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MAD STUDIES AND DISABILITY STUDIES

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Introduction

Mad Studies has developed from within, alongside and, at times, in dispute with Disability Studies. Disability Studies, although still relatively new as an academic discipline, is older and more developed in terms of scope, size and global reach. As such, it has accrued some of the benefits of a more established position in the academy and in policy and practice arenas, while Mad Studies is at a much more formative and potentially precarious stage in its evolution, albeit with deep roots in critical approaches to mental distress. Both fields are part of wider political projects, grounded in the communities from which they emerged, that seek to resist oppressive forms of knowledge and practice through the creation of new forms of knowledge embedded in lived experience and committed to creating and promoting inclusive and enabling practices.

People who experience mental distress and their perspectives have been present within Disability Studies and the disabled people's movement since their formation, although they have often been overlooked or silent (Plumb, 1994). There have been deliberate attempts to broaden the focus of Disability Studies from its initial concern with the experiences of those with physical impairments and ‘public’ and environmental barriers, to better include all disabled people and their experiences. Survivors and their allies have made significant contributions to the field, helping to expand the focus of the social model of disability to better incorporate their perspectives, especially in relation to psycho-emotional disablism (Reeve, 2015), participatory and inclusive research (Beresford and Wallcraft, 1997; Beresford and Carr, 2018) and practices of dissent (Plumb, 1994) and resistance (Hunt, 2019).

Peter Beresford (2000; 2004; 2012) has made a particular contribution to promoting a positive, respectful and purposeful dialogue about the relationship between Disability Studies and psychiatric system survivors and madness which pre-dates the emergence of Mad Studies as a distinct project ‘devoted to the critique and transcendence of psy-centred ways of thinking, behaving, relating and being’ (LeFrancois et al, 2013:13). Thus, Mad Studies is both a continuation and a fresh intervention in the tradition of critical approaches to mental health. It maintains a sharp focus on experiential knowledge and brings to the fore a reconceptualization of mental distress as ‘madness’ as ‘a reference to political categories of critique and exclusion’ (Spandler and Poursanidou, 2019:1).
Perhaps most importantly for Disability Studies the project of forming the field of Mad Studies as an in/discipline (Ingram, 2016) provides an opportunity revisit its core operating tenets. Ingram’s starting point in crafting Mad Studies (which he distinguishes from earlier work he describes as mad studies) was to consider the limitations of Disability Studies ‘as a space within which to do research focusing on madness and Mad people’ (2016:11). For him, thinking about madness was constrained by the ‘overarching, or governing, concept of “disability”’ which raises questions for Disability Studies itself that I will return to. The indiscipline of Mad Studies, echoes discussions from the formative days of Disability Studies, by raising questions about whether it is a ‘positive development if Mad Studies were to become an established academic discipline in universities’ as well as outside the academy (Ingram, 2016:13). These are debates that have remained live and at times fractious within Disability Studies when considering the place and role of non-disabled people, the in/formal relationship between Disability Studies and the disabled people’s movement and the extent to which Disability Studies realises its promise to effect transformation in understandings of disability and in naming and eradicating disablism.

Disability Studies

Disability Studies emerged in the 1980s in response to, and in dialogue with, the development of the disabled people’s movement in Northern Europe and America. This relationship with the disabled people’s movement is a defining characteristic of Disability Studies. It signifies a distinction between academic practices that start from the experiences of disabled people, seeing them as creators (and contesters) of knowledge than where they are the passive subjects of professional concern. Initially located in sociology, social policy and education, it has permeated the social sciences, humanities, health and professional education as well as other fields like design and engineering and become a global field of academic inquiry (Watson et al, 2012). While Disability Studies remains a broad church, inclusive of a wide range of disciplinary perspectives and areas of concern, what distinguishes Disability Studies from research and other scholarship ‘on’ disability is its foundation in the transformational work of the Union of the Physically Impaired Against Segregation (UPIAS). In their groundbreaking *Fundamental Principles of Disability* (1976) UPIAS rejected traditional notions that the disadvantage experienced by disabled people was the natural and inevitable result of their impairments arguing instead that it is society that disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society.

Thus, disablement is the outcome of a range of structural, social, cultural and political forces which are disabling, rather than the inevitable consequence of individual impairment. Sociologist Michael Oliver built on this analysis to articulate a social model of disability as a practical tool to help the social work students he was teaching understand the role of disablism economic, environmental and attitudinal barriers experienced by people with impairments (Oliver 1996). For Oliver (2004), the model was to be a ‘hammer’ to challenge the dominance of individual model understandings of disability (which views disability as a personal tragedy caused by impairment) and to identify and break down the barriers experienced by disabled people. As such, it has been extremely effectively wielded by the disabled people’s movement, as the basis for a collective political identity and to effect legal, policy and societal change.

As the disabled people’s movement and Disability Studies have grown in size and scope, so too has the social model and linked theoretical work evolved and expanded in response
to a range of developments and concerns. A number of these have particular relevance and implications for the place of mental distress and psychiatric system survivors in Disability Studies. An underpinning question or consideration is whether Disability Studies should seek to be more inclusive of the experiences and perspectives of survivors, and at the same time, what should perhaps remain outside of the scope (although certainly not of the interest) of Disability Studies and be the concern of Mad Studies.

The place and continued significance of the social model of disability remains an ongoing debate at the heart of Disability Studies with strong defences of its continued relevance and fundamental nature (Barnes, 2012) while others view it as one element of a ‘matrix of theories, pedagogies and practices’ (Garland-Thomson 2002 in Goodley, 2017:11) and suggest Disability Studies is now in a ‘post-social model’ era (Goodley, 2017:11). These debates have raised questions about the (continuing) adequacy or contribution of the social model of disability to Disability Studies and what is gained and lost by its continued centrality? (Watson and Vehmas, 2020). A linked debate is concerned with whether questions about madness and the experiences of mad people can adequately be considered or explained solely from a social model of disability perspective and, if so, how does the social model need to further develop to become more inclusive of these experiences?

If not, the alternatives are specific models of mental distress or madness that may or may not align themselves with Disability Studies. For my part, I favour a middle way that sees Disability Studies as a practice that is ‘in the wake of the social model’ which necessitates a ‘strong imperative to hold on to, return to and revisit its central texts and tenets’ (Morgan, 2018:13) as well as exploring and engaging with new concepts and approaches. Beckett and Campbell (2015) make a helpful distinction between the social model (lower case) which refers to UPIAS’ (1976) original work and Oliver’s (1990, 2004) formal articulation of the Social Model (capitalised), a more fruitful way of exploring these ideas than the somewhat sterile debate that has crystallised around what is criticised by many as dogmatic Social Model. In this spirit I suggest it is probably impossible for the development of Mad Studies to be other than in the wake of the social model and Disability Studies. Thus, the focus should be on what can be gained, learned and shared by those of us in this wake, whether our primary focus is on disability, madness or the space(s) in between.

Disability, impairment and madness

That impairment has ‘a unique, ubiquitous, and constantly troublesome position within disability studies’ (Sherry, 2016:729) cannot be understated. The simplicity of the distinction between impairment and disability delineated by UPIAS is one of the most powerful elements of the social model. It is easy to grasp, resonates with the experiences of disabled people and provides the liberatory message that as Liz Crow put it ‘gave me an understanding of my life, shared with thousands, even millions, of other people around the world …[that] It wasn’t my body that was responsible for all of my difficulties’ (1996:55). This creates a disability identity constituted through three components: the presence of impairment, the experience of disablism and self-identification as a disabled person (Oliver, 1996). This collective politicised disability identity has been a great strength of the disabled people’s movement, however, there are a number of issues in relation to the place of impairment and identification as a disabled person that are pertinent to this discussion.

An early criticism was that the movement and Disability Studies were based on the experiences of a particular group of disabled people, the ‘physically impaired’ named in UPIAS and thus failed to adequately include or address the experiences of those with different impairments,
especially people with learning disabilities and survivors, and the intersection with other forms of diversity like gender, race, sexuality and class (Oliver, 2004). I will return to this criticism in relation to mental distress and madness in the next section.

A second, and more enduring area of debate has been about the role of impairment. For many the distinction between impairment and disability appeared to signal a silencing of the experience of impairment, creating a significant gap in Disability Studies’ ability to engage with the totality of disabled people’s lived experience. Impairments are embodied, they have ‘effects’ (Thomas, 1999) which can be restrictive, painful and unpleasant. The experience of impairment is not neutral, it is mediated through social relations and structures that frequently don’t prioritise or value this experience with the result impairment effects and consequences can be exacerbated or prolonged.

There have been sustained, and successful, calls for a greater empirical and theoretical work within Disability Studies, not least from some who locate themselves centrally in the social model tradition like Paul Abberley (1987) and Carol Thomas (1999). Indeed Oliver (1990) called for a sociology of impairment to be developed alongside and in dialogue with a sociology of disability. A useful example of this work came from empirical work with people living with Motor Neurone Disease (also known as ALS), a degenerative condition with very limited treatment options and generally a short prognosis after diagnosis. Ferrie and Watson (2015) highlighted the emotional trauma and uncertainty generated by living with the condition and anticipating its progress. They identified the ways in which people living with MND experienced impairment effects in relation to personal relationships and in private spaces. Thus, these impairment effects also caused psycho-emotional disabilism, in terms of ‘barriers to being’, as Thomas (2007) puts it. This has the potential to resonate with the experience of some with mental distress where the impairment effects of their condition may be a barrier to creating and maintaining personal relationships.

For others, the conception of impairment as ‘lacking part or all of a limb, or having a defective limb, organ or mechanism of the body’ (UPIAS, 1976:14) was problematic because impairment remains a deficit or deviation from the norm. As Goodley suggests the word impairment ‘symbolises social death, inertia, lack, deficit and tragedy’ (2017:35). It is hardly surprising then that some disabled people reject the notion (and particularly the phrasing) of impairment. This has sometimes been based on a shared label of a particular impairment or condition. For example, Deaf people viewing themselves as a cultural or linguistic minority who are oppressed on that basis rather than in response to bodily deficit in relation to hearing norms (Scott-Hill, 2003). Similarly, some reject the notion of impairment because their experience of it is not as ‘impairing’ or restrictive of activity (particularly in inclusive contexts).

For others, it is the negativity of the phrasing and its failure to capture the diversity of the experience of impairment, which for some has benefits or is to be celebrated. For both reasons, impairment has been considered problematic in relation to madness. Many reject the notion of ‘mental impairment’ or the pathologisation of mental distress and highlight the difficulty of navigating a disability identity that requires professional classification and recognition of an impairment label for example as the basis for welfare benefits or to access treatment or other forms of support.

An interesting example that melds impairment and disability identities comes from discussions amongst people who identify as having ‘psychosocial disabilities’ in Asia (Davar, 2015). At a Trans-Asia Initiative event in 2013 in the light of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), there was recognition of an ‘identity crises’. ‘Mentally ill patient’ was a medicalised and legal(ly controlling) term, ‘user and survivor’ carried western baggage in a context where for many a lack of services meant ‘there was no
question of ‘using’ or ‘surviving’ a service’ although it was the preferred term for some, while others found ‘disability’ useful in emphasising discrimination (225). As Davar suggests there remained questions about how, and perhaps more importantly, whether these differences could or should be reconciled. She argues that the newly formed identity of being ‘psychosocially disabled’, as framed in the UNCRPD ‘comes with the promise of human rights and empowerment’ has greater potential particularly for greater inclusion in the disabled people’s movement and enabling those with this ‘emerging disability identity’ to organise collectively.

A helpful concept that has been developed in Deaf Studies and that could usefully be deployed more widely in relation to disability, is that of ‘deaf gain’ where the focus is on what is gained from being Deaf by the individual, the Deaf community and society more broadly (Bauman and Murray, 2014). Deaf gain is ‘a form of human diversity capable of making vital contributions to the greater good of society … without recourse to “normalization”’ (Bauman and Murray, 2010:210). A simple example is teaching babies sign language to enable greater communication before spoken language is acquired. By extension this approach can identify what is lost to society by having a narrow definition of what is normal or deficient (Bauman and Murray, 2010). There are parallels here with the affirmation model of disability (Swain and French, 2000) which builds on the social model to present a non-tragic view of impairment and disability (as a direct challenge to personal tragedy theory which Oliver (1990) describes as the grand theory underpinning traditional individual and medicalised understandings of disability). The model enables disabled people to assert positive identities of disability and impairment and as such is ‘an assertion of the value and validity of life as a person with impairment’ (Swain and French, 2000:578).

There has been some resistance or caution to this approach within Disability Studies, as there has been to impairment-specific organisations or research. As Crow suggests the ‘silence’ on impairment in early Disability Studies work was often motivated by a concern that discussing impairment might bring an individualised and medicalised focus back and therefore ‘impairment is safer not mentioned at all’ (1996:58). Reflecting on 30 years of the social model, Mike Oliver (2013:2026) argued that ‘emphasising impairment and difference was a strategy that was impotent in protecting disabled people’ and insufficient in these neoliberal austere times when many of the gains won by disabled people are being eroded.

What is clear is that Disability and Mad Studies will both continue to grapple with these tensions and the inherently ‘troublesomeness’ of impairment: its biological yet socially mediated nature, that it can be (sometimes simultaneously) a positive or a negative experience, and that it can be appropriate to prevent the creation of impairment while also accepting and embracing impairment in all its human diversity. Here there is opportunity for dialogue and collective learning that can enhance both fields.

Social models of disability and madness

There has been such protracted debate about the place and continued relevance of the social model of disability in Disability Studies that Mike Oliver demanded that ‘the talking has to stop’ (2013:1026). Despite this there is no doubt that the conceptual shift the model demands – from an individual personal tragedy to the collective experience of oppression – remains the fundament of Disability Studies. It is a threshold concept (Meyer and Land, 2003) that is, once understood, is transformative and irreversible (Morgan, 2012). As such it is impossible for Disability Studies to be otherwise than in its wake (Morgan, 2018), whether writers seek to extend or break with it. In either circumstance their thinking and practicing of Disability Studies is inevitably influenced. The same is true for social models of mental distress.
or madness, whether writers choose to locate themselves in Disability Studies or out with its scope/boundaries, the social model of disability remains both a starting and inevitable reference point for these models.

It is useful to remind ourselves why, given the seemingly endless debate about the relevance of the social model, models matter. Why not simply consign the model (and models modelled on it) to history as a useful starting point for a new social movement and academic discipline but now a relic to which homage may be due but whose relevance has passed? I contend models continue to have useful work to do in disciplines that seek to transform understandings and effect social change. As Finkelstein asserts

A good model can enable us to see something which we do not understand because in the model it can be seen from different viewpoints … that can trigger insights that we might not otherwise develop’ (2001:3).

Indeed, Finkelstein (2001) developed a number of models to describe different processes of disablement. Like Oliver, he saw such models as a helpful first stage in identifying and challenging dominant, seemingly common sense, ways of explaining and understanding social processes and relationships. Their potential to effect change in lay and activist contexts cannot be understated. While it is necessary for them to be underpinned by more theoretical and conceptual work, their transformatory nature and utility as ‘a hammer’ (Oliver, 2004) is essential for political movements agitating for change.

At the heart of both Disability and Mad Studies is a responsibility to hear the concerns of those with lived experience as well as producing knowledge that is useful in challenging the discrimination and oppression they endure and promoting their rights and aspirations. As praxis disciplines which are defined by their commitment to practical action through and alongside more theoretical thinking, our work needs to speak to and be accessible to a variety of audiences. Therefore, Disability and Mad Studies must utilise concepts, approaches and ideas that can be readily understood and applied by ‘lay’ people as well as being robust enough for academic debate and defence.

If the purpose and benefits of such models is accepted as such, then the first question here is whether the social model of disability is or can be sufficiently expansive to include the experience of those who experience mental distress and/or identify as mad. While the second is whether a social model of distress or madness is constituted within the auspices of the social model of disability as an extension that builds on social model foundations in a similar way to the affirmation model or whether it should be articulated as a separate and distinct model.

Building social model insights and concerns, two linked reports (Beresford et al, 2010; Beresford et al, 2016) highlighted a reluctance amongst survivors to identify as disabled or find the social model of disability helpful as well a number of recommendations for action in response to this (Beresford et al, 2010). These included encouraging Disability Studies writers exploring how the model could be more accessible to and inclusive of survivors, for survivors themselves to spend time considering how this could take place and for discussions between disabled people and survivors to enable learning about and with each other. The second report (Beresford et al, 2016) describes the findings of this work, which took place as ‘madness’ was becoming a reclaimed and organising concept within parts of the survivor movement. They found that ‘madness’ like the social model of disability received a mixed reception amongst ‘lay’ survivors. The report concluded that survivors valued social models (particularly as a rejection of medical models) but found the social model of disability too narrow in focus to fully incorporate their experiences. Similarly, madness and Mad Studies was viewed with some hesitancy.
Therefore, the answer to the questions posed above, remain in flux, and perhaps appropriately so. Models of disability, distress and madness must be accessible to those whose experiences they seek to represent. They inevitably create ‘troublesome knowledge’ that unsettles, which for some is transformative while at the same time remaining alien to the experiences and explanations of others (Meyer and Land, 2003 in Morgan, 2012). In this context, I disagree with Oliver, the talking between disabled people and survivors about the social model must not stop but be actively encouraged and supported and these discussions must inform academic thinking even if this is ‘troublesome’ for us. Moreover, both disciplines must remain vigilant in acknowledging the dominance of privileged perspectives and knowledge within as well as without. It is vital models and theoretical thinking are accessible, and learn from disabled and mad people globally, with particular recognition of the need to listen – and hear – indigenous and other marginalised voices, especially from the global south.

Doing Disability and Mad Studies: enabling and inclusive practices

As well as being fields of study Disability and Mad Studies are also practices or ways of being in the world, praxis disciplines (as I describe them earlier) that demand the practical utility of the knowledge we produce as well as practical application and action. We cannot interrogate ableism and disablism without a continuing reflexive examination of the ways in which we ‘do’ Disability and Mad Studies. As Beresford and Russo put it ‘the ‘how’ of Mad Studies is as important as its whys and whats’ (2016:273). That is, how we seek to teach, to research, to collaborate with and to serve disabled and mad people, colleagues, allies, activists, students and practitioners is as significant as the intellectual project underpinning both fields.

These were concerns that were more to the fore in the earlier days of Disability Studies, for example, debates in Disability & Society about the place of non-disabled people (Drake, 1997; Branfield, 1998; Oliver and Barnes, 1997) or on disability research more generally (Barnes and Mercer, 1997). Does this suggest that this a necessary stage or process in the formation of a newer field, that it is through this thrashing out of a set of values, etiquette and practices that a field is formed? Certainly, this appears to be the case in fields of study which are linked to identity and shared experiences of oppression and marginalisation. Developing these practices are a form of resistance against the traditional exclusions in established fields and opportunities for opening up more inclusive and attentive space for discussion. Disability Studies has rehearsed, although perhaps not resolved, many of the issues Mad Studies is grappling with. The questions raised by Spandler and Poursanidou in their recent article ‘Who is included in the Mad Studies project?’ (2019) echo earlier discussions in Disability Studies and benefit repeating. They suggest a necessary stage in any new project is establishing its boundaries and how permeable or malleable they should be asking ‘who is inside and outside, included and excluded’ (2019:1) Spandler and Poursanidou acknowledge there are inherent tensions in this questioning but that this is a necessity because it is in these borderlands and liminal spaces (Meyer and Land, 2003) that ‘new and important areas of inquiry and critique’ are opened up with the potential for the creation of ‘alternative counter–cultures of critical inquiry, support and solidarity’ (Spandler and Poursanidou, 2019:15).

However, as a field becomes more established and coalesces around particular values and practices, these values and practices can be taken for granted or assumed to remain relevant and inclusive. Recent interventions, frequently from early career academics, have questioned the accessibility of the academy for disabled scholars (Brown and Leigh, 2018), the inclusive nature of our practices like conferences and other events and of our discipline and debates about and
for groups more recently brought under the umbrella term disability, for example those living with chronic illness (Scambler, 2012) or trans (disabled) people (Slater and Liddiard, 2018).

What can Disability Studies and Mad Studies learn from this and from each other? This, I believe, is one of the most helpful parts of the relationship, as the disciplines evolve at different paces and are engaging with different and difficult thorny issues or troublesome knowledge at different points, from which much can be learned and shared. They also draw on different literatures, traditions and experiences which provides opportunities for connection, provocation and challenge. This, of course, assumes that the disciplines are listening and actively engaging with each other, this happens when we contribute to each other’s spaces but also create spaces for this to happen.

The recent dialogue between Mad Studies and neurodiversity is an example. It was ‘framed within the field of disability studies’ (McWade et al, 2015) at an event hosted at the Centre for Disability Research at Lancaster University, deliberately brought together participants from all three groups and from a variety of positions, academics, more established and early career, activists and those with lived experience (McWade and Beresford, 2015). The event led to a current issues piece in the journal *Disability & Society* written by three academics who would locate themselves within disability studies but also in Mad Studies (McWade and Beresford) and neurodiversity/critical autism studies (Milton). They build on Graby’s earlier (2015) work that suggested neurodiversity ‘bridge conceptual gaps between the disabled people’s and survivor movements’ (in McWade et al, 2015:306) and end with a concern about the wider current context of these discussions acknowledging that many activist concepts, from both Disability and Mad Studies, have been ‘co-opted, appropriated and politically neutralised’ (McWade et al, 2015:307). They end with the rallying ‘let us build upon the rich histories of activism and bring our shared experiences of oppression and marginalisation together’ (McWade et al, 2015:308).

**Concluding thoughts: more in common**

As I suggested in the section on models, one of the most significant challenges for Disability Studies, and perhaps even more so for the disabled people’s movement has been the adoption and co-option of its ideas and languages by politicians, policy makers and providers. The pre-eminence of the model led Oliver, to contend ‘it is tempting to suggest that we are all social modellists now!’ (2004:18). While initially welcomed as an indication of the impact and power of the approach, the formal adoption of the social model of disability by professionals, service providers and policy makers has resulted in a set of unforeseen difficulties (Roulstone and Morgan, 2009). As Oliver and Barnes foresaw ‘the assimilation of disability into mainstream political agendas will undermine the more radical aims and political struggles by disabled people and their organisations for social justice’ (2012:169). Indeed, as Sheldon had suggested earlier ‘perhaps the disabled people’s movement is floundering on the shores of its own success’ (2006:3). The implementation of anti-discrimination legislation like the Disability Discrimination Act 2005 (replaced by the Equality Act 2010) in the UK and the increased visibility of disabled people as the result of reforms to care and support can give the impression disabled people’s rights have been won and are assured.

The ‘common sense’ understanding of disability is starting to turn full circle, if disability is created by barriers and those barriers are removed, then what remains can again by explained by individualising the problem. There are, of course, many counters to this simplified neo-liberal reconceptualising of disability. For certain, many (although very definitely not all) of the most visible environmental barriers have been removed and there are reams of official
policies concerned with preventing discrimination and promoting independent living and human rights. However, this masks a number of enduring problems. Barriers are increasing those to ‘being’ rather than to ‘doing’, while the psycho-emotional impact of living in an increasingly hostile environment becomes intensified when the problem is returned to one of individual agency and resilience (Ryan, 2019). There is also insufficient recognition of the legacy of the cumulative impact of historic barriers and attitudes that remain engrained in public attitudes and practices. Identifying and challenging this usurpation while continuing to amplify the voices of disabled people and (re)generate progressive knowledge has become the moral imperative for Disability Studies.

Similar challenges face the nascent field of Mad Studies with key writers Beresford and Russo asking whether Mad Studies can be ‘protected from being undermined and subverted’ in the ways the key ideas of Disability Studies and earlier formations of critical approaches to mental health have been (2016:271). However, there is considerable scope for solidarity and collegiately here particularly if both fields coalesce around Plumb’s (1994) assertion that what unites them is a ‘non-conformist’ approach. The development of knowledges and practices that celebrate the non-conformism of the concepts of disability and madness retain great strength in challenging deficit thinking and provide a way to move on from the cul-de-sac of debate about impairment and sits more comfortably alongside the activism and identity of pride. Rather than focusing on differences and areas of discomfort (although they should continue to be areas of discussion and debate) we should take our lead from McWade, Milton and Beresford who argue we should seek dialogic alliances that move beyond the limitations of identity politics where ‘the aim is to stop thinking about how we are the same and begin to work with our differences collectively’ (2015:307). It is in this spirit that the vital and vibrant relationship between Disability Studies and Mad Studies can endure, respecting our differences and diversity, but remaining committed to that central claim ‘there must be nothing about us without us’.

References


Mad Studies and disability studies


Situating Mad Studies


