and outsider locations to understand the dynamics within my research. There are two projects which illustrate this. In the first, where I explored the experiences of self-injury, my apparent outsider status was not perceived as problematic by research participants. In the second project, where I investigated the health, identity and social impacts of cycling for people with physical disabilities, my self-identified insider-status was not always recognised by participants or of benefit to the research.

Although I have never used formal psychiatric services and, indeed, I have worked as a service-provider to those using such services, I have always had a strong affinity with the psychiatric survivor movement and their critiques of mental health theory, practice and research (e.g. Adame, 2014; Blackman, 2007; Faulkner, 2004; Pembroke, 1996). Indeed, survivor politics were a significant influence on my post-doctoral research in which I used creative methods to explore the experiences of self-injury from a user-led perspective (Inckle, 2010). During this research I was still ambivalent about my own experiences of distress and trauma and quite how I could – or should – understand, label and identify myself in relation to them. I found my ambivalence quite distressing in itself, and of particular concern to me was how I would explain myself to my research participants should they question my motivation or credentials in regards to the research. Given the location of

mental distress/madness within the broader category of disability, and coupled with the well-established politics of survivor research, I expected that participants would question my legitimacy and relationship to the topic.

However, this never occurred. None of the participants seemed to feel that they should hold me to account for the ways in which I may or may not identify with the topic in order to legitimate my presence as a researcher. The most that I was asked was how I became interested in the topic – a question which I could answer honestly and openly without having to make reference to whether or not I had direct personal experience of self-injury. More interestingly still, not only did participants *not* demand my identity credentials in regard to the topic, many of them also highlighted how participating in the research had been a very positive experience for them. For example, at the end of her interview Rachel⁸ laughingly stated: “I feel like I’ve had a therapy session – I don’t know what one of those is like – but I feel like I’ve had one!” To which I, also laughing, responded that if that was the case then I should charge her fifty pounds! In a more reflective mood Amanda described the research experience as “a release” that “I have peace in my heart about.” Claire also reflected positively on the interview: “Thank you very much for asking me to participate as well, yeah, it is great because you have [time] to air your views, you don’t get the chance, and this is the opportunity”. Overall, then, this research challenges some of the simplistic politics of identity in disability research: firstly, I made no attempt to identify personally with the topic of the research, and the participants did not seem to have expectations or judgments about me in this regard. Secondly, many of the participants gave unprompted positive feedback about their research interactions with me and highlighted experiences of being listened to and validated by the process. This combination of a non-identifying researcher and a positive experience for research participants sits in contrast with the next example – an example where although the politics of disability research are directly adhered to, the identification and positive impacts are not necessarily shared/experienced by research participants.

This example is from a more recent research project in which I used qualitative interviews to explore the health, identity and social impacts of cycling for people with physical disabilities (Inckle, 2019, 2020, 2020a). This project is directly premised upon the politics of disability research: it has been designed in conjunction with a user-led organisation and everyone involved in the project – the organisation, the participants and the researcher

(me) – identify as having a physical disability, impairment or mobility impairment. The outcomes are intended to directly support the work of the organisation by providing data which leads to policy change and improved access to cycling for people with disabilities.

I have cycled for all of my adult life, and cycling has always been the easiest form of mobility for me – whether that was during the years when I was still walking and using a standard bicycle (and figuring out various ways to carry my crutches with me) or in the present day where I have a handcycle which I attach to my wheelchair. As such, I have experienced a broad spectrum of barriers and possibilities that disabled people encounter when using a cycle. I expected this to promote significant rapport and shared understandings in my research, especially given that I had identified myself as a disabled person and handcyclist on the participant information sheet. However, in contrast to my expectations, I noticed that some of the participants focused on *differentiating* themselves from me rather than assuming a shared identity and experience. For example, Nasia emphasised that, “For *me*, it’s a mode of transport, it’s *my* mode of transport, *you’ve* got a wheelchair that’s your mode of transport, mine is a cycle”. Likewise, Paul distinguished both his experience as someone with an acquired disability and his experience of cycling from other disabled people (including me): “To my mind you can go one of two ways if you have an accident – obviously for people who are already disabled they have grown up with that.”

It’s easier for me than for a lot of people who might have different disabilities because I can pretty much get on with a normal bike and function as I did before, and I think if you have a different disability and maybe have to cycle with your *hands* then that might be a lot more difficult.

Neither of Paul’s statements are particularly controversial and I agree with both: it is very different to experience life-long rather than an acquired disability, and handcycling certainly brings forth a number of barriers that those using bicycles will not encounter⁹. However, what is interesting about Paul and Nasia’s statements is that they challenge the assumptions of shared identity and experience that disability research often foregrounds and, indeed, relies upon for political capital.

In both of these examples, then, my relationship, perceived and otherwise, to the research participants and their experiences and its impacts is much more complex than simplistic

identity politics would suggest. In contrast, both James and Andrew may be construed as much closer to the experiences of their research participants than I have been to mine. Andrew and James have both participated in elite sport, and they have both experienced significant physical injuries which changed the direction of their lives and work, although neither of them identify as disabled. Yet in the context of disability research, where disability identity is a privileged position, neither have felt “deserving” of insider status despite their experiences offering significant common ground with their research participants. This is another instance where *dys*-identification can be a useful mechanism through which to make sense of our research relationships and practices and help us to maintain a strong emancipatory approach, regardless of our identities, which is reflected in our participants’ confidence – and confidences – in us. At the same time, *Dys*-identification can also throw our own experiences, beliefs and identifications into question, in much the same way that our research questions more broadly attempt to challenge wider assumptions. This dynamic of being “doubled, away, asunder” (Leder, 1990: 89) may not always be a comfortable or comforting experience as Andrew recounts.

My formative years involved socialisation into what Ian Wellard (2009) calls “expected sporting masculinities.” I rigorously trained my body to achieve predictable performances. I was expected to ignore, mask and hide physical and emotional pain. Such experiences were made invisible, untellable and subjected to a narrative silence. In many ways I epitomised then, and still do, the *disciplined* body that defines itself primarily in actions of self-regimentation and experiences its greatest crisis in loss of control (Frank, 2013). As a disciplined body, my response to any bodily interruption, defined as a loss of control, remains framed by the *restitution* narrative which is underpinned by faith in medical cure (Frank, 2013). In my case, the narrative would go something like this: “Yesterday I was healthy and performing well, today I’m injured and cannot perform, but tomorrow I’ll be healthy and performing well again”. This narrative leads me to attempt to reassert bodily predictability through therapeutic regimes that have involved physicians, physiotherapists, osteopaths, acupuncturists and mental health professionals. Significantly, the disciplined body and the restitution narrative leave little space for the development of any form of self-compassion that, according to Kristin Neff (2020: unpaginated) entails being “warm and understanding toward ourselves when we suffer, fail, or feel inadequate, rather than ignoring our pain or flagellating ourselves with self-criticism We cannot ignore our pain and feel compassion for it at the same time”.

Thus, when the symptoms of PMR first began to visit me, when my shoulders and hips began to really ache in the morning, I put it down to some new exercises I had begun in my regular gym session. So, in keeping with the disciplined body, I changed my exercise regime to work around my “injury” in the hope that it would go away. I also visited my GP who agreed that I have probably strained some muscles due to weight training and prescribed a strong pain killer and muscle relaxant. These did not work. I kept going to the gym and working my body confident that if only I got the regime right, the worsening pain would subside. Ironically, at the gym where I continued to train up until my diagnosis, the weight loss brought on by PMR was applauded because it gave me a more “cut” and lean look. However, the pain and immobility did not subside. The next therapeutic regime I pursued was provided by a physiotherapist who massaged the painful areas and gave me a programme of stretching exercises to increase my joint mobility. Again, no improvement. Still, I held fast to the restitution narrative that my body could and would be repaired. This was the same narrative that I encountered some years earlier among men who had become disabled following an SCI (Sparkes and Smith, 2002; 2003; 2005; 2008) and later with a young athlete diagnosed with terminal cancer (Sparkes, Pérez-Samaniego and Smith, 2011).

Reflecting on the stories told by these men, at a *cognitive* level I understood that in certain phases of their lives, the restitution narrative as a companion can act as a gift by allowing them to hold their own own in difficult and stressful circumstances (Frank, 2010; Smith and Sparkes, 2004; 2005, Sparkes and Smith 2002; 2005; 2008). Equally, at a cognitive level, I knew that the same narrative as a companion in other phases of their lives can act as a danger and a narrative of “bad faith” (Craib, 2000) by keeping them in passive positions, inhibiting possible change, separating them from the authenticity of their lives, and preventing them from developing new and more compassionate body-self relationships over time. For this to happen, other narrative types (e.g. quest) that allow for different ways of living in and through their bodies needed to be accessed and acted upon. All this I knew from a distanced cognitive level. But then there was the *feeling* of the restitution narrative working up close in my flesh and guts which hampered my ability to recognise it as a dangerous companion in my own life, bid it farewell, and allow alternative narratives to become my companions in the future. For me, this struggle continues on a daily basis.

Overall then, our three contrasting experiences have highlighted that disability identity is not simple and, likewise, that simplistic identifications do not directly map on to research experiences in the way that the politics of disability research might sometimes suggest. For us a more nuanced politics of *dys*-identification have been helpful in working through the politics of our research and our relationship to ourselves, one another, our research participants and our work.

Concluding Reflections about “Us”, Disability Research and *Dys*-identification

Reflecting on our experiences as three differently identified researchers working, sometimes together and sometimes apart, in the field of disability studies we have drawn out three dilemmas for the politics and practices of disability research. These relate to: assumptions about identity and its implications for disability research, the experiential and political differences within categories of identity, and the problems of static binary positioning. We attempted to resolve these in a politics of *dys*-identification as an alternative to either normative identity politics or the wholesale dismissal of them.

Firstly, then, sharing a simplistically defined disability identity does not necessarily prefigure a shared politics, identification or experience. Nor does it guarantee either the politics, quality or outcome of the project. Secondly, it is important to pay attention to the differences between disabled people, in terms of how we are categorised and how we self-identify. Highlighting difference is key to recognising and respecting a diverse range of voices and experiences, as well as challenging problematic homogenous categorisations. Indeed, disabled people are often attuned to the significance of differences between us – and not just as Paul and Nasia illustrated (in Kay’s research, above), but also in terms of categories of privilege such as class, sexuality, gender and “race” which break up rather than unify disability identities. Fractures in identification such as these may position Kay as much more politically at odds with research participants who are elite disabled athletes than James, despite her being a wheelchair-user and him identifying as able-bodied.

Thirdly, simplistic identity politics reinforce binaries of able-bodied and disabled and risk shoring up the essentialist norms which the medical model emerges from and reproduces. At the same time, the problems of identity do not detract from the need for a position around which to establish a collective politics. Political solidarity is integral to the ethos and practice of disability studies research and activism, as well as movements for change more

broadly. For us, a politics of *dys*-identification enables us to avoid the traps of simplistic and essentialist identity politics while maintaining a clear political rallying point for our work.

Overall, our analysis of *dys*-identification has attempted to shift some of the conventional structures and assumptions within disability research. Rather than legitimacy being affiliated to particular body types/capacities, legitimacy is earned/evidenced through non-disabling practices and identifications. These practices and identifications challenge us all, regardless of our bodily, sensory or “mental” configurations and require us all to develop collective politics and practices which challenge the disabling world and engender social change. Overall then, the experiences, identities and politics we have explored in this paper have led to a new politicised relation to ourselves, one another and disability research. We have found this to be both politically salient and productively fruitful, and we hope it will generate further exploration and discussion.

Notes

¹ Some researchers in disability studies have challenged this framework for example on the basis that disability researchers should also be able to critique the disability movement rather than solely being accountable to it (Shakespeare, 1996).

² I should note, however, that many of these things have only become possible during my adulthood because of cultural and legislative changes in the UK (e.g. the 1995 Disability Discrimination Act and the 2010 Equality Act) which, while far from perfect, have improved accessibility and rights disabled people.

³ Workplace and welfare assessments seem to be the only places where a wheelchair does not symbolise being “genuinely disabled” or guarantee entitlement to adjustments and/or benefits and services.

⁴ I, Andrew, still live with PMR five years on and had a recent flare-up that necessitated me going back on high doses of prednisolone.

⁵ Leder (1990) inadequately acknowledges that disability and femininity undermine the possibility of bodily unconsciousness because they are structured in ways which draw constant attention to the body as, indeed, does racialisation.

⁶ Asking how people prefer to be greeted is good practice for supporting diversity in intercultural as well as disability contexts.

⁷ It is important to point out that it is not just able-bodied people who make such errors I, Kay, have also made social blunders in encounters with people who have different disabilities to me.

⁸ Names used are either chosen by the participants or given by me where participants did not express a preference.

⁹ This is not to suggest that disabled people who cycle bicycles do not face barriers, they certainly do, but they are different to those faced by people who use non-standard cycles such as recumbents trikes and handcycles (Inckle, 2019; 2020).

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