Hannah Morgan, BA (Hons), MA, PG Cert

In the wake of the social model:

Engaging with policy, theory and practice

PhD in Sociology by Published Work

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Dedication

This thesis is dedicated to my wonderful amazing Mum, Carrie Morgan (1947-2016), committed friend, citizen, social worker and activist (categories that were inseparable for her). Her unwavering commitment to promoting social justice in her professional and personal life has been the bedrock of my own. Her confidence and great pride in me continues to be a source of inspiration and strength. It is the source of sorrowful regret she isn't here to see the finished work, although she never doubted its completion and was a constant encouragement in the face of my own self-doubt. There are few, supervisors and examiners excepted, who read a thesis in its entirety, but I know my Mum would have (as she did everything I published or sent for her comments). She always equated her relative lack of higher education qualifications with a limitation in her ability rather than of opportunity, but she had a careful, rigorous and passionate engagement with ideas and their practical application that few in academia can rival. She leaves a considerable legacy of which this thesis is a very small part.

Abstract

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The 13 publications included in this thesis constitute a body of work situated within the interdisciplinary field of disability studies. As such, they are formed in the wake of the social model of disability, a radical, field-forming idea that dominates the disabled people's movement, disability policy and practice and disability studies in the UK. The works are clustered around two interlinked areas of concern: how disability studies is practiced and influences professional and welfare practices, and how disability policy formation emerges, shapes and impacts upon the lives and wellbeing of disabled people. The unifying argument is that disability scholarship should be aligned to the communities it produces knowledge for and about. It argues that disability studies and the practices which emerge from it should remain rooted in the social model and in the disabled people's movement.

Author's Declaration

I declare that this is my own work; it has not been submitted in substantially the same form for the award of a higher degree elsewhere.

Hannah Morgan

February 2018

Acknowledgements

Publications

1. Disability Studies Practices

Morgan, H. & Harris, J. (2005) Strategies for involving service users in outcomes focused research in L. Lowes & I. Hulat (eds) *Working Together: Service Users' Involvement in Health and Social Care Research.* London: Routledge pp. 163-170

Morgan, H. and Roulstone, A. (2012) 'Editorial' *Social Work Education* 31:2. Pp 137-141

Morgan, H. (2012) 'Threshold Concepts in Disability Studies: Troublesome knowledge and luminal spaces in social work education' *Social Work Education* 31:2. 215-226,

Morgan, H. [2014) Working with Disabled People in M. Webber (ed) *Applying Research Evidence in Social Work Practice* Palgrave Macmillan pp.182-196.

James, E. Morgan, H & Mitchell, R. (2017) 'Named social workers – better social work for learning disabled people?' *Disability & Society* 32 (10) pp. 1650-1655

2. Disability Policy Formation

Morgan, H. & Stalford, H. (2005) Disabled People and the European Union: Equal Citizens? In C. Barnes and G. Mercer (eds) *The Social Model of Disability: Europe and the Majority World.* Leeds: The Disability Press. pp 98-114

Morgan, H. (2005) Disabled people and employment: the potential impact of European Policy in A. Roulstone and C. Barnes (eds) *Working Futures? Disabled People and employment.* Bristol: The Policy Press pp259-272

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Morgan, H. (2013) User-led organisations: facilitating Independent Living' in J. Swain, S. French, C. Barnes & C. Thomas (eds) *Disabling Barriers – Enabling Environments* 3rd Edition. London: Sage. Pp. 206-213

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Supporting Document

Preface

'In the wake of its purposeful flow' (Sharpe, 2016)

The impact of the social model of disability on contemporary academic, policy, practice and popular thinking about disability and disabled people cannot be overstated. It has been transformational in the way in which it has named and challenged dominant conceptions of disability as impairment, deficit and inherently individual and tragic. The reconceptualization of disability as a form of social oppression experienced on top of impairment (UPIAS 1974, 1975) and as the basis for collective political action (Oliver 1990) has been revolutionary in its impact.

Reading *In the Wake: On Blackness and Being* by Christina Sharpe (2016)[1] while I was compiling this thesis provided a helpful framework to explore my academic and activist engagement with the social model. I have found Sharpe's use of multiple understandings of the wake and particularly of undertaking *wake work* valuable. For Sharpe the *entirety* of the meanings of a wake as:

keeping watch with the dead, the path of a ship, a consequence of something in the line of flight and/or sight, awakening and consciousness (18)

enable a form of "wake work" as an *analytic* in academic practice that 'avails us particular ways of re/seeing, re/inhabiting, and re/imaging the world' (22). As such "being in the wake" is an ethical choice and engagement with a history, an evolving body of ideas and with imagined and as yet unimagined futures.

Being in the wake of the *purposeful flow* of the social model raises questions about what it means to be working in the wake and doing wake work in disability studies. This collection of publications reflects my

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[1] My thanks to my thesis mentor Imogen Tyler for recommending the book to me.

engagement with the social model of disability over almost twenty years as a researcher, educator, activist and in everyday encounters. It also provides an opportunity to consider how well the social model has weathered the storm. At a time when the model appears ubiquitous, almost hackneyed, there remains a strong imperative to hold on to, return to and revisit its central texts and radical tenets. To chart and to question the extent to which disabled people's lives have changed, to examine what progress there has been towards the claims of the disabled people's movement, particularly in terms of citizenship and independent living, and to consider the extent to which these gains are ephemeral or secure.

Introduction

This supporting document accompanies the submission of 13 journal articles and book chapters published between 2005-2017 for examination for the award of PhD by published work. All the publications fall within the interdisciplinary field of disability studies. I am a Senior Lecturer in Disability Studies based in the Department of Sociology, Lancaster University and Director of the Centre for Disability Research (CeDR). I have been working in Disability Studies since 2000, initially in research posts at the Centre for Disability Studies University of Leeds and the Social Policy Research Unit (SPRU), University of York. Since 2003 I have worked as a Lecturer at Lancaster University first in the Department of Applied Social Science and since 2013 in the Department of Sociology.

This body of work draws on a number of research projects and collaborations I have been privileged to be part of over the last 17 years since taking up my first academic post. This includes research projects funded by the National Lottery, Department of Health, British Academy, and local authorities and health trusts. There are a number of collaborations that have played an important role in the development of this body of work, notably the mentorship and encouragement of Professor Colin Barnes, research partnerships with Professor Alan Roulstone and Dr Karen Soldatic and more recently a research and practice partnership with Elaine James and Rob Mitchell at Bradford Council. As I will go on to discuss, working collaboratively and in partnership with user-led organisations is a central tenet of my practice of disability studies.

In this supporting document I provide a critical overview of my published research and the original contributions this body of work has made to the field of Disability Studies. I start by charting my journey into Disability Studies and provide an overview of the development of the discipline in the United Kingdom and what I consider to be its defining characteristics. I then summarise each of the publications submitted and outline their interrelationship, highlighting the key issues and themes that have

characterised my contribution to the field. My publications are grouped into two broad clusters *Disability Studies Practices* and *Disability Policy Formation*. Appendix 1 is a copy of my CV to give a fuller picture of the ways in which my academic practice, in the form of academic or disciplinary citizenship (Macfarlane 2007), has contributed to developing, nurturing and extending the field of disability studies.

Disability Studies in the UK

I came to disability studies after a first degree in Politics and Parliamentary Studies at the University of Leeds. Hearing about a sociology option module in disability studies from an exchange student in one of my final year politics classes in 1998 was the entry point for a transition to a disability studies community of practice that has captured my imagination, enthusiasm and commitment ever since. A knock on the door of Colin Barnes to ask about the MA in Disability Studies lead to his generous support and encouragement first to apply for ESRC funding for the programme, then as a masters student grappling with the shift from political science to a subject grounded in sociology and social policy and then as a research officer in my first academic post. While in many ways serendipitous, my interest in disability has deep roots in familial experience of impairment and disability and encountering the social model of disability was for me, as it is for many, a life-changing experience.

Disability Studies is a burgeoning area of global academic inquiry demonstrated by the expanding list of dedicated journals in the field (cf. *Disability & Society, Scandinavian Journal of Disability Research, Disability Studies Quarterly, Canadian Journal of Disability Studies, Alter, Disability & the Global South*). Disability Studies emerged in the early 1980s in response to development of the disabled people's movement in Northern Europe and America in the 1960s and 1970s, but it is no longer solely the preserve of the disciplinary and geographic areas where it originated. It has permeated the social sciences, humanities, health, and professional education as well as other fields while a review of the delegate lists at international conferences (including the bi-annual disability studies hosted

at Lancaster University) demonstrates its wide geographic reach. This proliferation is to be celebrated, although it can make it harder to define the parameters of disability studies. In this section I provide a brief overview of what, for me, characterises British disability studies.

Disability Studies in the UK has its roots in the disabled people's movement that emerged in the 1960s and 1970s and has a firm foundation in the work of the Union of the Physically Impaired Against Segregation (UPIAS) and its seminal policy statement (1974) and Fundamental Principles of Disability (1975). Their analysis challenged the prevailing view that the disadvantage experienced by disabled people was the direct result of their impairments by arguing that:

In our view, it is society which 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 (UPIAS, 1975 unpaged)

This idea, that it is society which is disabling, reframes disability as an outcome of structural and social forces, rather than a consequence of individual impairments. This *social model of disability* is the grounding idea of the disabled people's movement (Hasler, 1993). It was first articulated in depth by Mike Oliver while teaching social work students in the early 1980s. As Oliver made clear when he explained his translation of the ideas of UPIAS into the social model of disability:

There was no amazing new insight on my part dreamed up in some ivory tower but was really an attempt to enable me to make sense of the work for my social work students and other professionals whom I taught (1996:30).

The social model remains at the heart of the disabled people's movement and disability studies in the UK. Its pre-eminence lead to Oliver's contention that 'it is tempting to suggest that we are all social modellists now!' (2004:18). This apparent orthodoxy in thinking about disability somewhat belies the ongoing debate within disability

studies about the position and continued relevance of these foundational ideas. What it does capture is the almost ubiquitous commitment to a social model of disability in disability policy, the disability sector and professional practice. Debates about the meaning of the social model, and policies and practices which seek to realise the practical potential of the social model, have been a central focus of my work.

The social model has been the subject of much justified (and some spurious) critique since its inception. Oliver (2004) noted this in one of his final publications before his retirement where he acknowledged and sought to address these criticisms. These criticisms which have been the subject of considerable debate and some very helpful and considered work within disability studies, from Carol Thomas and Donna Reeve's work on psycho-emotional dimensions of disablism (Thomas 1999, Reeve 2004), by work which considers the accessibility of the social model for different groups of disabled people (see for example Chappell et al 2001 in relation to learning disabilities, Beresford 2000 on mental distress and Oldman 2000 on older people), to an expanding body of work on cultural representations of disability (cf. Riddell and Watson 2003, Ellcessor & KirkPatrick 2017) and research on different experiences of impairment and disability across history and in diverse geopolitical contexts (Stiker 2000, Burch & Rembis 2014, Hanes, Brown and Hansen 2017). Thus as Tom Shakespeare and Nick Watson conclude 'those who develop and refine the social model ensure its renewal and continuing relevance' (1997:299).

A somewhat futile debate has been played out over the question of whether the social model is adequate as a theory of disability. As Oliver maintained in *The Politics of Disablement* 'nothing less than a "social theory of disability"… 'located within the experience of disabled people themselves and their attempts, not only to define disability but also to construct a political movement amongst

themselves and to develop services commensurate with their own self-defined needs' (1990:11) is necessary to challenge the dominant medical and deterministic definitions of disability. Oliver calls the social model a hammer, a tool for political action . He argued that the model should 'contribute rather than be a substitute for the development of an adequate social theory of disability' (Oliver 1996: 42). Theory-making, he argued, is the purpose of disability studies, to explore, debate and develop understandings that are rooted in a rejection of the implied inherent link between impairment and disability. Following Oliver, I reject Barnes and Mercer's charge that disability theory is 'extravagant flights of fancy' (2003:2). Rather, I would argue that disability theory, and the diverse epistemologies of disability which the field has produced, create spaces for critical debate and reflection which are essential to disability activism. Indeed 'Finkelstein and the other founders of the British disabled people's movement who united in the Union of the Physically Impaired against Segregation (UPIAS) were clear that such theorising was a necessary pre-requisite for the more practical social model of disability and thereby significant social change' (Morgan 2013:411). As Dan Goodley and colleagues note disability theory provides 'a resource… to advance the cause of disabled people' (Goodley et al 2012 cited Morgan 2013a:412-3).

While the place of the social model within disability studies may remain contested its orthodoxy in disability policy, the disability sector and professional practice appears increasingly hegemonic in ways that are problematic for the disabled people's movement. The model's seeming simplicity makes it vulnerable to co-option as a form of 'common-sense' policy that mobilises largely unreflexive and unquestioning public support (Hall and O'Shea 2015). The problem with hegemonic –rather than critical and changing - understandings of the social model, has been a central theme in my research. Particularly in regard to how common-sense applications of the social model manifest in professional practice and the implications of this

for disabled people's organisations. These tensions between the theory, hegemony and practice of the social model of disability are a thread that runs through this submission, particularly in the second cluster of work.

Disability Studies Practices

As well as being a field of research, disability studies is also a practice or way of being in the world. A defining feature of disability studies is that we cannot interrogate ableism and disablism without a continuing reflexive examination of the way we 'do' disability studies. Thus this section is concerned with practices within disability studies, that is, how we seek to teach, to research and to collaborate with students, colleagues, disabled people, allies and activists. Following Lawthom's articulation of "communities of practice" within community psychology drawing on We 'a group of people who share a concern or a passion for something they do and learn how to do it better through regular interaction' (2011:162), I situate myself within an international disability studies community of practice where I have sought to contribute to discussions about how we 'do' disability studies with passion, authenticity and rigour.

This section introduces five publications concerned with the ways in which I have 'done' disability studies during my career to date. It raises questions about how research that locates itself within disability studies should be conducted or aspire to be constructed, the impact of research on disability from within and without the discipline and the place of disability studies in professional education and practice. As I commented in *Threshold Concepts in Disability Studies: Troublesome knowledge and liminal spaces* many disability studies 'foot soldiers now ply their trade in applied subjects' (2012:216) and for me this offers exciting opportunities to test out and apply the key concepts, ideas and approaches developed by the disabled people's movement and disability studies.

'Strategies for involving service users in outcomes focused research' a book chapter co-authored with Jennifer Harris (Morgan and Harris 2005) was my first formal publication, beyond research reports and book reviews. We were drawing on our work on the *Outcomes for Disabled Service Users* project which was one of four research streams of *the Department of Health Outcomes Programme, 2001-2005* at the Social Policy Research Unit

(SPRU), University of York. We were invited to produce the chapter for *Involving Service Users in Health and Social Care Research* edited by Lesley Lowes and Ian Hulatt (2005) after running a workshop with the same title (Morgan and Harris 2002b) at the Consumers in NHS Research Conference in 2002. 'Strategies for involving service users in outcomes focused research' 'details the attempts of the authors to develop meaningful involvement with service users in a project that researched the development and utility of an outcome focus in assessment and review work with disabled adults of working age' (163). As such it is an initial exploration of the practice of disability studies, here in relation to a research project commissioned by a government department.

Our discussion starts by outlining the challenges posed to researchers seeking to practice within the *emancipatory research paradigm* developed initially by Mike Oliver (1992). We quoted Colin Barnes to summarise this:

Simply put: 'Emancipatory research is about the systematic demystification of the structures and processes which create disability' (Barnes 1992:122 *cited* 163)

Emancipatory research has become the 'second clarion call' of disability studies (the social model being the first) (Watson 2012:95). There has, and continues to be, considerable debates within disability studies about the contribution research can and should make to identifying and challenging disablism and we referred to Stone and Priestley's 1996 article 'Parasites, pawns and partners: disability research and the role of the non-disabled researcher' which articulates the key principles of this approach:

- the adoption of a social model of disablement as the epistemological basis for research production
- the surrender of claims to objectivity through overt political commitment to the struggles of disabled people for self-emancipation
- the willingness only to undertake research where it will be of practical benefit to the self-empowerment of disabled people and/or the removal of disabling barriers

- the evolution of control over research production to ensure full accountability to disabled people and their organizations
- giving voice to the personal as political whilst endeavoring to collectivize the political commonality of individual experiences
- the willingness to adopt a plurality of methods for data collection and analysis in response to the changing needs of disabled people

<div align="right">(Stone and Priestley 1992: 706).</div>

The central and defining element of these principles is the recognition that disability is a political and collective issue and experience. This is non-negotiable, without this the other principles lose their power of transformation and contribution to change, for example research controlled by a disabled people's organisation that was not constituted within a social model understanding of disability would not be emancipatory. In the same way adopting a plurality of methods without the social model as the epistemological basis similarly fails to be emancipatory. Therefore, as I discussed in relation to disability studies more broadly in the introduction, adopting the social model of disability as an epistemological core demarcates disability studies research from other research concerned with disabled people.

The clear and concise nature of the six principles outlined by Stone and Priestley echo the apparent simplicity, and linked attraction, of the social model of disability. However, their inspirational nature can belie the complexity of mobilising their ethos and principles in practice, particularly in the marketised neo-liberal university. Stone and Priestley explore the difficulties they each encountered in their doctoral research highlighting a recurrent theme in disability studies, that of being open and reflexive about the challenges and constraints influencing research and wider partnership with disabled people and their organisations. Seeking to implement the principles of emancipatory research while maintaining, and being acknowledged as maintaining, academic rigour they conclude 'must ultimately be the disability researcher's obligation and contract' (715).

Thus 'the challenge for those of us undertaking disability research with a commitment to a social model of disability is how we seek to adhere to these principles within existing confines, not least the precarious nature of contract research careers and the dominance of funding institutions in the field' (Morgan and Harris 2005: 164). There are tensions when leaders in the field, such as Oliver, advocate only 'pure' emancipatory research or make the (unfair) claim that the researcher is the main recipient of the majority of academic research (Oliver, 1997). A key theme of this body of work is how to weave a way through these tensions and dilemmas with integrity.

'Strategies for involving service users in outcomes focused research' and the project *Outcomes for Disabled Service Users* on which it was based was part of a larger stream of work investigating the development of outcome based adult social care. Building on work undertaken predominantly with older people and carers[2] it was a three year study on social care working with disabled people of working age (then 18-65 years) with physical and sensory impairments conducted in partnership with a large local authority in the north Midlands.

The *Outcomes* programme was commissioned by the Department of Health which had, and continues to have, an explicit commitment to involving people who use services in research. However, there were not specific guidelines or standards issued by the Department but instead 'the extent of commitment is generally expressed in terms of the financial resources allocated, and these must be kept in modest bounds' (165). The rest of the chapter 'Strategies for involving service users in outcomes focused research' describes the various innovations and strategies deployed for involving service users. A significant element of our strategy was to involve disabled people and their organisations more generally rather than focusing solely on people who were current users of social care services. This was rooted in our understanding of disability as a collective as well as individual

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[2] Unpaid or informal carers not paid care workers.

experience of oppression and a recognition that many disabled people will be unable or unwilling to engage with statutory services.

A key element of this approach was to work with the local Coalition for Disabled People, one of the leading organisations of disabled people in the country, responsible for substantial innovation in support provision and with a specific focus on research. Their Research Manager was an instrumental and critical friend to the project and served as a member of the Project Advisory Group (PAG) alongside senior managers from the local authority, policy makers and academics. He and the Coalition also played a pivotal role in facilitating relationships with local disability groups and individual disabled people living in the county. We were also able to 'learn how to put [our] knowledge and skills at the disposal of disabled people' (Barnes 2014:39) by working with the Coalition to produce a joint research funding bid to the Social Care Institute for Excellence. However, the formal relationship with the Coalition was ended when they felt continued involvement with the project 'might be construed as support of the more general aims of the Social Services Department with which they were at odds' (166). The potential of appropriation and politicisation (against their interests) of disabled people's ideas and organisation (Morgan 2013b) was a significant concern for the Coalition, and one that has become increasingly realised in many areas of disability policy and practice (Roulstone and Morgan 2009).

We also worked in partnership with *Shaping Our Lives*, the national service user network, who had also produced work for the Department of Health on outcomes. We co-produced a 'Social Care Outcomes Seminar: Issues for Professionals and Service Users' event in London on 8th May 2002 (Morgan and Harris 2002b). The seminar brought together representatives of service user organisations, local authority social services staff and academics to share research findings, practice experience and provide a space for dialogue about how to build upon the co-production of the event to influence policy and practice. As Hazel Qureshi and Peter Beresford acknowledged in their forward, it was 'the fruit of a long collaboration

between a service user controlled organisation and a university research unit. It is a sign that such collaborations *can* work and can offer a helpful way forward for policy and practice development – when trust and shared understandings develop' (Morgan and Harris 2002b:1).

Commenting on the dominance of services to older people and carers in social care at the time, we noted that these areas were 'less politicized…and do not, as a rule, conform to the tenets of the social model of disability and are less likely to recognize its importance' (165). This was often also the case in organisations supporting disabled people. One of the most significant shifts in the period I have been working in disability studies is the extent to which the social model of disability has been incorporated – rhetorically at least - into disability practice and this is a key theme in this body of work.

What was particularly helpful about the local authority we were working with (and part of the rationale for developing the partnership with them) was that they had recently disaggregated their social care services for disabled people from those of older people, offering an opportunity to foreground issues such as access to employment and parenting. There are parallels here in social work education. Social work with children and families, and particularly child protection has dominated debates about the profession, pedagogy and practice. For example, the most recent range of reforms to social work and social work education, including the professional capabilities framework (PCF), emerged from the response to the death of Peter Connolly (Baby P) in 2007. Similarly the introduction of the 'elite' fast track graduate programmes Frontline (child protection) in 2013 and Think Ahead (mental health) in 2015 have a minimal, if any, focus on disability and ageing.

An innovation in user involvement that we trialled was the development of a 'virtual panel' with 'fluid but inclusive boundaries' (167). This was in part pragmatic, it is difficult to bring together disabled people, particularly those dependent on services, from across a large geographic area. This is a recurrent theme in my work where distance and access to transport

hampers disabled collectivities, for example for day service users (Roulstone and Morgan, 2009) or user-led and peer support organisation (Morgan 2014; Morgan 2017). However, it was in equal measure an attempt to resist a traditional 'service user panel' where users were brought together to be consulted, a practice common in service provision and research but frequently tokenistic, remaining secondary and subservient to the more prestigious project advisory group. The intention of the panel was to complement the involvement of the Coalition on the project advisory group and to enable participation by a wider range of disabled individuals and organisations. We rejected a traditional meeting structure with set agendas but rather sought to 'join groups already in existence where the membership were in control of the agenda and decision making processes, and could set the terms of their involvement' (167).

A second stand of the panel was to have flexibility in the medium of participation. We explored using email and post lists for sharing project documents. In the event these routes were not taken up to any great extent, a reflection on a preference for face-to-face contact and the ability to have a conversation between the research team and participants. This also allowed 'a greater element of reciprocity in the relationship' as we were able to share 'expert' knowledge, whether about the research locality, experiences of service provision or access to research and policy developments. Looking back the very basic email mailing list and preparation of audio cassettes with project material seems rudimentary in comparison to developing work on and in the disabled people's movement, particularly online activism (Morgan 2013b), but it is also part of a continuing tradition within disability studies. We might think, for example, of the central role of letter writing and circulation of duplexed newsletters of grass roots activism and communication initiated by Paul Hunt (1966; 1973)

We concluded by arguing that user involvement in research has to an extent become 'internalized by researchers' (169) and supported by the development of expertise around meaningful forms of engagement.

However, key challenges remain about how to adequately resource to enable meaningful engagement we highlight that there is rarely funding to work with user-led organisations to develop research bids, and there are costs to be born by researchers who seek to work in this way. In addition, there are frequently costs to be borne by researchers who seek to work in this way. There can be tensions about who appropriate (or conversely compromised) funders are and of the necessity to produce, and often prioritise, work in more traditional academic formats. It is also often simply more expensive to work in inclusive ways. For example, the Lancaster Disability Studies Conference (discussed in more detail towards the end of this section) attracts a much higher proportion of disabled delegate than other conferences, which have significant resource implications (as well of course bringing significant disability gain).

'Working with disabled people' (Morgan 2014) was an invited contribution to Martin Webber's edited collection *Applying Research Evidence in Social Work Practice*. This book, aimed at social work students and practitioners, provides a helpful critical discussion about the place of research and evidence in social work practice. *Applying Research Evidence in Social Work Practice* is structured into two sections. The first considers the key issues in applying research evidence in practice and the second, where my chapter is located, focuses on specific user groups. The specification for 'Working with disabled people' was to offer an overview of social work practice with disabled people. The standard format of these kinds of chapters is to offer a précis of the state of current research, followed by a case study which would illustrate how research evidence can be used to inform practice. However, from a disability studies perspective, simply providing an overview of current research evidence is problematic as it fails to acknowledge that much existing practice and research is based on or is the legacy of traditional understandings of disability. Therefore the starting point for 'Working with disabled people' was to ask more 'fundamental questions about how disability is understood, how this informs the production of research and, therefore, what the purpose of social work practice with disabled people is'(182).

'Working with disabled people' revisits some of the formative texts of disability studies that have had a profound effect on my own thinking about disability. These were texts I had first encountered as a Masters student and that have remained touchstones as I have developed my own disability studies practice. Situating this discussion about research evidence within the debates first espoused in the formative days of the movement and discipline clearly signals the continued relevance of these texts. For example, Paul Hunt's paper 'Settling Accounts with Parasite People' which was published posthumously in the first issue of *Disability Challenge* in 1981. *Disability Challenge* was the magazine of the Union of the Physically Impaired Against Segregation (UPIAS) with an open call for contributions from 'able and disabled people, whether Union members or not' (1981:7). What is significant is that it seeks to provide 'an important forum for clarifying matters amongst ourselves' (1981:7). Similarly, documents like the *Fundamental Principles of Disability* (1975) that set out the distinction between impairment and disability were the starting points for discussion and debate rather than a fixed, unreflexive and 'outdated' ideology that some have criticised it for being (c.f. Shakespeare and Watson 2001).

Hunt sets out a stringent critique of research undertaken by Eric Miller and Geraldine Gwynne that was published in 1972 as *A Life Apart: A Pilot Study of Residential Institutions for the Physically Handicapped and Young Chronically Sick*. The project came to symbolise the problematic and exploitative nature of disability research. It juxtaposes the analysis developed by the Union that 'Instead of physically impaired people having to adapt to an hostile environment ... the means now exist to create a physical and social environment that takes account of the needs of people with physical impairments' (37) with the positions taken by 'experts' 'blinkered by their vested interest in the continuation of the traditional segregating practices and institutions which disable us' (38). Hunt explains how he and the other residents felt 'conned' by the work and that the primary motivation for researchers like Miller and Gwynne was 'concerned above all with presenting themselves to the powers-that-be as indispensable in training "practitioners" to mange the problem of disabled people in

institutions' (39). The research relationship was thus one of exploitation. For Hunt the crux of the issue was that Miller and Gwynne were 'profoundly biased' but that this bias was hidden by the presentation of the research as scientific and, that the terms on which the research was based meant the focus was only on improving the institutions rather than asking more fundamental questions about what "the problem" of disability was—and why people ended up segregated in institutions in the first place.

'Working with disabled people' also provided an opportunity to revisit the challenges of user-led research. Working on the *Creating Independent Futures* project (2000-1) with Colin Barnes and Geof Mercer at the Centre for Disability Studies, University of Leeds, was an exciting opportunity to participate in user-led research. The project had been developed in collaboration with the National Centre for Independent Living (NCIL) and the British Council of Disabled People's Research Committee and its research unit based at the University of Leeds. This sort of research 'wears its heart on its sleeve' adopting an 'overtly political' approach which has lead to criticism that it is partisan and lacking in rigour (187). While this type of criticism can be countered particularly by the open and transparent nature of user-led research a second and perhaps more insidious challenge to emancipatory research is that it is a form of elite activity. For example, the binarism that accompanies claims that research is either emancipatory or it is not (and thus oppressive). Many forms of research will be inhibited from fully adopting the principles outlined by Stone and Priestley (see above) and negotiating the multiple demands of research design and practice is particularly an issue for early career staff who need to secure employment and the increasingly powerful neo-liberal imperative that research is funded (especially from particular sources) and demonstrates 'impact'. There are also tensions for those of us working in disciplinary areas or Research Excellence Framework subject panels or within appraisal and promotional frameworks that privilege sole-authored outputs that do not sit comfortably with collaborative working and co-production.

In negotiating these issues, I have found it helpful to acknowledge a continuum of user involvement and academic control in the development and application of research. What matters is that this process is transparent and that there is space within disability studies for a variety of methods and modes of knowledge generation and research production. Emancipatory research is a process and disabled people's organisations shouldn't 'control all research' but rather 'research produced by user-led organisations' should be accepted on equal terms and valued for the particular contribution it makes' (187).

This is a principle I have been able to embed in my teaching, placing disabled people, their experiences and materials produced by the movement at the heart of my modules on the qualifying social work programmes at Lancaster University. The challenges and constraints for greater collaboration and co-production in teaching are similar to those identified earlier in relation to user-involvement in research. There is official support, and indeed requirement in social work education, for user-involvement. However, university practices and processes, including the resources available to adequately fund this involvement and the extent to which the significant investment required to undertake co-production meaningfully is mediated by the lack of formal value ascribed to such activity, particularly in relation to more measurable, monetarised activities in the academy.

The chapter concludes by identifying two inter-related messages that emerge from a (select and partial) review of research to inform practice with disabled people. First, that the primacy of 'evidence-based practice' should be subject to an on-going critique of who commissions, shapes and interprets that evidence, and perhaps more importantly that second 'our starting point should be on embedding values, rather than mechanisms' in practice. This would challenge the ritualised way in which provision adopts the language of the social model and of independent living.

Disability Studies and Social Work Education (31: 2) was a special issue of *Social Work Education: The International Journal for Social Work and Social*

Care Education, Training and Staff Development which I guest edited with Alan Roulstone in 2012. The special issue was the culmination of a symposium Bob Sapey and I convened in 2009. The symposium *Teaching Disability Studies to Social Work Students* emerged from discussions about our experiences of teaching social work students from a social model perspective (I taught modules on disability, ageing and social care while Bob taught mental health). At a by invitation event we brought together colleagues who were at different stages of their engagement with disability studies to 'collate and share knowledge and experiences of people and programmes' where disability studies makes a significant contribution to social work teaching (Morgan and Roulstone 2012:138). The format of the symposium, was to have a number of invited papers circulated with participants committing to have read the papers in advance to allow as much time as possible for discussion and debate[3]. Alan Roulstone and I presented the key themes from the symposium at the Joint Social Work Education Conference (JSWEC) in 2009 (Morgan and Roulstone 2009) which lead to an invitation from one of the journal's editors to guest edit a special edition.

We issued an open call for papers which enabled some of the participants who had not presented to develop an article (Rees and Raithby; Gutman et al. and Reeve), new perspectives (Evans, Cameron and Tossell) and for the inclusion of international perspectives (Dupre, Canada; Gutman et al Israel; Soldatic and Meekosha, Australia). The special issue comprised our editorial, six articles and four *ideas in action*, shorter pieces designed to stimulate debate and/or report innovative methods or practice. In many ways the purpose of the special issue was to celebrate the exciting work being undertaken by disability studies colleagues working in social work education and, we hoped, to further encourage a more central role for disability and disability studies in social work education, publishing and research.

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[3] We have now used the format of a symposium at CeDR on a number of subsequent occasions, for example with symposiums on space and place (Soldatic et al 2014), mental distress (Spandler et al 2015), work and welfare (Grover & Piggott 2015)and mad studies and neurodiversity (McWade et al 2015).

Our editorial started by reminding readers that the social model of disability had been developed by Mike Oliver as, in his words, 'an attempt to enable me to make sense of the world for my social work students' (1990:2 cited 137) and reflected upon the on-going relationship between disability, disabled people, disability studies and social work. Ostensibly a social model approach ' makes sense' for social work given its close alignment with anti-oppressive/discriminatory practice. However, as I discuss in more detail in my contribution to the special issue, there remains a dissonance between declarations of commitment (for example the adoption of the social model by the British Association of Social Workers (BASW) in 1986) and the 'established and hegemonic approaches to education and practice that are frequently disabling in their ethos and application (Sapey 2004)' (216) that practitioners and educators continue to contend with.

As I will return to in more detail in the next section the exclamation by Mike Oliver that 'It is tempting to suggest that we are all social modellists now! (2004:18 cited Morgan 2009:216) is perhaps the greatest challenge for disability studies because the adoption of the social models as policy and practice orthodoxy belies the ways in which it is *'becoming increasingly contested, not just its definition but also in terms of its usefulness and applicability'* (Oliver 2004:18). The ways in which the language and methods of the disabled people's movement have been adopted or appropriated by mainstream and traditional practitioners of research, policy and practice is perhaps the most dominant theme in my work and this submission.

The Social Model of Disability as a Threshold Concept: Troublesome Knowledge and Liminal Spaces in Social Work Education is a reflection upon my experience of teaching social work students since 2003. It was written initially for the *Teaching Disability Studies to Social Work Students* symposium after I was introduced to *threshold concepts* by Jill Anderson of Mental Health in Higher Education (MHHE) and spent considerable time discussing the place and implications of threshold concepts with my colleague Joanne Wood the Faculty Student Learning Advisor.

Threshold Concepts provide a framework for considering why we struggle with certain types of ideas or approaches. Meyer and Land (2003) drew a distinction between 'core concepts - the building blocks of a subject that need to be understood to enable the progressive understanding of that subject - and threshold concepts which lead to 'new and previously inaccessible ways of thinking about something' *(Meyer and Land 2003:1)'* (218). Core concepts are ideas or bodies of knowledge that can be understood or 'learned' in the moment but not necessarily retained. In contrast threshold concepts are a portal through which the learner must move to gain a new understanding of a subject. Meyer and Land 'use the example of Adam and Eve's transformation from innocence to experience in the Garden of Eden as a way of illustrating the crossing of a threshold into a new understanding' (219). In teaching I've used the image of Lucy Pevensie entering the wardrobe and stepping into Narnia from the recent film adaption of *The Lion, the Witch and the Wardrobe* as a way of introducing threshold concepts to first year undergraduates.

The threshold concept was useful for me because one of the things I had struggled with as a student, and then as a researcher, was whether I was missing something about the complexity of the social model of disability. I had formally been introduced to it when I began considering an MA in Disability Studies as the next step from my undergraduate studies. Disability had been always present in my life and while it might not have been something I had given a great deal of considered thought to, my views were not akin to those described by Sapey et al (2004) as a lay approach. A lay approach is a way of describing popular but not deeply thought about understandings of disability. Heavily influenced by and reflected in popular culture and often presented as 'common sense' in their rationale, this approach views disability as the tragic and inevitable result of impairment and is perhaps best captured in the phrase 'better dead than disabled'. This simply didn't resonate with my personal experience, the disabled people I knew weren't inherently tragic nor did they perceive themselves as such. While the impairments and health conditions they lived with certainly did cause problems, forms of social inequality and discriminatory attitudes

caused far greater harm. In our family disablism was likened to apartheid and in the Christian context of our home was considered abhorrent, given a central tenet of our faith was that we were all created in the image of God and thus of intrinsic value echoed in Morris' philosophy of independent living that all human life is of value (Morris 1993). So, for me, it was challenging when there was resistance or opposition to this approach from social work students.

The seeming simplicity of the social model can conceal the conceptual and ontological shift in understanding which it requires (Cousin 2006:4). For the artist and activist Liz Crow it was a road to Damascus moment, where things fell into place and she had an explanatory model she 'had sought for years' (1996:55 cited p 119). It changed how she thought about herself, about the world around her and gave her access to a collective identity of a disabled person (Oliver 1990). However, the transformational nature of ideas like the social model of disability can be extremely challenging as well as liberatory. Not everyone experiences a straight-forward shift through the threshold portal. For many, it will represent *troublesome knowledge*. Drawing on Meyer and Land I outline the ways in which the social model can be ''alien', counter-intuitive or even intellectually absurd at face value' (2003:2) for social work students. The dominance of social and cultural narratives of disability as a form of personal tragedy remains hegemonic despite the reframing of disability as an equality issue. Disabled people's continued segregation from mainstream spaces and places (Soldatic et al 2014) means their lived experience remains at a distance and frequently mediated through political discourse, media representations and the ways in which forms of support construct disabled people.

In the article I describe a number of ways in which I have structured and developed my teaching in response to the *liminal spaces* occupied by students during their engagement with disability studies. This is summarised by two phrases often repeated by students – 'I don't get it' and 'the social model is ok in theory, but it doesn't work in practice' – which represent two different responses to the troublesome knowledge they are wrestling with.

The first group are those students who have moved from a 'pre-liminal state, where they are unaware both the threshold and of the reasons for seeking to pass through it, into a liminal space' where they are often grappling with 'the ontological implications of the shift' (221). These students need a safe space in which explore the concept which can be limited in the short time frame allowed by the modular structure of most programmes. The nature of formative assessment means students can be under pressure to 'get it' before they are ready which can lead to *mimicry* and or *ritualised performance* (Cousin 2006) of what they think the threshold concept is.

The second group are akin to Cousin's 'defended learners' 'who can see where a threshold is leading and yet become resistant to it' (221). For some, this is because they do not wish to relinquish the power of professional status, while for others the 'implications for practice are unworkable'. For some this was because 'there is no single blueprint or handbook for social model services or practice' (188), translating a social model ethos into practice requires individuals and organisations to 'get it'. For others, *e*xternal pressures are narrowing the focus of social work education to its statutory base to the exclusion of social work that takes place in other spaces (a distinction between Social Work and social work perhaps). This, coupled with the impact of "austerity policies" introduced in the UK in the wake of the 2008/9 financial crisis, upon user-led organisations and other third sector organisations, is limiting the opportunity to practice in ways that are rooted in the social model. However, as I have been exploring in a burgeoning research, practice and education partnership with the Principal Social Worker and Head of Adult Social Care Policy and Strategy there remains significant opportunities to 'do' disability studies in social work which I will explore later.

The article won the journal's inaugural 'best conceptual article' award in 2012 (Teater and Taylor 2013). The criteria used by the editorial board was: 'importance/significance; originality/Innovation; rigor in conceptual thinking or research methodology; and, attention to diversity' as well as the

'importance, significance and timeliness of the article topic, its applicability and links to social work education and practice'. It remains one of the journal's most read articles [4063 views altmetric 24, 53 citations google scholar]. The article was chosen by the JSWEC (Joint Social Work Education and Research Conference) Journal Club (@jswecjour13) for a twitter based discussion linked to a keynote talk 'Collective Consciousness through Creative Connectivity' by Jon Bolton, Amanda Taylor and Denise Turner.

Examples of tweets #jswecjour2013/jswec13
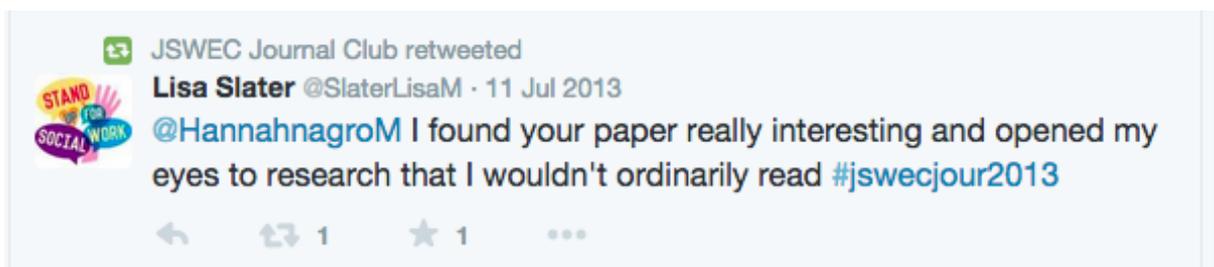
'Named social workers – better social work for learning disabled people?' is a short article in the *current issues* section of the journal *Disability & Society*. The purpose of the section is to provide a space for short pieces 'which seek to raise the voices of those who are seldom heard in academic journals and we welcome articles which air controversies and contentions and which stimulate discussion and debate'. Our article was based on our (Lancaster University and Calderdale Council) involvement in a pilot of named social workers for people with learning disabilities between October 2016 and March 2017. The pilot is part of the Department of Health's response to the 'No voice unheard, no right ignored' consultation for people with learning disabilities, autism and mental health conditions (Department of Health 2015) which acknowledged the slow response in the sector to the commitment to transforming care for learning disabled people in the wake

of the 2011 Winterbourne View scandal. The consultation committed to '(subject to successful pilot) roll-out access to a named social worker who will provide professional advice and support, be the primary point of contact for the service user and their family/carers wherever the person is being supported, and provide a professional voice across the system' (Department of Health 2015). The Department of Health issued a call for expressions of interest in summer 2016 and our application was accepted as one of the six pilot sites.

Our application was part of a developing practice and research partnership with Elaine James, Head of Adult Social Care Strategy & Policy and Rob Mitchell, Principal Social Worker both working at Calderdale Council at that time and now at Bradford Council. Initially a relationship that developed on twitter where there are dynamic, passionate and fast moving discussions and debates about social care, social work and the lives of disabled people, our partnership has evolved to be one primarily concerned with the contribution social work and wider social care practice can make to the lives of disabled people. A central concern was the way in which social work practice often operates in a problematic way in disabled people lives, at best often ineffectual in upholding people's rights and at worse oppressive and highly damaging. What we share is a commitment to holding professional practice (including our own) to account and to ensuring local authorities are 'servants not masters' to the people they are privileged to support (Munby 2011).

At the heart of our involvement in the pilot was a discussion about what better social work for learning disabled people would look like, as part of a wider discussion about the role of social work in adult social care. Our contention is that much social work practice explicitly or by omission results in disabled people 'living lives confined by restrictions placed on them by health and social care professionals' by wrapping them in 'forensic cotton wool' (A NHS Trust v P & Non 2013). The hypothesis we want to test, one that emerged from our respective areas of practice, including academic research, qualifying education, social work practice, commissioning and

policy development was 'a reimagined social work role, as an applied social scientist (Croisdale-Appleby 2014) steeped in the social model of disability and as an expert in equality, mental capacity and human rights law, could act as a challenge to other professional voices within the health and social care system'. This draws on Finkelstein's work on professional attitudes (1981), *the helper/helped* relationship (1981) and professions allied the community (1991) were professional practice, developed in partnership with disabled people and their organisations, rejects a model of professional expertise and assessment and instead seeks to uphold disabled people's rights and support their aspirations. One of the exciting things about this approach is that 'Such an alliance has the potential to reintroduce innovation, initiative, excitement and personal reward in delivering the community based support that disabled people want' (Finkelstein 1991:3).

For us 'good' social work 'is professional practice which is both grounded in the social model of disability and in mental capacity and human rights legal literacy' (Morgan 2012, 3). However, this needs to go beyond social work education that introduces social work students to a social model approach to disability because social work retains 'a chequered relationship with the model and the challenge it brings of truly giving up professional power and devolving it back to people (Morgan and Roulstone 2013)'. It requires an on-going critical engagement with disability studies and disabled people's organisations through partnerships like the one we have established and through continued professional development opportunities that privilege the contribution disability studies can make to 'social model practice'.

Together, this cluster of publications explores what it means to practice disability studies as a researcher, educator and activist. Debates continue within disability studies about the purpose, methodology and impact of research on social understandings of disability and within disabled people's lives. The dominance of neoliberal imperatives within the academy make it harder to carve space to put our skills at the disposal of the disabled people's movement. For me, involvement needs to be accessible and meaningful which often means it is, by necessity, small scale and

cumulative. Developing reciprocal relationships with disabled people, their organisations and other disability activists is central to this process.

An area in which I have sought to demonstrate this approach has been in the organisation of the Lancaster Disability Studies conference. The first conference was instigated by Bob Sapey and John Stewart at Lancaster University and Jennifer Harris and I then based at the Social Policy Research Unit (SPRU) at the University of York with support from Colin Barnes at the University of Leeds. The conference took place in September 2003 with the title *Disability Studies: Theory, Policy and Practice* and intended to:

bring together people involved in disability studies throughout Europe to share their knowledge and experience of studying disability issues, and to act as the launch pad for a disability studies association in the UK.

The conference ran for a second time in 2004, this time wholly organised by Lancaster University, after which we made the decision to run it on a biennial basis to alternate with the Nordic Network on Disability Research (NNDR) biennial conferences and, in recognition of the significant amount of work the organisation requires to make it sustainable in the long term. The conference has now run eight times, most recently in September 2016 and the ninth conference is scheduled for September 2018. The conference attracts over 270 delegates including academics, researchers, post-graduate students, policy makers, practitioners and activists from the UK and internationally. The conference is well-received with many participants becoming regular attenders as well enabling a steady diversification of the disability studies field. These are some typical emails I have received after the conference:

It was the second time I attended the conference and despite the fact that I am fairly early in my research journey (I am currently a postgrad student), I felt truly as an equal participant at the conference. I thoroughly enjoyed the open and friendly atmosphere at the conference and met some very inspiring and lovely people. Thank you for making that possible!

that's the third conference I've been to and, for me, was by far the best _ I really enjoyed it : met some lovely people , heard some really good speakers and was not only very moved by the Justice for LB campaign but really pleased to see the Conference so actively engaged in campaigning . For me academic endeavour has no point unless it's very firmly connected to and having a positive impact upon people's every day experience of the world..

Just a very quick note to let you know how much I enjoyed the Lancaster Disabilities Studies Conference, I have come away from the conference feeling motivated and rearing to go.   Living in such a remote part of the world with little opportunity to meet with academics and my peers in research makes for a lonely and sometimes a lonely and disheartening journey.   Everything about the conference was brilliant, my only complaint was that it was so short and given the amount of streams per session I found it very difficult to see all the presenters on my 'want' list.   I want more!

Just writing to you to thank you for leading on the organisation of yet another great conference. The papers I chaired/heard and the keynotes were of a really high standard and dare I say the discipline of disability studies feels happier in its own skin, whatever views are being expressed.

A particular privilege provided by organising this conference has been the opportunity to sponsor (in the widest sense) events and other developments within disability studies, examples of which are discussed elsewhere in this document (cf. Roulstone and Morgan 2012; Soldatic et al 2014). In 2014 the conference hosted a mad studies stream convened by Peter Beresford and Brigit McWade in response to 'a critical moment in which activists, academics, service-users, practitioners and services can come together and address integral issues in the field of madness and disability' (McWade 2014). The stream sought to provide 'opportunities for discussion, connection, and debate, as well as the possibility of some collective work in the future' and has led to a number of important contributions to the developing field of Mad Studies including a wordpress site, a follow up symposium at the 2015 NNDR conference and 'Mad Studies and

Neurodiversity – Exploring Connections' held at Lancaster in June 2015, which demonstrated the wider impact of the conference (Beresford 2014). A second mad studies stream was convened at the 2016 conference (McWade 2016). The stream expanded significantly hosting two keynote addresses and a diversity of presentation opportunities, in part to enable a greater variety of presentation type but also as a way of accommodating the high number of participants. There was also a sexualities stream in 2016 and I am currently collaborating with PARC, the Participatory Autism Research Collective, to develop a neurodiversity stream and work to curate more neurodiverse spaces at the 2018 conference.

I have also sought to use the opportunity of the keynote addresses at the Lancaster Conference as a way to invite and support the development of early career researchers, particularly disabled women, for example Sonali Shah (2012), Nicola Burns (2014), Susie Balderston (2016) and Phillipa Wiseman (2018).

A second area I have been able to develop since taking on the Directorship of the Centre for Disability Research (CeDR) in 2016, is in working with colleagues to put our skills at the disposal of and in support of the disabled people's movement. This has been particularly linked to a stream of work and activism in response to the death of Connor Sparrowhawk in 2013 while in the 'care' of Southern Health NHS Trust. Connor, the son of an Oxford based disability studies colleague Sara Ryan, died a preventable, unnecessary and needless death. Our participation in the 107 days of action campaign (a reference to the 107 days Connor spent in the assessment and treatment unit before his death) has involved organising seminars, integrating Connor's story into teaching about institutional abuse and an exhibition at Lancaster University's Peter Scott Gallery in May 2015. A broader parent-led campaign 7 days of action has sought to bring attention to learning disabled people and in particular young adults in Assessment and Treatment Units. The campaign has organised two 7 days of action in 2016 and 2017 which have been supported by research reports written by CeDR colleagues in partnership with activists (James et al 2016; Brown et al

2017). CeDR has published these report and sought to disseminate widely, for example through campaigns in mainstream and social media and through the production of easy read summaries of these reports but also of other research about or relevant to people with learning disabilities.

These practices cumulatively constitute 'doing' disability studies within an international community of practice constituted of academics, activists, allies and accomplices. The interplay and interaction between these different, sometimes disparate, and always diverse elements enriches the field of disability studies and provides a myriad of opportunities to be held to account for my commitment to social model based practices.

Disability Policy Formation

The second larger cluster of publications grouped here under 'Disability Policy Formation', addresses ways in which citizenship, employment, social care, independent living and welfare are formed and experienced as social policy. As Roulstone and Prideaux note 'Disability policy is neither linear, inherently progressive nor equitable, and suffers from the vagaries of time, place and ideological change' (2012: xvii). Thus, these pieces explore how these 'vagaries' impact on disabled people, as both the individual and collective subjects or recipients/subjects of a particular policy and more widely as a result of the underpinning narratives and discourses that construct disability and disabled people in particular ways.

The first two chapters *Disabled People and the European Union: Equal Citizens* and *Disabled People and employment: the potential impact of European Policy* are concerned with the ways in which the European Union responded to disability. ***Disabled People and the European Union: Equal Citizens*** (Morgan and Stalford 2005), is a chapter co-authored with socio-legal scholar Helen Stalford, developed from papers presented at the inaugural Lancaster Disability Studies conference (Morgan and Stalford 2003) and at the ESRC Seminar Series 'Implementing the Social Model of Disability: from Theory to Practice' hosted by the Centre for Disability Studies at the University of Leeds (Morgan and Stalford 2004). In this paper, and then chapter, we wanted to explore what the status and practice of European citizenship meant for disabled people and to question to what extent disability alters conceptions and experiences of EU membership (Morgan and Stalford 2005).

The 1992 Treaty of Maastricht established Citizenship of Union based on member state nationality with an accompanying 'right to move and reside freely within the territory of the Member States' (Article 18 EC)' (p.99). However, freedom of movement is a hollow concept for many European citizens who face very significant barriers to mobility. In particular we wanted to highlight the ways in which this right is tied to traditional notions of employment, family and dependency in ways that are at odds with a

rights based understanding of disability. In *Disabled People and the European Union: Equal Citizens* we outlined how European Union citizenship is constrained by the ways in which the European Union, via European Court of Justice (ECJ) case law, interprets what it means to be a 'worker' or 'dependent family member' when citizens seek to exercise the free movement and (of particular importance to disabled people) to 'obtain access to the panoply of social rights in another Member State' (100).

We summarised the free movement provision criteria as follows:

You have to be an EU national and you have to be economically active (i.e in work) or economically self-sufficient (that is, not dependent on welfare benefits). If you are neither of these, you can migrate as a dependent family member (that is, as the spouse, child or parent) of the migrant worker (100).

During the 1990s and early 2000 there had been considerable academic and activist attention on the ways in which these criteria disproportionately marginalised certain groups, notably women and children, same-sex and cohabiting couples and third country nationals. There was emerging European level activism by disability organisations but a paucity of academic discussion of the implications for disabled people or the contribution disability studies could make to critical discussions of concepts like "worker" and "in/dependence".

As we noted very few ECJ cases referred explicitly to disability or demonstrated taking any account of the specific barriers disabled people face when seeking to participate in the labour market or exercise mobility within the EU. The extension of the concept of what constitutes a "community worker" to incorporate less traditional forms and patterns of work, clearly had potential for extending the status of worker to larger numbers of disabled people. However, we suggested it was the interpretation of "dependency" that held most significance for disabled people.

Dependent adult children and relatives in the ascending line (usually parent) enjoy derived rights based on their relationship to an EU migrant worker. The ECJ had not explicitly set out what constituted dependency but emerging case law (such as Inzirillo 1976 and Diatta 1985) associates dependency with financial dependency on the migrant worker. In particular the Diaata ruling held that this form of dependency did not require the dependent family member to live in the same household. We argued that a more appropriate interpretation of dependency by the ECJ would acknowledge (mutual) relationships of practical and emotional support. This could recognise the contribution all members of a family make (regardless of their own levels of dependency).

Our reading of the ECJ case law in relationship to the statuses of worker and dependent family member highlighted two significant limitations of the free movement provisions for disabled people. First, that the rights and entitlements arising from free movement are based on an ethic of non-discrimination which may be a deterrent to mobility. The migrant worker or dependent family member is only entitled to receive the same benefits as nationals of the host state, however generous or limited they may be. In addition to potentially lower levels of entitlement, migrants may loose entitlement in the sending state and be subject to qualifying periods in the receiving state.

The emphasis on economic contribution via waged labour as the basis for entitlement is the second limitation we explored. The 'genuine and effective' nature of employment, echoed by the UK Coalition government's introduction of a minimum earnings threshold for migrant eligibility for benefits (Department of Work and Pensions, 2014), fails to acknowledge broader economic and social contribution. In particular disabled people as consumers of goods and services as well as their unpaid or informal contributions to families and communities. This coalescing of entitlement around paid work rather than a broader notion of contribution was a dominant theme from our interviews with disabled women living in rural areas (Soldatic and Morgan, 2017; Morgan 2017).

We situated our discussion in *Disabled People and the European Union: Equal Citizens?* within the optimism generated by the designation of 2003 as the European Year of Disabled People, which was intended to 'generate a more concrete political commitment to disabled people's inclusion within mainstream European law and policy' (98).

The sister chapter *Disabled people and employment: the potential impact of European policy* (Morgan 2005) considers shifting paradigms that have emerged in European policy making at the intersection of employment, social policy and disability. It was originally presented at the Socio-Legal Studies Association conference in 2004 and was an invited contribution to *Working Futures? Disabled People, policy and social inclusion* edited by Alan Roulstone and Colin Barnes. This chapter considered the place of disability and disabled people in the European project. It drew on Castells' concept of 'project identity' (1998) to argue that the European Union had shifted its primary focus from economic integration to the development of a 'blueprint of social values and institutional goals that appeal to the majority of citizens without excluding anyone in particular' (1998:333 cited 259). The chapter identifies three broad phases in the development of an emerging European Union disability policy. The first phase was one of 'benign neglect' (1958-81) when the European Economic Community (EEC) paid no real attention to disability as a social or political issue. As *Disabled People and the European Union: Equal Citizens* made clear the principal concern of the EEC was economic integration, the free market and the free movement of workers. Thus, those not defined as workers were 'only indirectly the concern of the EEC and beneficiaries of the creation of the common market' (261). Therefore, social policy (limited as it was) was subordinated to economic policy and concentrated at the member state level. Disabled people, or at least those who were not independent workers, or who were 'dependent' in part or wholly on the state or others for care and/or support, were simply not on the agenda of the EEC.

The second phase, characterised as *creeping softly,* was driven by a concern from within that the EEC was of benefit to business but not to workers or

indeed other citizens. Jacque Delors' presidency of the EC promoted the creation of a European social area to match its economic one. However, the EEC was constrained by the limited competences granted to it by treaties. Therefore, the EEC used a process of competence creep utilising soft law measures as a method to widening its project identity and raise awareness of the potential of Europe as a lever of social policy actions amongst communities, such as the disability movement.

The third phase was the development of a rights-based strategy which was more closely aligned with a social model or barriers approach to disability and other forms of social oppression. The culmination of which was the inclusion of disability in the anti-discrimination clause of the Treaty of European Union in 1997. A central element of this approach, initially adopted in relation to gender, is mainstreaming whereby policies and processes are assessed for their impact on particular groups. Its effectiveness is limited by a lack of legal basis for action as well as competition between different groups and the potential for overload.

The chapter also considered the extent to which disability policy paradigms are likely to become 'Europeanized'. Europeanization has the potential to reduce the differences in the ethos and practice of member states responses to disability. These differences remain a significant barrier to disabled people's ability to move freely within the EU the key way in which most citizens realise their rights. However, the consensual nature of EU policy development combined with the continued strong commitment to subsidiarity, limits progress in the extension of tangible entitlements. Instead there may be greater potential in the platform the EU provides for 'exposing and crediting disabled people's contribution to society through their formal and informal, direct and indirect participation in the labour market' (268).

User-led organisations: facilitating Independent Living (Morgan 2013) is an invited chapter in the popular and enduring edited collection *Disabling Barriers – Enabling Environments* (Swain et al) now in its third edition. The chapter was an other opportunity to revisit and reflect on the *Creating*

Independent Living Project. The project was commissioned by the National Centre for Independent Living (NCIL) and funded by the National Lottery in 2000-1. The purpose of the chapter was to outline how independent living is understood and applied by disabled people's user-led organisations (DPULOs) in the UK. The proliferation of organisations run and controlled by disabled people since the creation of the first Centres for Independent Living in the early 1980s has resulted in great diversity of structure, purpose and role. However, as the chapter asserts, 'what unites these diverse organisations is a commitment to the social model of disability and to having a constitutional structure that ensures control rests with disabled people' (206). This has occurred at a time when many traditional disability charities and organisations have 'discovered' and adopted a social model as well as making commitments to greater accountability to disabled people. Participants in the four seminars held during the first stage of the project (Barnes et al 2000) highlighted the necessity of an agreed standard or 'kitemark' for DPULOs to distinguish them from what have been termed 'organisational wolves in sheep's clothing' (Disability Listen Include Build 2008 cited 210). This later category includes large scale charities like Mencap or Scope who 'seek to both represent disabled people in policy discussions and provide services to meet their needs' (208), and in attempting to do both of these, often fail to include disabled people within the design and running of independent living projects.

Thus a key question for this chapter was what defines a 'social model organisation' and how this can support the original aims of the British disabled people's movement: which Jane Campbell and Mike Oliver summarise as 'entail[ing] collective responsibilities for each other and a collective organisation. Independent living wasn't about individual empowerment it was about individuals helping one another' (Campbell and Oliver 1996 cited 208). The collectivist and campaigning nature of the disabled people's movement is often lost in more recent policy-led articulations of independent living that are individualistic in nature. However, as the various iterations of Centres for Independent, Integrated and Inclusive Living (as well as many other organisational structures)

demonstrates there is strong resistance to forms of independent living that atomise disability and disabled people.

DPULOs have developed a range of services, forms of supports and 'ways of doing' independent living encapsulated in Derbyshire CILs *seven needs* of disabled people, more recently updated by Hampshire and Southampton CILs as *basic rights*. This signalled a shift in the way in which disabled people's claims have been articulated and acknowledged in legislative and policy contexts as rights, and as essential to their participation as full citizens. The formal adoption of a social model understanding of disability in 2005 Cabinet Office report *Improving the Life Chances of Disabled People* included a commitment to a user-led organisation in every locality by 2010. This suggested that DPULOs 'occupy, formally at least, a central and influential position in shaping and leading disability policy and the provision of services seeking to meet the needs and aspirations of disabled people' (210).

However, this (still unmet) commitment belies the threats and challenges facing user-led organisations, many of which we had initially identified during the *Creating Independent Living* project. These have intensified in the intervening period as a result of the increasing individualisation and marketization of disability policy and latterly the implementation of austerity (the retrenchment of welfare state which has particularly impacted on local council services and budgets). One of the most striking characteristics of the user-led organisations we worked with was their precarious position. Many were dependent on very short term funding that was tied to service provision, providing little resource for the infrastructure of the organisations, including their capacity to bid for additional funding. As I argue in the chapter this 'creates a tension at the heart of the DPULO movement' (210). ULOs are caught in a bind where larger charities and other disability organisations are 'adopting the formal trappings of a DPULO' which makes it 'increasingly difficult to tell them apart' (210). I drew on Jenny Morris' analysis that 'adjusting one's language to suit the prevailing discourse' (2011 cited 211) may appear a 'pragmatic and often very

effective strategy to adopt', it leaves the disabled people's movement 'vulnerable to colonisation' (211). This appropriation of disabled people's language and activism has infiltrated many of the spaces and places originally occupied by disabled people's organisation, such as the provision of direct payment assistance or peer support. This situation is exacerbated by a 'lack of formal evidence of the added value provided by DPULOs' (211).

The chapter concludes by briefly considering the future of DUPULOs in an age of austerity and in doing so highlights several of the key themes the remainder of the pieces in this section explore in greater detail. The first is the growing contradiction between the adoption of the social model of disability as a form of policy and practice orthodoxy and the way this is operationalized in service provision and experienced by disabled people. I draw in particular on the work of Dave Gibbs, then Research Manager at the Derbyshire Coalition of Disabled People (DCIL) and a member of the Project Advisory Group on the outcomes described in the 'Strategies for involving service users in outcomes focused research' (Morgan and Harris 2005) chapter discussed earlier. Gibbs describes 'social model services' as an oxymoron, arguing that 'the social model is non-reducible, it cannot be implemented by any programme of services that is separate for other functions' (2004 cited 211). The experience of DCIL, who working with the local authority, had set up a separate centre for integrated living to provide a range of services only to decide the separation of campaigning and service provision was not tenable. This was in part a response to the changing political and funding landscape but also a recognition that it was difficult 'to safeguard the original wide-ranging objectives and community emphasis' of the organisations (DCIL cited 211).

That '*there is no single blueprint or handbook for social model services or practice*' (Morgan 2012: 188) has been a central theme of my disability studies practice. While the seeming simplicity of the social model of disability is key to its popularity and effectiveness, the tendency to equate this with particular forms of support, assessment technologies, or 'brand' creates a range of new challenges and tensions that become particular

acute in an age of austerity. Disabled people are, without doubt, some of the 'hardest hit' by welfare reform (Duffy 2013) and significant numbers of disabled people live in relative and absolute poverty (Department of Work and Pensions 2013). This is creating very real threats to individual disabled people and their families, to user-led organisations and perhaps to the movement itself. However, as I concluded, new opportunities and spaces are opening up, for resistance and a reinvigoration of the disabled people's movement and for user-led organisations 'who have an established track record in providing innovative and effective solutions' at a time when established structures and funding streams are being fundamentally re-envisaged.

Neo-Liberal Individualism or Self-Directed Support: Are We All Speaking the Same Language on Modernising Adult Social Care, was co-written with Alan Roulstone and published in *Social Policy & Society* (Roulstone and Morgan 2009). It was based on research Alan had undertaken on the modernisation of day services in a large English city in 2006 and provided an opportunity to reflect on the 'philosophical question [that] inheres in the future relationship between individualised and collective lives for disabled people' (333). At this point the initial optimism generated by policy commitments to putting independent living at the heart of social care provision was starting to become qualified as the individualist nature of implementation became increasingly apparent. "Personalisation" was starting to deviate substantially from the collectivist ideology of the early disabled people's movement to become synonymous with technologies of assessment and delivery, mechanisms firmly focused on individual disabled people. The 'modernising' of adult social care was driven by a number of factors that coalesced under the broad banner of 'personalisation'. In policy terms, it has its roots in the deinstitutionalisations of the 1970s and 1980s and promise of care in the community. However, community care became equated with care management, greater managerialism and with a growing imperative to contain and reduce costs. The development of forms of self-directed support, particularly those which provided "cash for care", by disabled people's organisations, found favour with a Conservative

government keen to reduce the power of local authorities and to promote a social care market.

What is significant was the apparent "convergence of views" between government policy and the independent living agenda being promoted by disabled people. I referred earlier to the development of a social model "brand" which is mirrored here by the evolution of personalisation as a narrative defined in terms of choice and control. The promotion of personalisation as a way of doing social care support is frequently presented in short, simple slogans, most notably 'choice and control'. It also became associated with a range of personal narratives, where the promise of personalisation was marketed through individual stories and folksy examples (Needham, 2011). As Needham identified, personalisation was sold around five key themes or narratives – personalisation works, it is financially more efficient, it is person (not service) centred, it has a broader application to the welfare state and, repositions individuals (not professionals) as the experts. This powerful narrative has produced a new orthodoxy in social care, akin to the apparent orthodoxy of the social model in disability services, which has become homogenized in a much more narrow and constrained range of assessment technologies and delivery mechanisms than its personalised ethos suggests.

In this article we make two linked arguments. First we argue that 'what is novel in more recent policy and programme debates is the borrowing by the English government of the language of radical disability politics, which makes criticism of its key precepts seem misplaced and 'unreasonable' (334). Second, that the individual/individualist tenor and operationalization of personalisation fails to acknowledge the diversity of disabled people and the inherently collective nature of independent living. These are themes that echo and preface discussions elsewhere in my writing and continue to be central to my teaching and research interests.

The co-option of disabled people's ideas and ways of organising by policy makers and others in the disability industry has resulted in policies and procedures that **mimic the language of the social model and independent**

living, but fail to adhere to their underpinning principles, politics and ethos. The rebranding of traditional forms of service provision, without a concurrent shift in attitudes and values, means such provision remains firmly within humanitarian and compliance approaches to welfare (Oliver 2004 adapted in Morgan 2014). These approaches, developed by Mike Oliver when evaluating Birmingham City Council's formal adoption of the social model of disability, are a useful tool (another of Oliver's hammers for action) to critically interrogate what lies beneath the rebranding of many social care services. It is the argument of our article that a humanitarian approach, based on a individual model of disability that positions the service provider as expert and positions disabled people as grateful recipients, combined with a compliance approach, focused on meeting laws, rules and regulations leading to a checklist or minimum standards, fails to adequately meet the needs, entitlements and aspirations of disabled people. In place of this, following Oliver, we advocate a citizenship approach to welfare, rooted in a social model understanding of disability that recognises disabled people as full, active, citizens with all that implies in terms of rights and responsibilities.

As I noted in 'Working with disabled people', 'these approaches not mutually exclusive, different elements of the same organisation or service may embody all or none of the approaches' (Morgan 2014: 188). A full transition to a citizenship approach is rarely achieved in statutory settings where a range of vested interests, including service area fiefdoms, and professional, provider and service user resistance, mitigate against such a paradigm shift in how support for disabled people is organised and delivered. Social care providers, and other disability service providers, have been extremely effective in rebranding their "offer" to be one focused on individualised provision and independent living under the portmanteau of personalisation.

That personalisation can be read as a short hand for individualisation in social care has gained substantial currency (cf. Beresford, 2014; Ferguson and Lavalette, 2014) since we wrote the paper in 2008. There is now

considerable support for our argument that 'without … financial and organisational support, self direction takes on distinctly neo-liberal characteristics' (343). Chief amongst these characteristics has been the promotion of individualism 'as the basis of social and economic efficiency' (339) and the practical organisation of financial mechanisms, such as direct payments and individual budgets, and forms of support focused on individual service users. In this context we noted therefore that it is a 'challenge to envision the individualisation of adult social care without individualism' (339). There are very real tensions between collective nature of self-organisation and the disabled people's movement and a rejection of inevitably collective institutionalised forms of provision.

In this article we posed the question 'can an individual choice discourse contained in the modernisation agenda be applied unproblematically to disabled people who have had no prior exposure to rights-based opportunities' (333). The de-institutionalisation of disabled people is undoubtedly one of the most significant achievements of post-war disability policy. The belief that few disabled people now live in large-scale institutional provision and that disabled people should be supported 'in the community' has become embedded in the policy and practice lexicon. However this shift from institutional to community provision has also been a shift from collective to individualised provision to the extent we suggested many disabled people 'risk being moved from a position of enforced collectively to one of enforced individualism' (334). In short, there have been losses as well as gains, with "community provision" increasingly, in the context of austerity driven policies which seek to cut state welfare to the bone, minimal or no provision at all.

Enforced individualism, as the result of the closure of collective provision or of insufficient funding to enable someone to enjoy the level of social contact they want. As we found 'a great deal of centre-based time was beginning to be spent at home' (342) rather than in public settings or communal spaces. This is supported by the "social isolation indicator" introduced to the Adult Social Care Outcomes Framework in 2013/4. The

indicator records the proportion of those who use services who 'have as much social contact with people' as they would like to be fairly static between 42-44% over the last three years (Department of Health 2014: 26).

While there are significant problems in institutionalised collective provision like day centres, these forms of 'enforced collectivism turned out to be an important collective identity for some centre users' (341) as this quote from Billy (32 years old, day centre user for four years) suggests:

Day centres are in my mind are a key place to get together, most people in the city and that are mindin' their own business, by themselves like, that's the way of the world. I mean I've been at work – but since then have enjoyed the thing of being with others, I wouldn't want to lose that – also I met [current partner] through the day centre. I understand people with physical disabilities – wouldn't turn my nose up to people with disability as I know what its like to be disabled – somethin' in common (341).

While the community provided by institutional settings frequently lacks the politicised peer support of user-led organisations it does afford 'an opportunity for both solidarity and sanctuary for service users from often inaccessible and disabling mainstream spaces and locations' (337). The importance of these safe spaces was, and remains, vital in a context where many 'service users had little knowledge of what the modernisation agenda meant for them in practical terms and could not envision what a self-direct daily life would feel like' (340).

The publication of the article led to an invitation to evaluate the modernisation of day services in Halton Borough Council (Morgan and Roulstone, 2011) which provided an opportunity to develop our analysis of the role space and place play in policy formation and implementation and in the ways in which disabled people experience policy and practice spatiality and temporally. At the same time Karen Soldatic visited CeDR as a British Academy Fellow extending her work on disability, rurality and welfare reform in Australia to a British context. Together we hosted a research

symposium _Disability, Spaces and Places of Exclusion_ (16-17th April 2012)
which brought together disability studies scholars to consider and reflect on
the themes of geographies of disability and the changing relations of space
and place, the inter-play between disability policy and spaces of work and
welfare restructuring and relationships to disability activism. The main
outcome of the symposium was an edited collection _Disability, Spaces and_
Places of Policy Exclusion (Soldatic, Morgan and Roulstone 2014) published
as part of the Routledge Advances in Disability Studies series.

In the editorial, **Introduction: disability, space, place and policy: new**
concepts, new ideas and new realities (Roulstone, Soldatic and Morgan,
2014), we situate the collection at the intersection of 'three critical, yet
often contrasting, ideas, of disability, space and place _and_ social policy
regimes' (2) recognising that interest in space and place in disability studies
had been largely limited to more technical discussions of building
regulations and access while of particular concern to us was the way in
which disability policy had 'not been conceptualised as a spatial
phenomenon' (1).

In inviting Rob Imrie to give the keynote address at the symposium and to
frame the collection in his opening chapter 'Space, place and policy
regimes: The changing contours of disability and citizenship' we
acknowledged the antecedence of disability geographies produced by
authors like Rob Imrie, Brendan Gleeson, Rob Kitchin, Ruth Butler and
Hester Parr while seeking to 'expand the current geographical frame of
reference operating within the realm of disability' (2). The particular
contribution this volume makes to disability studies, and to more general
discussions of social policy, is to apply this 'wider panoply of geographical
insights' on disability and emplaced disabled bodies 'systematically to the
forms of policy and legal exclusions experienced by disabled people in
contemporary society' (p1) Thus, the collection seeks to broaden the
reading of space from the material and structural to consider the ways in
which disability, disabled bodies and disablism are constructed and
mediated 'symbolically, culturally and materially'(2). Space and place, in

all their manifestations, is contested terrain that is re/mapped, re/framed and re/shaped by legal and policy regimes.

In his review of seven key disability studies texts published in 2013-4 for *The Years Work in Critical and Cultural Theory* Rembis (2015) agreed that 'place matters in myriad ways when theorizing disability' concluding that the book was a 'provocative collection of essays that sit at the intersection of geography , sociology and policy studies' that 'taken together, the chapters included in *Disability, Spaces and Places of Policy Exclusion* offer compelling evidence of the need to bring together multidisciplinary work that specifically addresses and critically analyses the uniquely and locally situated nature of global disability experiences' (Rembis 2015:24). Similarly in her review for the international journal *Disability & Society* Fenney (2016:986) described the collection as an 'important contribution to the literature addressing geographies of disability' that 'offers rich evidence for the relevance of a spatial and temporal analysis of social policy'.

The book is structured into two parts, firstly conceptual and then empirical in focus. Part one conceptualises disability in spaces and places of policy exclusion and is the location for **Accessible public spaces for the 'not-obviously disabled': Jeopardized selfhood in an era of welfare retraction** (Roulstone and Morgan 2014). The work was originally presented at the Disability and Public Space Conference held at Oslo University College, Norway (Morgan and Roulstone 2011) and revised for the Disability – Spaces and Places of Exclusion symposium in 2012 (Morgan and Roulstone 2012). It builds on our 2009 article and research report for Halton Borough Council (Morgan and Roulstone 2011) and sought to respond to 'changing and increasingly critical discourses of public space, participation and legitimacy and their implications for disabled people' (64). A great strength of disability studies scholarship and activism has been to highlight and challenge 'exclusive public space' and disabled people's removal from it or segregation within it. Similarly much work has been done to make spaces (more) accessible for disabled people. However, much of this early work in the field shared dominant understandings of space as 'a technical, physical

measurable space' (64) while we sought to extend this analysis by drawing on the work of Fruend (2001; Fruend and Martin 2001) who stressed *sociomaterial space* which 'exposes and structures life' (65). Our intention was to 'broaden the analyses in a way that accounts for the overt politicisation of the public realm and, in turn, public space' (66).

Disabled people move through spaces and places within 'potent psycho-social environments created by public discourses' that are becoming 'much harsher, much more judgemental, as to who counts as legitimately disabled and just who "belongs"'. This is particularly the case for those with hidden, contested or fluctuating impairments whose legitimacy as disabled people is increasingly called into question as policy, along with political rhetoric and media culture, constructs a category of 'faux' disabled people whose (re)classification renders them as insufficiently disabled to deserve welfare provision (Soldatic and Morgan 2017). We reviewed the language utilised by government ministers and media commentators in their justification of welfare reform which frequently conveyed the suggestion many of those in receipt of benefits were exercising choice, a finding echoed by Briant et al's (2011) review of the shifting media coverage of disability.

We utilised Tyler's (2013) work on symbolic violence used to 'harden public opinion into consent' to illustrate the ways in which forms of direct and indirect forms of targeting disabled people in public discourse result in public spaces that are 'uncomfortable and inhospitable' for disabled people (73). These *jeopardised spaces* are particularly problematic for those deemed or at risk of being deemed *faux*. We cited a number of examples from social media (and echoed in wider research) that capture the pervasive climate of fear 'which places some disabled people in a twilight world: one where they are afraid to be seen doing anything that might be constructed as at odds with benefit criteria' (75). This dissonance between a welfare policy based on 'an independence-driven agenda' (74) and disabled people's lived experience of welfare reform supports our earlier identification of 'discursive inconsistencies' (2009:333) at the heart of government disability policy and its 'reform'.

A central element of welfare reform has been the whipping up of a moral panic over disabled people's 'dependency' on welfare provision (Roulstone 2000) as a way of building public consent for the steady chipping away of their status as 'deserving' recipients of state support by successive governments (Roulstone and Morgan, 2014). Despite very low levels of fraud in disability benefits, estimates by the Department of Work and Pensions (2014) detail a fraud and error level of 1.9% for Disability Living Allowance (of which 0.5% was fraud, 0.6% claimant error and 0.8% official error), considerable government and media attention has been focused on 'faux' disabled people. This conceptualisation of a "disability panic" is one that I have further explored in partnership with Karen Soldatic.

The final two pieces in this submission **"The way you make me feel": Shame and the neoliberal governance of disability welfare subjectivities in Australia and the UK** (Soldatic and Morgan 2017) and **Hiding, Isolation or Solace? Rural disabled women and neoliberal welfare reform** (Morgan, 2017) extend these discussions about disabled people's experience of space and welfare reform drawing upon empirical work conducted as part of Karen Soldatic's British Academy International Fellowship at CeDR in early 2012. The Fellowship 'Disability and Welfare: Rurality, Gender and Ethnicity' provided rich empirical data from interviews we conducted with disabled women living in rural areas in the North West of England which we used alongside data collected as part of Karen's earlier work on disability and rurality in Australia. The chapter initially presented as 'Disability welfare reform in Australia and the UK: a comparative analysis' at the Centre for Disability Studies, University of Leeds during Karen's fellowship in April 2012 and revised as 'Neoliberalising Disabled Subjectivities: Gender, Emotion and Spaces of (In)Security at part of the Identity and Politics of Emotions Panel a the European Consortium for Political Research Conference (Soldatic and Morgan 2014). This chapter was published in the edited collection *Edges of Identity: The Production of Neoliberal Subjectivities* in 2017.

The chapter situates the experience of welfare reform in Australia and the UK in the context of what we describe as 'neoliberal statistical panic' that utilises select statistics to precipitate a form of 'disability anxiety' that casts disability welfare as unaffordable and a cause, as well as necessary target, of austerity. Following the argument developed by Roulstone and Morgan (2009) we highlight the ways in which a 'precarious position of convergence' has emerged centred on the primacy of labour market participation and a 'right to work' alongside a 're-regulating [of] the relationship between the labour market and state welfare provisioning by making welfare supports dependent upon individualised economic contribution'.

This "disability panic" creates a common-sense populist rhetoric that repositions disabled people outside of the concept of the 'deserving poor' that had initially located meeting their (albeit very limited in its definition) needs at the heart of state welfare provision. Reclassifying disabled people as a significant cause of the crises of the welfare state took place as the same time as the dramatic erosion of public understandings of collective responsibility and care for others.

Building on our (Roulstone and Morgan 2014) argument that disabled people, particularly those dependent on welfare and social care provision, face a future isolated within their communities, we (Soldatic and Morgan 2017) propose that 'affective effects of neoliberal shame' violates disabled people's sense of identity and undermines their security and safety when they are 'out of place' (6). Thus, disability shaming is a structural collective act that is experienced individually and collectively by disabled people 'ooz[ing] through a range of spaces and places to hide the structural effects of social inequality, exclusion and deprivation' (7). The way in which forms of neoliberal governance shame disabled people into the 'performance of market behaviour' requires they deny self-care and care for others whilst having to perform 'care for the nation' via the realm of work'(4). This is a 'highly masculine able bodied project' with the same undermining of the ontological wellbeing of disabled people that characterises successive waves

of welfare reform and disability (re)classification, which mirrors the pattern of welfare reform identified by Deborah Stone in her study *The Disabled State* (1984): which focused on welfare reform in Germany, England and the US.

As we explored in *Accessible public spaces for the 'not-obviously disabled': Jeopardized selfhood in an era of welfare retraction* the violence experience by disabled people includes 'forms of material violence that are embodied and lived' (Tyler, 2013:212 cited 73). Drawing on Young (1990), we argue that welfare retraction 'generates a heightened sense of fear for disabled people when navigating the world due to the frequency, irregularity and randomness of this violence' (5). We examined the way in which the neoliberal affect of shame is highly mobile travelling for example, 'from the home to the place of disability verification' (13) where disabled people's navigation of spaces and places becomes a location for scrutiny, regulation and performance. This echoes the descriptions collated from social media (Roulstone and Morgan 2014) which made apparent disabled people's fears about the ongoing impact of welfare reform and its accompanying 'common sense' narratives of "welfare scroungers" and "disability fakers".

What emerged from the interviews in both Australia and England was that disabled people are on the frontline of welfare reform. Further, those anticipating reassessment and the potential loss or great conditionality of their benefits, 'actively internalised the public shame of being unemployed and on welfare as a moral evaluation of the self'. The 'songs of shame' they shared with us demonstrated a strong link between the increasingly vitriolic public discourse about welfare entitlement and their feelings of internalised shame, inferiority and unworthiness. For most of the people we talked to this manifested in forms of hiding or withdrawal from public places and from the incursion of the apparatus of welfare reform into their homes and other private or personal spaces. For example, Rachel took her phone off the hook, isolating herself from her primary form of connection with the wider world to avoid the 'haranguing and bullying' from her workfare case worker.

In the UK the 'interscalar labour of neoliberal shame asserts its authority over everyday life' epitomised for many by the distinctive brown envelope used by the Department of Work and Pensions to send 'invitations' for reassessment or to deliver the outcome of that process. The envelope performs a dual purpose drawing attention to an individual's status as a welfare recipient 'potentially 'scrounging'', while also representing the latent threat and ontological violence of losing one's disability status.

Despite this, the narratives we examined demonstrated a range of strategies deployed to protect and sustain emotional well-being in the face of 'the barrage of neoliberal workforce policies that shame them into compliance'. The final (and last completed) piece in this collection considers this through the experience of a disabled women living in rural northern England.

Hiding, Isolation or Solace? Rural disabled women and neoliberal welfare reform (Morgan, 2017) is an invited chapter in *Disability and Rurality: Identity, Gender and Belonging* edited by Karen Soldatic and Kelley Johnson of University of New South Wales, Australia for the Ashgate Publishing's Interdisciplinary Disability Studies series. The book seeks to address the lacuna that exists around the experiences of disabled people in rural landscapes. My chapter focused on Jenny's story as a way of exploring the contradictory space of the rural for disabled women when enduring the harsh realities of neoliberal welfare reform.

The chapter begins by mapping how disabled people 'are largely absent' from social geographic and sociological imaginings of the rural despite a 'considerable interest in "hidden others"' (Cloke and Little 1997, 97). Even with the emergence of this rich body of work that particularly considers the intersection of gender, rurality and other forms of diversity, disability 'remains marginalized' (98) in writing about the rural. Similarly, disability studies is 'largely silent on rurality, the experiences of rural disabled people and of disablism in rural settings' (98). Thus the opening section *emplacing disability: writing in the rural* identifies strands from existing rurality and disability literature that provide a foundation for exploring the experiences of the disabled women we interviewed in northern England in 2012. The

'writing of the rural' undertaken by Cloke and colleagues (Cloke et al 1994; Cloke and Little 1997) exposed the way in which myths and stereotypes of the rural idyll that occupies such a powerful position in the British imagination have 'masked diversity and concealed social problems' (97). Fixed notions of the rural, whether of location or identity, have been contested with accounts that privilege 'people's everyday interpretations of rural places and ideas of the rural' (Jones 1995 cited 98).

Writing from disability studies 'provide a lens through which to examine the experiences of rural disabled women' (98). Kitchin's reminder that disabled people are frequently 'out of place' compels us to look for the structures, attitudes and policies that create 'landscapes of exclusion (Kitchin 1998:351). Similarly Reeve's development of the concept of *psycho-emotional disablism* produces a theoretical frame for understanding the ways in which 'disablism has become more insidious' as more obvious physical barriers to inclusion and participation are dismantled. The experience, or premonition, of moving through 'increasing hostile and problematic' public spaces (99) and the way in which this permeates more private and personal spaces (Soldatic and Morgan 2017) results in forms of psycho-emotional disablism 'that are restricting and limiting the participation of disabled people' (99).

The chapter draws on our analysis of the 'toxic environment' for disabled people created by neo-liberal discourses that posited disability and disabled people as undermining the ''health' of the nation' (Soldatic and Morgan 2017:1). The 'whipping up of a moral panic' over disabled people's 'dependency' and creeping entitlement to welfare provision has lead the particular focus on 'faux' or potentially 'faux' disabled people outlined in Roulstone and Morgan (2014). What was particularly interesting about Jenny's story was that while it exemplified the ways in which 'the rural as a place of refuge was under threat for the disabled women we talked to' (100) it also demonstrated a 'narrative of mobility' (Soldatic and Johnson 2017: 8) about the potential of rural communities to offer access to safe spaces and collective forms of support.

For Jenny, the rural hamlet in which she had grown up and where her parents continue to live is where she is able to 'be herself' with a 'sense of attachment and rootedness' (Cresswell 2015:39 cited 100). The 'isolation and solitude' of the countryside provides respite from 'the stimulation and close quarters of busy urban settings' and access to the practical and emotional support provided by her parents. This echoes the dominant conception of the rural as idyll, a place to 'get away from it all' however, as Jenny's account exposes, the rural is at the same time a 'more complex, contradictory and disabling space than traditional literature and popular imagining suggests' (100).

As we argued in *Accessible public spaces* (Roulstone and Morgan 2014) current welfare narratives are especially problematic for those with invisible and/or fluctuating impairments. Jenny walks a tightrope between being sufficiently disabled to retain her entitlement to the benefits which are critical to enabling her well-being and the way in which 'her sense of belonging was contingent on…. "passing" as "normal"' and thus 'conditional on a series of standards she had imposed on herself' (102). Having a 'formal or officially sanctioned diagnosis' was 'critically important' for Jenny as a way of presenting her entitlement to benefits and a life outside of paid work. But the binaries presented in welfare and media discourses discussed in the earlier chapters (Roulstone and Morgan 2014; Soldatic and Morgan 2017) are at odds with the lived experience of impairment and disablism where disabled people are required to work hard to perform in socially acceptable ways. Jenny recounts the emotional energy and cost of living under welfare surveillance and of performing to different audiences, like her parents or partners friends. Her account highlights the importance of peer support and access to people who have the same disabling experiences. In contrast to the more conventional impairment specific groups which Jenny found to be 'full of retired people' with whom she 'didn't have much in common', it was a disability arts group that provided the sustenance and solidarity envisaged by Finkelstein (1987 cited in Roulstone and Morgan 2009:337). This return to a focus on the significance of peer support and user-led disability (rather than impairment) groups takes me back to the

focus of the first research project I was employed on *Creating Independent Futures* (at Leeds University 2000-1) and highlights a number of the threads and strands that have emerged and re-emerged in this collection of work.

Conclusion

To summarise, I have presented a selection of my academic publications, and associated practices which makes a distinct and significant contribution to the field of disability studies. This is supported by a copy of my curriculum vitae which details a range of other activities, including publications, presentations and activities that seek to enhance disability studies as a field of politically committed and engaged inter-disciplinary inquiry. The clustering of the work under consideration here around two broad and overlapping areas of concern which are at the heart of disability studies, the disabled people's movement and the lives of disabled people – how disability studies is practiced and influences practices and how disability policy formation emerges, shapes and impacts upon the lives and wellbeing of disabled people.

I have sought to navigate a path in disability studies and the academy more widely that adopts a position of what Gill terms "critical respect" (2007). Gill likens critical respect to that of a member of a solidarity movement who is 'offering support, but recognizing that the support is worth more when the person giving it has not given up their right to engage critically, to ask questions, rather than be rendered a mute supporter' (2007:78). This is particularly pertinent in relation to the place and purpose of professional practice in the lives of disabled people. Making the case for social model rooted, and disability studies grounded practice, is the central argument I have sought to advance in my work.

While there is a strong and lively tradition of critical engagement with professional practice within disability studies, my contribution to disability studies is inherently collective. It is underpinned by a commitment to scholar activism within the wider "disabled commons" (Runswick-Cole and Goodley 2013) that is "in the wake" (Sharpe 2016) of the social model of disability and draws on the legacy of Finkelstein's conception of professions allied to the community (1991). This touchstone for my practice provides an intellectual and moral framework within which to undertake disability studies. In short, it is the contention of my work that disability studies

academics should be aligned to the communities they produce knowledge for and about, and locate their work within disability social movements.

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Appendix 1: curriculum vitae

Hannah Morgan

orcid.org/0000-0003-1039-9337

My research interests are primarily located in the interdisciplinary field of Disability Studies and I am committed to the development of this field in a way that is inclusive and respectful of the experiences, priorities and aspirations of disabled people. A central strand of my research has been the design and facilitation of accessible, inclusive events and activities that have contributed to Lancaster's reputation as a world-leading centre for Disability Studies, particularly the highly regarded biennial Lancaster Disability Studies Conferences (2003-; income to date £450,500). My current research focuses on the way disabled people are constructed and categorised in social policy, particularly in welfare reform and health and social care, and the implications of this for disabled people, their families, user-led organisations and critical professional practice.

Current Post

08/16 -   Senior Lecturer in Disability Studies, Department of
Sociology

Previous posts

08/13-08/16   Lecturer in Disability Studies, Department of Sociology

12/03-08/13   Lecturer in Disability Studies, Department of Applied
Social Science

01/02-12/03   Research Fellow, Social Policy Research Unit (SPRU),
University of York

01/00-12/01   Research Associate, Centre for Disability Studies,
Department of Sociology & Social Policy University of Leeds.

Academic Qualifications

2006   Post Graduate Certificate in Academic Practice, Lancaster University

1999   MA in Disability Studies, University of Leeds

1998   BA (Hons) Politics and Parliamentary Studies (2:1) University of Leeds

Academic Prizes & Distinctions

2012   Best Conceptual Article 2012 by *Social Work Education:* 'Threshold Concepts in Disability Studies: Troublesome knowledge and liminal spaces in social work education' *Social Work Education* 31:2. 215-226

External Research Funding (awarded at Lancaster)

2017-8	Named Social Worker Pilot – Phase 2 Bradford MDC Principal Investigator	£25,000
2017-8	Tackling violence and abuse against disabled women and girls in coproduction with mental health, social care and housing services. Disability Research in Independent Living and Learning (DRILL) Big Lottery Co-Invesigator (Lancaster Lead(	£39,959
2016-17	'My named social worker' Named Social Worker Pilot Phase 1 Calderdale Adult Social Care Principal Investigator	£50,000
2016-17	Sociocultural influences of learning-disabled men's self-harm on locked wards: Staff perspectives Mersey Care NHS Foundation Trust Principal Investigator	£5,000
2013-4	'Alcohol and sight loss: a scoping study' Alcohol Research & Thomas Pocklington Trust Co-Invesigator	£64,826 (+ £481 in 2015)
2010	'A systematic evaluation of the modernisation of day services for disabled adults' Halton Borough Council Principal Investigator	£17,455
2010	'Designing and Inclusive Curriculum in Higher Education' Higher Education Academy Principal Investigator	£11,000
2003-	Lancaster Disability Studies Conference (2003;2004;2006;2008;2010;2012;2014;2106;2018)	£450,500

Conference Organisater	

Journal Editorial Boards and Advisory Boards:

Disability & Society Member of the editorial board 2002-, Book Reviews Editor 2012-, Executive Editor 2015-

Disability Studies Quarterly Member of the Editorial Board 2015-

Social Work Education Member of the Editorial Board 2015-

External Examiner on degree programmes

2014-16   BA Society Joint Honours: Part Route in Disability Studies, Northumbria University

Critical friend in the Programme Approval process for Welsh Social Work Continuing Professional Education and Learning (CPEL) 2014-5

Publications

Citation indices (Google Scholar February 2018)

	All	Since 2013
Citations	298	182
h-index	9	5
i10-index	8	4
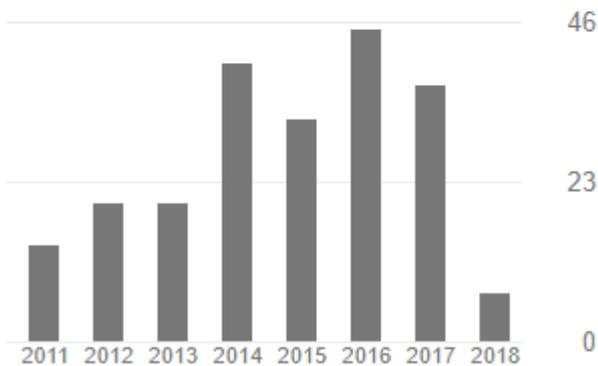
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*Galvani, S, Livingstone, W & Morgan, H 2016, 'The relationship between sight loss and substance use: users' perspectives' Drugs: Education, Prevention, and Policy, vol 23, no. 6, pp. 476-483.

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*Broadhurst, K, Dimopoulou-Lagonika, M & Morgan, H. (2007) 'Reflections on an English/Greek exchange in Erasmus' anniversary year. Is English practice learning out of sink with global flows and scapes?' *The Hellenic Journal of Social Science and Social Work* September pp. 167-188 (Greek translation only)

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Conference and research seminars

Invited and plenary speaker

Isolated, Jeopardised and Faux. Disability, Spaces and Places of Policy Exclusion
Postgraduate Medical Humanities Conference June 2017, Exeter

Threshold concepts in Disability Studies Northumbria University June 2015

'They're two spinning balls, one egging the other on' Understanding the relationship between Alcohol, other drugs and Sight Loss. Qualitative Health Group, University of Durham, 11th March 2015.

A year on has there been a lasting shift in attitudes towards disability? One year on from the Paralympic Games – what is the positive legacy for the Cultural Sector and what are the challenges and opportunities ahead of us? 2013, Brighton

Using Grademark to engage students with assessment feedback The Role of Technology in Teaching and Learning Sharing Practice Day Lancaster University 2nd July 2013

Disability welfare reform in Australia and the UK: a comparative analysis. Paper presented at the Centre for Disability Studies, with Karen Soldatic April 2012 Leeds University, UK.

Disabled People and the European Union: Equal Citizens? with Helen Stalford. ESRC Seminar Series: Implementing the Social Model: Europe, University of Leeds January 2004.

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User-led Research: Gathering the Evidence, Workshop What Works in Community Care? Oxford, September 2000.

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Morgan, H and James, E. (2017) 'My social worker' Putting #SWisHumanRights into practice Nordic Network on Disability Research, Orebro, Sweden

Benson, D. and Morgan, H (2016) Disabled refugees, continence and humanitarian innovation, Lancaster Disability Studies Conference 2016

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Morgan, H and Whitaker, D. (2015) 'A gilded cage is still a cage' yet vulnerability remains inherent: Optimism, contradiction and dissonance in Court of Protection judgments and its influence on safeguarding 'adults at risk' practice Nordic Network on Disability Research 2015, Bergen Norway'

Soldatic, K and Morgan, H (2014) Neoliberalising Disabled Subjectivities: Gender, Emotion and Spaces of Social (in)Security Identity and Politics of Emotions Panel ECPR General Conference 2014, Glasgow

Morgan, H Sherrington, C and Machin, L (2014) Clinical Ethics Forums: Using ethical engagement to overcome professional boundaries and facilitate inter-professional learning. JSWEC Conference: Social Work Making Connections Royal Holloway, University of London

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Accessible Public Space for the 'not obviously disabled'? Jeopardized selfhood in an era of welfare retraction with Alan Roulstone Disability - Spaces and Places of Exclusion Symposium 16 - 17 April 2012, Lancaster University

Morgan, H (2011) A road less travelled? A critical disability studies reading of the mobility paradigm Theorizing Normalcy and the Mundane, Manchester Metropolitan University, 14-15 September 2011.

Morgan, H & Roulstone, A (2011) Bridging collective roots and individual choices: a critical reflection on disability and community in the 21st century Nordic Network on Disability Research 11th Research Conference, Reykjavik, Iceland May 27-28, 2011.

Morgan, H & Roulstone, A (2011) Accessible Public Space for the 'not obviously disabled'? Jeopardized selfhood in an era of welfare retraction with Alan Roulstone. Paper presented at the Disability and Public Space Conference, Oslo University College, Oslo, Norway, 28-29th April 2011

Morgan, H & Roulstone, A. (2009) Teaching Disability Studies to Social Work Students Paper presented to the 11th UK Joint Social Work Education Conference, University of Hertfordshire 8-10 July 2009.

Morgan, H (2007) Career, Mobility and Motility: the experiences of disabled academics and researchers Nordic Network on Disability Research Biennial Conference, Goteborg, Sweden. May 2007.

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Morgan, H (2005) Disability, career and mobility in Europe Colloquium on Researching Innovative Themes in Skilled Mobility: The Centre for the Study of Law and Policy in Europe, University of Leeds May 2005.

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Social Model Outcomes? Nordic Network on Disability Research Annual Conference: Networking, Social Capital and Welfare Society, Jyvaskyla, Finland. September 2003

European Union Citizenship and Disabled People: Developing a Social Model with Helen Stalford Disability Studies Association Conference: Disability Studies: Theory Policy and Practice, Lancaster University. September 2003

Strategies for involving Service Users in Outcomes focused research workshop with Jennifer Harris Consumers in NHS Research Third National Conference: Making A Difference Harrogate. November 2002

Creating Independent Futures: User-led Research into User-led services workshop Making Research Count in the Personal Social Services, London. December 2001

Research Leadership: Organizer of conferences, workshops, research groups and seminar series

CeDR

Member Management Committee 2005-, Co-Director 2012-2016, Director 2016-

2012   Disability - Spaces and Places of Exclusion CeDR Symposium. Organised with Dr Karen Soldatic (British Academy Fellow)

2009   CeDR Symposium: Teaching Disability Studies to Social Work Students - CeDR Symposium. Organised with Bob Sapey

2009   Literary, Cultural, and Disability Studies: A Tripartite Approach to Postcolonialism. Organised with Dr David Bolt (CeDR Honarary Research Fellow)

CeDR Seminars, Reading and Film groups

Social Work Book Club - Lancaster Co-ordinator

Supervision and Teaching

PhD

2 supervised to completion, 4 current. I have been internal examiner on 1 PhD.

Doctoral Students (2 supervised to completion, 8 current)

Dates	name	Area of research	Type of funding
Awarded 2013	Laura Snell	Cochlear Implants and the Deaf Community	Departmental fees bursary

Awarded 2013	Christopher Spooner	Experiences' of Disabled Business Leaders	Self-funded (part-time)
2014-	Magda Szorta	Disabled Women's Movement in Poland	Dual Phd Candidate with Graduate School for Social Research, Polish Academy of Sciences
2015-	Toby Atkinson	The gendering of Autism in contemporary British popular culture	Faculty Bursary, ESRC DTC (Science Studies Pathway) +2
2015-	Brid Joy Blended Learning PhD Programme, Division of Health Research	A Qualitative Study to explore Mental Health Social Worker`s Perceptions and Experiences of Recovery Oriented Practice.	Self-funded
2016-	Cara Williams	Disabled people, employment and Small Medium Enterprises	ESRC DTC (Social Work Pathway) 1 + 3

MA:

Swk.439 Social Work in Adult Social Care - convenor

Swk.439 Social Work Dissertation - module convenor and supervision

Socl949 Dissertation - supervisor

Undergraduate:

swk.116 Contemporary Social Problems – module convenor, lecturer & seminar tutor

swk.278 Social Work in Adult Social Care – module convenor

swk.371 Social Work Dissertation – supervisor

socl245 Welfare Practices and Resistance –module co-convenor

Departmental administrative roles

2015-   Chair MA Social Work Exam Board

2016-   Director – Centre for Disability Research (CeDR)

2013-2017   Convenor swk.116 Contemporary Social Problems

2013-   Director of Studies MA/PGDip Social Work

2013-   Health Care Professions Council Liaison

2012-4   Director of Studies Applied Social Studies (Social Work exit route)

2006-14   Director of Studies BA Social Work

2007-09   Department of Applied Social Science Representative – Faculty Undergraduate Studies Committee

2004-11   Department of Applied Social Science – Disability Representative

2003-06   Social Work Service User and Carer Co-ordinator

Appendix 2: Publications Included in this thesis

1. Disability Studies Practices

Morgan, H. & Harris, J. (2005) Strategies for involving service users in outcomes focused research in L. Lowes & I. Hulat (eds) *Working Together: Service Users' Involvement in Health and Social Care Research.* London: Routledge pp. 163-170

Morgan, H. and Roulstone, A. (2012) 'Editorial' *Social Work Education* 31:2. Pp 137-141

Morgan, H. (2012) 'Threshold Concepts in Disability Studies: Troublesome knowledge and liminal spaces in social work education' *Social Work Education* 31:2. 215-226,

Morgan, H. [2014) Working with Disabled People in M. Webber (ed*) Applying Research Evidence in Social Work Practice* Palgrave Macmillan pp.182-196.

James, E. Morgan, H & Mitchell, R. (2017) 'Named social workers – better social work for learning disabled people?' *Disability & Society* 32 (10) pp. 1650-1655.

2. Disability Policy Formation

Morgan, H. & Stalford, H. (2005) Disabled People and the European Union: Equal Citizens? In C. Barnes and G. Mercer (eds) *The Social Model of Disability: Europe and the Majority World.* Leeds: The Disability Press. pp 98-114

Morgan, H. (2005) Disabled people and employment: the potential impact of European Policy in A. Roulstone and C. Barnes (eds) *Working Futures? Disabled People and employment.* Bristol: The Policy Press pp259-272

Roulstone, A. and Morgan H. (2009) 'Neo-Liberal Individualism or Self-Directed Support: Are We All Speaking the Same Language on Modernising Adult Social Care? *Social Policy and Society* 8 (3) pp 333-345.

Morgan, H. (2013) User-led organisations: facilitating Independent Living' in J. Swain, S. French, C. Barnes & C. Thomas (eds) *Disabling Barriers – Enabling Environments* 3rd Edition. London: Sage. Pp. 206-213

Roulstone, A. Soldatic, K. and Morgan, H. (2014) Introduction: disability, space, place and policy: new concepts, new ideas, new realities in K. Soldatic, H. Morgan & A. Roulstone (2014) (eds) *Disability, Spaces and Places of Policy Exclusion* London: Routledge pp 1-9

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Soldatic, K & Morgan, H (2017) "The way you make me feel" Songs of Shame and the neoliberal governance of disability welfare subjectivities in Australia and the UK in J. Louth & K. Harrison (eds) *Edges of Identity: The Production of Neoliberal Subjectivities* Chester: University of Chester Press.

Morgan, H. (2017) 'Hiding, Isolation or Solace? Rural disabled women and neoliberal welfare reform' in K. Soldatic & K. Johnston (eds) *Disability and Rurality: Identity, Gender and Belonging* Ashgate

Morgan, H. & Harris, J. (2005) Strategies for involving service users in outcomes focused research in L. Lowes & I. Hulat (eds) Working Together: Service Users' Involvement in Health and Social Care Research. London: Routledge pp. 163-170

Introduction

This chapter details the attempts of the authors to develop meaningful involvement with service users in a project that researched the development and utility of an outcome focus in assessment and review work with disabled adults of working age. The strategies employed are discussed within the context of wider debates about disability research, the influence of the funding agency and resource constraints.

The development of a social barriers/model understanding of disability, initially by disabled activists (Union of the Physically Impaired Against Segregation (UPIAS) 1976) and latterly by academics (Oliver 1983; Barnes 1991) has challenged the traditional notion that impairment – whether physical, sensory or cognitive – was the main factor in the disadvantages experienced by disabled people. Therefore, barriers rather than impairment are a more appropriate focus of disability research. Furthermore, research based on individual or medical understandings of disability was recognized as contributing to this process of disablement by perpetuating an understanding of disability as individual limitation causing disadvantage.

This led to the charge that disability research is often a 'rip-off' (Oliver 1992), expecting the participation of disabled people as passive subjects without any real benefit for disabled people, either individually or collectively.

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.

(Oliver 1992: 105)

There has been considerable discussion within disability studies and more widely about the emancipatory potential of research to illuminate, challenge and remove disabling barriers including the development of an emancipatory research paradigm (Oliver 1992) and the articulation of its key principles (Stone and Priestley 1996; Barnes 2004). Simply put: 'Emancipatory research

is about the systematic demystification of the structures and processes which create disability' (Barnes 1992: 122).

Emancipatory research is an epistemological approach to research rather than a methodology, and the principles that underlie it can be summarized as adherence to a social model perspective, accountability to disabled people and their organizations, and a commitment to producing research that is empowering both in its process and its outcomes (Barnes 2004). At the heart of emancipatory research is a rejection of the positioning of the researcher as an objective neutral participant in the research process. Instead, considerable attention is paid to the social relations of research production with the recognition that the emancipatory potential of research is determined by the extent to which disabled people (and other oppressed groups) are 'actively involved in determining the aims, methods and uses of research' (Zarb 1997: 52). It is vital that the social relations of research production are transparent and that it is clear where power resides and how it is being utilized.

The challenge for those of us undertaking disability research with a commitment to a social model of disability is how we seek to adhere to these principles within existing confines, not least the precarious nature of contract research careers and the dominance of funding institutions in the field. This chapter draws upon the experience of the authors undertaking a specified project, discussing the strategies for involving service users employed within a wider context of confines and limitations. Consideration is given to the effectiveness of these strategies and the relative impact of external factors.

The context of the project

The Outcomes for Disabled Service Users project, currently ongoing with a three-year lifespan, is an innovation to research the development of outcome focused assessment and review processes in services for disabled people of working age. The project forms the first attempt to introduce a focus upon the outcomes that disabled people wish to see from social services. It is fully compliant with the core principles of the social model of disability and, as such, makes an important contribution to debates concerning the best means of identifying and achieving the types of service that disabled people aspire to receive. It is core funded through a government grant programme and sited within a British university. The project works with one Social Services Department's disability service, which is responsible for all services provided to people with physical and sensory impairments aged 18-65 years.

The research team, being wholly committed to a social model of disability (Oliver 1983), have striven to incorporate key features of the

original model and later developments into the project at every opportunity. These include awareness of, and willingness to, address environmental and attitudinal barriers to service provision and user led (not service led) provision of services to disabled people. The latter is considered extremely innovative within the context of social service provision in the United Kingdom. There is also wholehearted commitment to involving service users in the research about services in creative and meaningful ways.

Confines and limitations of the project

Undertaking research that forms part of a wider programme of work necessitates adherence to guidelines and codes of practice that are inherent to the programme, but which do not necessarily chime well with the ideals of researchers or practice within the field. Research conducted with disabled adults is often (as in our case) conducted within the wider remit of adult social care, in which the main focus is on the requirements of older people and, to a lesser extent, informal carers. These latter fields of practice, being less politicized in the United Kingdom than in other areas of the world (notably the United States), do not, as a rule, conform to the tenets of the social model of disability and are less likely to recognize its importance. It is frequently difficult to summon sufficient tact in rejecting the terminology and patronising practices that are widespread within the field of social care with older people. These tensions also exist in social care provision for younger disabled people, because most Social Services budgets are committed to older people's services and where practitioners still work 'across the age boundaries' (under and over the age 65). Thus inappropriate practice is often transferred from one group of service users to the other, despite the relevance of a social model perspective in practice with older people.

There are also considerable constraints exercised through the medium of the funders of the research. While the Department of Health is committed to 'user involvement' in research funded through the programme, the extent of direction and commitment to it is not explicitly expressed. As with all other aspects of research, the extent of commitment is general expressed in terms of the financial resources allocated, and these must be kept within modest boundaries. Furthermore, as part of a long-term research programme there is less room for manoeuvre in terms of involving users in shaping the main aims and objectives of the project, as the main research aims and question had been predetermined as an earlier part of the programme. This inflexibility inevitably conflicts with both the political and philosophical commitments of the authors and creates tensions that must be managed within the confines of commissioned government research agenda.

Strategies for involving service users

Notwithstanding the constraints discussed above, the research team and the wider unit in which it is situated have a long-standing commitment to meaningful service user involvement in research (Heaton 2002; Lightfoot and Sloper 2003). Therefore, the project was able to build upon extensive experience of working collaboratively with disabled people and service users, and draw on existing relationships with organizations of disabled people and a developing pool of knowledge about good practice.

Project advisory group

In common with the other projects that constitute the Outcomes Programme, a project advisory group was established and a rage of 'experts' invited to join. This included the research manager from the Coalition of Disabled People based in the partner local authority. The involvement of a grassroots organization of disabled people from the research locale was felt to be significant for a number of reasons. First, and perhaps most importantly, because the inclusion acknowledges the user perspective as equal in value to those of other (more traditional) 'experts' in the research field, such as academics, policy customers and the voluntary sector. Furthermore, it allowed a representative user voice to be heard much more centrally and at an earlier stage in the research process. An additional benefit was the ability of the local organization of disabled people to have both a local and national perspective on policy developments and the research project.

The input to the project advisory group provided by the user representative was invaluable both in terms of assisting the general progress of the project but more specifically in advising the research team about methods and strategies for increasing the level and quality of user involvement, for example through introductions to other groups. Indeed, the relationship developed to such an extent between the research team and the disability organization that a joint bid for research funding from the Social Care Institute for Excellence was submitted. While the bid was unsuccessful, its significance lay I the lead role taken by the Coalition and the potential for a reciprocal working relationship to be established.

However, tensions emerged due to the difficult relationship between the organization of disabled people and the local authority and ultimately the representative withdrew his membership of the project advisory group. It was made clear this withdrawal was not related to either the content of the research project or the activities of the research team, but rather the organization of disabled people felt that their continued involvement with the project might be construed as support of the more general activities of the Social Services Department with which they were at odds.

This turn of events illustrates the difficulties posed for researchers when seeking to balance the involvement of a range of stakeholders, particularly those who feel their credibility may be compromised by shared membership of an advisory group. On one level, it was frustrating for involvement to break down due to external factors after considerable effort had gone into developing the relationship. However, on the other hand, it gave the research team considerable insight into local relations, and in some senses should be seen as part and parcel of the challenge of increasing the meaningful engagement if often conflicting or even contradictory perspectives and stakeholders.

Service user panel
The 'usual' means of involving service users in research of this kind is to form a service user panel that meets two of perhaps three times a year to discuss the progress of the research and to give a steer on important issues. At the outset of the project, the researchers discussed this form of involvement and found it lacking in some important respects. First, our commitment to real and meaningful involvement mean that the constraints of meeting with service users only six times in three years would limit the amount of influence they could realistically exert over the decision making process. Second, there were very real concerns about how representative any small group of service users could be due to the huge geographical area covered by the research. The site includes affluent rural areas and pockets of extreme deprivation. The issue of representativeness also applied to inclusion of different impairment groups and other types of identity such as ethnicity, gender and age. It would be impossible to include serve users from all impairment and other groups and, inevitably, the selection process would exclude many. Third, the huge geographical area would have implications on the willingness and ability of individual service users to travel to meetings. Again, a few people who either happened to live in one area or had access to transportation could dictate membership and influence. Furthermore, as suggested earlier, involvement has to be resourced within the financial constraints of the project and there were concerns that large chunks of the 'involvement' budget might be eaten up by transport and other access costs, thereby limiting the number of participants.

Bearing all these in mind, our strategy developed along the lines of 'lateral thinking', particularly in terms of developing better ways of utilizing limited resources to maximize both the quantity and the quality of involvement.

The 'virtual panel'
The first decision taken was to disband the idea of using any static formalized regular meeting process. This overcame most of the issues highlighted above,

including geographical and transportation problems. Once this decision has been made, the task became how to set up a 'virtual panel' with fluid but inclusive boundaries. Thus, service users and disabled people (as either individuals or organizations) could join, participate and leave at any stage of the life of the project (a conscious decision was taken to include disabled people who both used and did not currently use services). This had obvious advantages for many service users as well as for the project, since some issues are most interesting to some individuals than others, but also life circumstances and impairment effects (Thomas 1999) may dictate the extent of available personal energy and thus commitment that can be given to the work. Similar issues apply to organizations of disabled people and service users who are characterized by precarious funding and are, by and large, staffed by volunteers (Morgan et al. 2001).

Under the 'traditional' service user involvement design, the research team are in the driving seat, with service users playing an advisory role. This generally extends to the formalized meeting structure with agenda set in advance, usually by the research team. However, a decision was made that where face-to-face consultation and advice giving was necessary, it would be far better to seek to join groups already in existence, where the membership were in control of the agenda and decision making processes, and could set the terms of their involvement. This proved to be an important strategy in terms of the exercise of users' 'voice' and recognition if control issues. This type of consultation can be challenging for researchers as striving for greater equality in relationships between researchers and service users inevitably involves shifting power and control from the hands of the research team to reflect a more equitable balance. It means that issues about the research are not necessarily at the top of a disability group's agenda and that the priority given to particular aspects of discussions are determined by the membership in attendance, rather than the researcher. This can lead to tensions for researchers who may be under pressure to undertake consultation on certain issues at specific stages of the project when this does not tally with the priorities of the partner organization.

Flexibility also extends to the media of participation. Once the traditional structure was disbanded, it became possible to envisage new forms of participation, such as email lists for consultation on document content and postal participation. In the event, neither of these strategies were taken up by service users to any great extent, for reasons that are unclear, but which may have been to do with access to computer equipment in the former. It was also apparent that many of the groups involved appreciated face-to-face contact as it made it easier for them to exercise control and choice over the way in which information was exchanged, e.g. it allowed questions to be

asked of the research team and issues explored in 'real time' rather than the more extended toing and froing of email or postal conversations. Face-to-face meetings also allowed a greater element of reciprocity in the relationship. Groups could tap into the specialist knowledge of the research team and exploit in a small way the contacts and resources of a research institute, for example through sharing information about recent research and policy developments.

However, the inclusion of such strategies allows for a much wider range of consultation, both for targeted and routine purposes, and it ultimately far more inclusive than traditional groups.

Developing accessible consultation

To maximize levels of involvement, it was felt important to pay considerable attention to developing accessible methods of communication. As a matter of routine, all project documents were made available in large print, electronically, in Braille and on tape. Due to resource constraints, it was not possible to routinely produce documents in community languages, although a commitment was made to production should it be requested. This was felt to be a reasonable compromise because there were only occasional instances of service users in the research locations requesting their social services documents in community languages compared to levels of request for large print and other alternative formats. It was made clear on any project document that all efforts would be made to produce alternative formats if they were requested.

Any attempts to increase the quantity and quality of involvement and participation requires attention to be paid to the process of ensuring informed consent from participants. The project developed world already undertaken by the research unit on the development of clear and concise documents to enable participants to make informed decisions about their involvement (Heaton 2002). Considerable attention was paid to ensuring leaflets were clear and concise with an emphasis on plain English and demystifying the research process. Furthermore, it was decided to produce two video versions of the leaflets. Two versions were produced. The first, in plain English and aimed at people with learning difficulties or with acquired hearing loss, was recorded by an actor and subsequently subtitled. The second, aimed at British Sign Language (BSL) users, was developed in consultation with a BSL tutor/consultant. While the research team had the advantage of having a member with considerable expertise in D/deaf research as well as being a BSL user it remained a difficult process to translate abstract English concepts into BSL.

Wider consultation

It was felt important that the project involved disabled people and their organizations more generally and service users at a national level as well as within local authority. Therefore, at an early stage in the project, a seminar was jointly organized with Shaping Our Lives, the national user network, to bring together service users, practitioners and academics to discuss their different perspectives on the utility of an outcomes focus in social service provision. The seminar built on the existing relationship between the research unit and Shaping Our Lives, who were also conducting outcomes focused research (Shaping Our Lives 1998, 2002).

The day stimulated lively discussion (Morgan and Harris 2002) and while disagreement remained about the way in which agreed outcomes are produced, the seminar was characterized by a respect for differing perspectives and recognition of the validity of the contribution from each participant. This kind of coming together of different stakeholders in research helps to make dialogue an ongoing process rather than something that solely occurs at particular stages in the research process. Participants are able to shape each other's thinking and gain access to views, perspectives and knowledge that they may not come into routine contact with otherwise. Furthermore, the involvement of representatives from funding agencies and policy customers means users, practitioners and researchers can influence the embryonic stages of research agenda and development.

Conclusion

User involvement and consultation, whether in service development, provision and evaluation, or in research about services, is 'no longer simply a good thing' (Beresford 1992). It is required by legislation and policy guidance and demanded by service users and their organizations. This is supported by the articulation of a social model of disability, the evolution of critical disability studies and the development of an emancipatory paradigm in disability research. Increasing levels of involvement in all stages of the research process have been broadly welcomed by researchers as contributing to the validity and quality of the research produced and as a positive influence on the process of research and its impact on all participants.

However, consensus about the best ways of involving users and the manner in which this participation should be resourced has not yet been achieved. Thus frequently leaves researchers with the challenge of aspiring to meaningful engagement within contexts that may not be fully supportive of, or may even be counter to, this involvement. The most obvious of which are the levels of resources the major funding agencies are prepared to commit to involvement in particular projects. While levels have certainly increased in recent years, and funding agencies are increasingly receptive to more

creative methods, funding for involving service users outside the confines of particular projects remains constrained. Most research units, whether within or without higher education institutions, rarely have sufficient funding to involve users routinely in the development of research bids. This is compounded by the relative absence of service user voices in the genesis of research agendas and programmes. Thus, considerable effort needs to be directed at engaging service user perspectives at the macro-level of research production.

However, as we have suggested, much is possible at the micro-level or coalface of research production. Expertise is growing around the most effective ways of involving users at all stages of research and this can be seen as a cumulative process whereby user perspectives are increasingly 'internalized' by researchers, informing their thinking and practice. It is clear that negotiating new relationships and new ways of 'doing user involvement' can be a steep learning curve for all concerned and so the emphasis needs to be on learning from this process rather than feeling under pressure to get it right straight away.

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It is almost 30 years since Michael Oliver developed the social model of disability as 'an attempt to enable me to make sense of the world for my social work students' (1990:2) in his now seminal book, *Social Work and Disabled People* (1983). Originating from UPIAS' *Fundamental Principles of Disability* (1975), the social model of disability has resulted in a seismic shift in the way in which disability has been understood. Breaking the causal link between impairment and disability has engendered a radical response from the disabled people's movement and the allied inter-disciplinary field of academic work disability studies. The 'problem' of disability has been recast as disablism, a form of oppression akin to racism and sexism. Identifying and challenging disabling barriers has been central to this project.

Despite social work's early engagement with the social model, initially in the classroom for Oliver's students and now formally acknowledged in GSCC specialist standards and requirements for post-qualifying social work education as the appropriate model to underpin genuine partnership with service users (2006), the relationship between social work and disability has remained chequered. Writing in *Social Work and Disabled People*, Oliver suggested that unless social work was able to meet the challenge issued by the social model it would become irrelevant to the lives of disabled people and cease to exist as an area of practice. Writing more recently in a pre-retirement evaluation of the development and impact of the social model, Oliver argued that, in the intervening period, social work had failed to meet the needs of disabled people with the result that 'We can probably now announce the death of social work at least in relation to its involvement in the lives of disabled people' (2004).

While many within the disability movement and disability studies share this analysis, there are others of us who contend that social work has great potential to develop enabling practice and work partnerships with disabled people and their organisations (cf. Harris and Roulstone 2010) this special issue is premised on the view that professionals have a continued role to play in working with disabled people; however, our shared starting point is that the context for their work and the nature of their relationship has and will continue to change. What unites these papers is a commitment to enabling practice and to a continuing dialogue between social work, disability studies and the disabled people's movement.

Our proposal for this special edition emerged at a symposium *Teaching Disability Studies to Social Work Students,* hosted by the Centre for

Disability Research at Lancaster University in May 2009. The lack of books and papers in social work journals suggested that disability is a neglected area of social work education and that engagement with the social model of disability is not widespread either in the UK or internationally (Sapey 2004). These findings were confirmed in a recent review of social work education in the UK (Boulshel *et al.* The purpose of the symposium therefore was to collate and share the knowledge and experience of people and programmes where this is happening. The papers given, and the discussions they ignited, provide the basis for a number of the articles presented here and stimulated our wider call, particularly for international perspectives.

We would like to acknowledge and express our gratitude for the significant contribution of Bob Sapey, Senior Lecturer in Disability Studies at Lancaster University and co-author of latter editions of Social Work and Disabled People (Oliver et al., forthcoming) to this project. Bob has played a critical role in ensuring disability has remained on the agenda of social work education through his early work with BASW and latterly with the Higher Education Academy Social Work and Social Policy subject centre. Bob instigated and co-organised the symposium and has provided great support and encouragement to many of us working in this area.

The first article is a reflection by Alan Roulstone on the progress of social work education to date in realising the vision of enabling futures made plain in the work of Vic Finkelstein and Paul Hunt in the early formulations of enabling services and professions. Seeing social work as having a continued and important role, Roulstone explores those factors that continue to limit the enabling potential of developments. He points to the knowledge base of social work, sitting as it does in sociology and social policy, as part of the explanation. Not that these disciplines are inappropriate, more simply that these subjects themselves have been relatively silent on progressive and disability-led insights into disability. Roulstone also sees the lack of clarity in much of the social sciences as to who counts as disabled people, leaving many, otherwise key texts in social work rather thin and nebulous in the area of disability. Disability studies has a key role in informing better responses to disability, in academic writings and practice guidance.

Peter Beresford and Kathy Boxall's paper explores the implications of service user contributions to social work education in the light of historical critiques of disability research. The paper reflects on the authors' dual service user and academic perspectives as well as their dual disability studies and social work disciplinary affiliations. Referring back to early critiques of disability research, it argues that isolated user involvement in social work education can be problematic, particularly where that involvement is under the control of the academy. Drawing on feminist critiques of traditional social science, the authors present arguments for the collective involvement of service users in research and underpinning knowledge for social work as well as in social work education.

Marilyn Dupre explores notions of culture and cultural competence in her article. Writing from a Canadian perspective she argues that essentialist

concepts of culture, as represented in assimilationist and pluralist social work approaches, provide social workers with the false belief that there are cultural competencies that one can develop that are sufficient to become more culturally sensitive. Dupre argues that the critical theory underpinning disability culture demonstrates that an understanding of cultural politics is fundamental to social work education if it is to support the work of the disabled people's movement in demystifying and deconstructing the norms, discourses and practices of dominant culture which are represented as neutral and universal.

The paper by Jo Rees and Michele Raithby from a Welsh social work context explores how previous research has indicated relative reluctance among student social workers to plan future careers working with people with physical impairments. The paper relates interim findings from a longitudinal study which has followed one cohort of undergraduate social work students from induction onwards, to investigate and contribute to the development of effective curriculum strategies in preparing students for contemporary generic social work practice in relation to disability issues. A mixed methodology approach utilising questionnaires and focus groups was used to track the development of social work student perceptions of their preparedness for working with disabled people at different points in their education.

Carolyn Gutman and colleagues present a piece on social work with disabled people in Israel. The article examines the contribution of partnering with service users to the training of health and welfare professionals in Israel. These professions, while professing a shift to the social model of disability, still practise according to a medical model, which functions to strengthen the legitimacy of the professional and sustain the dependency of their clients. Adopting the social model of disability, they present a new pedagogic model in which social work students engage throughout the course with a co-teacher service user to contest these traditional methods and deconstruct accepted hierarchies.

Hannah Morgan considers the way in which much disability studies knowledge can be 'troublesome' for social work students. Viewing the social model of disability as a threshold concept that students will need support to move through offers the opportunity to enable students to genuinely adopt enabling practice rather than ritualised performance. By drawing on threshold concepts students can gain a depth of insight into disability and practice challenges in contemporary British social work.

In an article that builds on Morgan's paper, Donna Reeve suggests that introducing the concept of recognition, as articulated by the philosopher Axel Honneth, to students early in their education provides an opportunity to 'smooth the[ir] subsequent passage' (p. 228) through this threshold. Both papers call for theoretical clarity around the disability 'problem' if disaled people are to be supported to realise choices, rights and belonging.

Clare Evans's article provides a detailed insight into the role and value of practice placements for social work students in Disabled People's Organisations (DPOs). The article draws on Clare's experiences of and insights into student placements at Wiltshire and Swindon Users' Network in collaboration with a number of universities over a 15 year period, 1993–2008. Clare argues that the disability-led approach at the core of DPOs and the freedom from local authority cultures can afford particular and enabling insights for social work students. Close working with disabled people and an understanding that goes beyond the personal to the collective struggle for rights sits at the heart of the placement experiences. This approach is seen as particularly helpful in supporting enabling practice with disabled people.

Colin Cameron and David Tossell provide an article using a dialogue approach to exploring the complexities of disability and impairment. The dialogue follows a real teaching dilemma faced by an experienced social work lecturer in planning an introductory life course lecture about people labelled as having learning disabilities. The dilemma related to a teaching session and whether or not to begin with a quote from a parent reflecting on her own feelings shortly after her twin children, aged six months, had been identified as having a congenital impairment. The article then goes on to reflect on the medical and social models of disability and the limitations of those models in framing the dilemma above. The article suggests that an affirmative model of disability can best support enabling education and practice in social work.

In the final article, Karen Soldatic and Helen Meekosha explore the implications of the spread of neo-liberalism to Australia and its impact on social workers, disabled people and their families. Social workers under neo-liberalism are having to negotiate the competing demands of these policy constraints alongside the needs of the disabled people they work with. New moral dilemmas have emerged where they are actively faced with the question of 'who to serve?'. Soldatic and Meekosha draw on disability studies and feminist insights to explore the problems of contemporary Australian social work.

We hope that the papers in this special edition will encourage more social work educators to think critically and reflexively about the place of disability and disabled people in social work education and be inspired to work in partnership with disabled people and their organisations.

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Abstract

This paper draws on the notion of threshold concepts to consider the way in which disability studies has the capacity to transform social work students' understandings of disability and therefore influence their practice. Most students enter social work programmes with the professed aim of 'helping' and so to be confronted by an approach (the social model of disability) and a body of research and theorising (disability studies) that challenges their taken-for-granted assumption that social work practice is 'helpful' is unsettling and can lead to resistance. The purpose of this article is to interrogate practice on a social work programme where a commitment to social model practice is explicated and embedded with the purpose of identifying what it is we want students to 'get', whether they find this troubling and how they can be effectively supported as they move through liminal spaces in social work education.

Keywords: Disability Studies, Social Work Education, Threshold Concepts

Introduction

The relationship between disability studies and social work education has a long, although not unproblematic, history. Indeed, it was while teaching social work students in the early 1980s that Mike Oliver coined the term *social model of disability* as a way of translating the ideas formulated by UPIAS (UPIAS/Disability Alliance, 1975) into practice contexts. Thus as Oliver suggests:

This was no amazing new insight on my part dreamed up in some ivory tower but was really an attempt to enable me to make sense of the world for my social work students and other professionals whom I taught. (Oliver, 1990, p. 2)

Since then, disability studies has emerged as a vibrant and diverse discipline in higher education.1 While disability studies (in the UK) may have its roots

in more traditional disciplines such as sociology, social policy and cultural studies, many of its foot soldiers now ply their trade in applied subjects such as nursing, education, psychology and social work. This enables disability studies to influence and shape the education and eventual practice of professions and occupational groups that continue to exert significant influence over the lives of disabled people. However, notwithstanding considerable rhetoric about the common ground between these professions and the aims and objectives of the disabled people's movement, disability studies educators continue to contend with established and hegemonic approaches to education and practice that are frequently disabling in their ethos and application (Sapey, 2004). In addition, disabled people's exclusion and marginalisation persists within professional education and practice with the result that their lived experience remains alien to many students and practitioners (cf. Thomas, 2009).

That disability studies has much to offer social work education is no longer the subject of debate. The language of the social model permeates policy and practice guidance and the GSCC specialist standards and requirements for post-qualifying social work education and training (2006) explicitly state that social workers should engage with the social model in their practice. Moreover, there are strong messages emerging that the on-going implementation of the personalisation agenda will only be effective if it is grounded in the work of the disabled people's movement and disability studies (Glasby, 2009; Harris and Roulstone, 2010). It is a model and approach to practice that is valued and prioritised by service users (Morgan and Harris,2003; Beresford, 2007) and their organisations (Barnes and Mercer, 2006). As Oliver contends, 'It is tempting to suggest that we are all social modellists now!' (2004, p. 18). However, as evaluations of social work practice have made clear (cf. Sapey and Pearson, 2004; Harris, 2004), simply singing (or mouthing) along to the same hymn sheet is insufficient to effect the scale of change required.

The aim of this paper is to draw upon the experience of an established disability studies led approach to teaching social work to facilitate a discussion about *how* we teach disability studies in a way that effectively scaffolds and supports student learning and practice.

Context: Disability Studies and the Lancaster Social Work Programme

Social work has been taught at Lancaster University for over 30 years. It is a well-established and highly regarded qualifying programme that is taught at both undergraduate and postgraduate level. A key aspect of the programme has been the emphasis on providing an education rather than training for social work. This approach prioritises students acquiring and developing skills, such as critical thinking and reflexivity, that will withstand the pressure and constant changes of practice. This represents a move away from a still dominant 'tool-box' approach that is organised around modes of

service provision and service user groups, i.e. 'social work and disabled people' or 'personalisation'. It is also a strategy that seeks to respond to an increasingly 'stuffed' curriculum by focusing on the development of key skills and, as I go on to discuss, threshold concepts.

This approach is exemplified by the first-year undergraduate module *Disability in Society* that takes the social model of disability as a foundation for students' understanding of social divisions and inequalities. This becomes the basis for critical discussion about the potential of social work to meet the needs of disabled people rather than starting from how social workers should work with disabled people or from a focus on the mechanism of service provision. The module therefore supports students to develop a critical perspective on the purpose and potential impact of social work rather than teaching them how to deliver 'community care' or 'self-directed support'.

In the wake of the Baby P scandal there was considerable debate about the balance between academic and practice learning with significant concerns raised in response to calls from the then Secretary of State for 'more on-the-job training and less theory for students' (Doughty, 2008). Clearly, a balance needs to be struck between the academic and practice components of social work education but there appears to be a growing dissonance between academics working in social work education who would prefer a reduction in the number of practice learning days and the emphasis on 'on the job' training frequently favoured by politicians, practice assessors and often students. This tension is exacerbated in a field like disability where much practice remains dominated by individual model influenced and procedure driven practice.

This frequent clash between professional values and organisational demands means that one of the most important outcomes of a social work programme should be equipping students with the requisite skills to be able to successfully navigate the difficult terrain of practice drawing on the professional values they seek to personify. Social work students can feel bombarded on all sides, with popular and media vilification, increasing pressure in terms of targets and other priorities from government and what often appears to be a very critical evaluation of their worth and contribution from disability studies and other user perspectives. A student who encounters Oliver's contention that 'we can probably now announce the death of social work at least in relation to its involvement in the lives of disabled people' (2004, p. 25) will find it difficult to consider a future working in the disability field. However, as Lymbery and Postle suggest, discussions around social work 'should not be limited to the narrow discharge of statutory functions that has characterised its recent history in the UK' (2007, p. 3). There is considerable scope for social work (as opposed to Social Work that is social work undertaken in statutory settings by practitioners using the prescribed title 'social worker') in the broader

disability field, such as working as an independent support broker or within a user-led organisation. Students will require support to envisage these alternative spaces and roles for practitioners with social work values and skills, particularly as it appears that this is where the most effective change is enacted (Barnes and Mercer, 2006).

Threshold Concepts

The social model of disability and more broadly disability studies has undoubtedly resulted in a paradigm shift in the way in which disability or more accurately disablism is understood and responded to. Its impact is transformation, both individually and collectively. For individuals it involves the questioning and rejecting of what has appeared straightforward and common sense—that impairment is an individual personal tragedy—often accompanied by a challenge to existing values and allegiances. Collectively, an understanding and adoption of social model principles results in a radically different approach to meeting the needs of disabled people. Services that seek to ameliorate the disadvantages 'suffered' by disabled people are replaced by a more holistic evaluation of the extent to which societal structures, processes and cultures are disabling and the identification of strategies to remove these barriers and promote more inclusive environments and practices. The radical and profound nature of this seismic shift cannot be underestimated both in terms of the scale of response necessary and, perhaps more significant, in relation to social work education, the shift in understanding and subsequent repositioning that is required in response to a social model approach to disability.

The extent, nature and transformative impact of this shift is helpfully captured in the notion of *threshold concepts* which emerged in the early 2000s from the work of Erik Meyer and Ray Land (2003). It has since been developed (Land *et al.*, 2008) and applied in various disciplinary contexts [cf. Clouder (2005) on 'care' and Anderson and Sedgewick (2010) in relation to mental wellbeing]. Their work makes a distinction between *core concepts*—the building blocks of a subject that need to be understood to enable the progressive understanding of that subject—and *threshold concepts* which lead to 'new and previously inaccessible ways of thinking about something' (Meyer and Land, 2003, p. 1). Thus, a threshold concept is a gateway or 'portal' to a new understanding of a subject:

It represents a transformed way of understanding, or interpreting something, or viewing something without which the learner cannot progress. (Meyer and Land, 2003, p. 1)

There are five central characteristics of a threshold concept:

 1.　　　　transformative;

2.   irreversible;

3.   integrative;

4.   bounded; and

5.   troublesome.

The defining characteristic of a threshold concept is that it is *transformative* resulting in a 'significant shift in the perception of a subject, or part thereof' which in the case of 'specific politico-philosophical insights' like that advanced by disability studies 'may lead to a transformation of personal identity, a reconstruction of subjectivity' (Meyer and Land, 2003, p. 4). This also means that these insights will often be at odds with the knowledge of other figures such as practitioners and/or other academics, resulting in paradigm clashes. An obvious example here is between professionals adopting individual and social model understandings of disability.

Cousin suggests such transformations involve an 'ontological as well as a conceptual shift', that is, 'We are what we know' (2006a, p. 4). This resonates with the description of the impact of the social model by Liz Crow:

My life has two phases: before the social model of disability, and after it. Discovering this way of thinking about my experiences was the proverbial raft in stormy seas. It gave me an understanding of my life, shared with thousands, even millions, of other people around the world, and I clung to it.

   This was the explanation I had sought for years. Suddenly what I had always known, deep down, was confirmed. It wasn't my body that was responsible for all my difficulties, it was external factors, the barriers constructed by the society in which I live. I was being dis-abled—my capabilities and opportunities were being restricted—by prejudice, discrimination, inaccessible environments and inadequate support. Even more important, if all the problems had been created by society, then surely society could un-create them. Revolutionary! (Crow, 1996, p. 55)

Therefore, threshold concepts are usually *irreversible*, that is they are likely to change a perspective in a way that is hard to undo. Meyer and Land (2003) use the example of Adam and Eve's transformation from innocence to experience in the Garden of Eden as a way of illustrating the crossing of a threshold into a new understanding. A difficulty with this type of

transformation is that once it has occurred it can be difficult to 'step back' to an earlier stage of 'innocence' in order to tease out why others are struggling through the threshold. This can be exacerbated when threshold concepts operate as 'tacit constructs that often sit behind explicit domain knowledge' resulting in assumptions in writing and teaching (Webb, 2008, unpaged). Some threshold concepts may need to be identified and critiqued in order for new and/or alternative concepts to be understood. Another example here would be the positioning of professional as expert that has been implicit in a range of disciplines and professions. Students need to own that this is a threshold they have crossed (albeit unwittingly) in order to be receptive to new concepts. This is particularly challenging given the usually irreversible nature of such concepts.

Threshold concepts are *integrative* in that they 'expose the previously hidden interrelatedness of something' (Meyer and Land, 2003, p. 4) and that mastery of that concept 'often allows the learner to make connections that were hitherto hidden from view' (Cousin, 2006a, p. 4). Similarly the social model is utilised because it offers us a different way of looking at something familiar. As Finkelstein proposes:

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, p. 3)

While many of those who seek to counter criticisms of the social model often emphasise its status as a model (rather than a theory) (cf. Oliver, 2004), in this context it is more than a model because it becomes a portal or threshold through which students must pass in order to be able to understand the interrelatedness of forms of oppression and disablism. They need to 'get it' to be able to think and practise differently. The alternative, as discussed below, can be mimicry and ritualised performance (Cousin, 2006a, p. 5). There are resonances here with the *compliance approach* (2) to service provision that frequently dominates in disability-related practice and service provision (Oliver, 2004).

Another characteristic of a threshold concept is that it is usually *bounded* in that 'any conceptual space will have terminal frontiers, bordering with thresholds into new conceptual areas' (Meyer and Land, 2003, p. 5). Meyer and Land suggest that this *boundedness* may constitute the demarcation between academic disciplines and within disability studies there remains debate about whether work without a broad interpretation of the social model can or should constitute disability studies (Goodley, 2010). This can also trigger questions about *whose* threshold concepts are, particularly when there are clashes or contradictions between such concepts in overlapping disciplines like disability studies and social work.(3)

Finally, and perhaps most important in the context of a discussion about teaching and learning, is that threshold concepts can frequently

constitute *troublesome knowledge* (Perkins, 1999 cited in Meyer and Land, 2003, p. 2) which is '"alien", counter-intuitive or even intellectually absurd at face value' (2003, p. 2). Clearly a social model perspective can be all three to some learners. Many students are distant from the lived experience of disability and take their cues from wider social and cultural depictions of and scripts for understanding disability. The idea of disability as an individual's personal tragedy is so hegemonic that it is extremely difficult for some students to grasp an alternative despite the modelling of similar approaches to issues like gender and ethnicity and the pervasiveness of claims to non-judgementality and anti-discriminatory practice within social work. Threshold concepts like the social model can be 'subversive' and undermine deeply-held beliefs and attitudes and, in the context of social work, they trigger fundamental questions about the nature, practice and future existence of social work itself. This can involve 'an uncomfortable, emotional repositioning' (Cousin, 2006a, p. 4) that may prompt 'hesitancy or even resistance in learners' (Meyer and Land, 2003, p. 3).

Meyer and Land suggest that the transition to mastery of a threshold concept 'may be sudden or it may be protracted over a considerable period of time with the transition to understanding proving troublesome' (2003, p. 1). During the transition students occupy a *liminal space* (Meyer and Land, 2003, p. 2), which is 'an unstable space in which the learner may oscillate between old and emergent understandings' (Cousin, 2006a, p. 4). The significance of this space is that the student is engaged in an attempt to master the concept rather than remaining unaware or choosing to reject the concept. Cousin (2006a) suggests that students will construct *conditions of safety* during this transition and this can result in mimicry (and potential plagiarism) and ritualised performance which may only be uncovered when the performance slips.

The Troublesome Nature of Disability Studies for Some Social Work Students

This section will consider some areas of *troublesome knowledge* for social work students and will evaluate a number of strategies that have been employed to support students as they seek to pass through this threshold. It will draw predominantly on the first-year undergraduate module discussed earlier although some reference will be made to an equivalent module on the postgraduate programme.

The starting point of the module is to provide a rationale for why the social model is a threshold concept for social work students. One of the opening statements in the first session of the module is

For many disabled people social work has been part of the problem. Social work and social workers need to acknowledge and respond to this if they are to be part of a solution.

This makes clear from the outset that the module involves engaging with troublesome knowledge. First, that social work is part of the problem for disabled people. Students enter social work professions with the professed aim of 'helping' and so to be confronted by an approach (the social model of disability) and a body of research (disability studies) that challenges the taken-for-granted assumption that social work is helpful is unsettling and can lead to resistance. Indeed, when students reported this statement to a colleague the potentially positive message had been lost. Second, situating social work as (potentially) only part of the solution also challenges what appears to be a firmly held view amongst social work practitioners and academics that what is usually required is more and better social work. A social model perspective makes clear that social care can only provide part of the solution in terms of eradicating the barriers and discrimination that disabled people face in terms of full and active participation.

The presentation of this rationale and accompanying evidence of disabled people's lived experience provides a powerful catalyst for most students to move from a pre-liminal state, where they are unaware both of the threshold and of the reasons for seeking to pass through it, into a *liminal space*. Here they will grapple with the ontological implications of the shift required for mastery of the concept. Some students will remain fixed in a pre-liminal state, perhaps because they continue to be unconvinced of the rationale for change or because the implications of the transformation are at odds with the values or positions they hold. Cousin (2006b) terms these students 'defended learners' who can see where a threshold is leading and yet become resistant to it. Others will positively engage with the process but become stuck at various points. A key challenge for effective teaching is to be able to anticipate these points and to develop a range of strategies that support students in their transition.

'I Don't Get It'

Students often get stuck with particular aspects of the social model. Understanding the reasons for this can be challenging when the teacher's transition through the threshold was less problematic or occurred a period of time before. As Meyer and Land suggest, it can be difficult to 'step back' through the portal and see it from the other side. For example, for me the distinction between impairment and disability has always been unproblematic and 'common sense'. It was not an aspect of the threshold I struggled with. Therefore it has taken some time to develop a range of explanations, tasks and activities that support students to think through the issue and to understand the distinction and its implications. Similarly many students get bogged down in the implications of rejecting an individual model. Frequently, as indeed occurs in some disability studies literature (cf. Swain *et al.*, 2003), the individual model is equated with a medical model with the assumption by students that the rejection of this implies the rejection of all medical intervention and treatment for disabled people. This

is not something even the most radical social modellists would suggest but is perceived by many students to be a significant flaw in a social model perspective.

'The Social Model is OK in Theory but it Doesn't Work in Practice'

A common response from students, particularly those with experience in statutory settings, is that they 'get' (or at least know they need to appear to 'get') the social model but that its implications for practice are unworkable in the current context. There is considerable evidence that many practitioners struggle with issues such as the relinquishing and sharing of power and control, having a wider focus than the traditional remit of social care and being able to develop more creative solutions outside the traditional palette of service provision (Harris, 2004; Sapey and Pearson, 2004). Therefore, the message from practice and within practice learning settings can be very negative about the potential for social model based practice.

Developing a range of resources that showcase alternative, creative and effective forms of practice and service provision has a considerable impact on student's ability to envisage working in these types of ways and enables them to think about the sorts of skills, knowledge and experience they will need to develop and hone in order for them to undertake social model based practice. On the undergraduate disability module this includes the provision and discussion of resources including those produced by user-led organisations and teaching input from disabled practitioners from statutory and user-led organisations. This services the dual purpose of providing examples of good practice and of signalling to students that they will encounter disabled people in a range of roles, such as colleague, manager or practice educator and not just that of service user. An opportunity for students to consider the implications of this is provided in the module's law examination.

Law is one of the five key areas in which students must undertake specific learning and assessment (DH, 2002). Understanding the legal framework within which they practise and, perhaps more importantly, the implications of this for the service users with whom they work is an essential task for social work students. Moreover, students are required to demonstrate this understanding and their ability to utilise it during their practice learning placements evidenced by fulfilling the required National Occupational Standards (TOPSS, 2002). At Lancaster University, law teaching and assessment is integrated into a range of modules and pieces of assessment, including law examinations for specialist modules. Initially—across all the modules—the emphasis was on the rote learning of legal knowledge. Latterly, there has been a shift to assessment that requires students to think about the application and implications of legislation and law. On the disability module, this has taken place through a concentration on disability

discrimination legislation. Given that most students will only have very limited experience of disability-related practice at this stage of the degree, the assessment focuses on thinking about the implications of the legislation for an area they are familiar with—social work education.

Sample examination question Jason is blind and a student on a qualifying social work programme. The Practice Learning Co-ordinator identified a placement with a Children and Families team that meets the learning needs identified in Jason's personal profile. However, before the pre-placement visit the Practice Educator notified the Practice Learning Co-ordinator that the team was unable to take a blind student because of the risks to children of having someone who was unable to see the child. She is worried Jason would not be able to see bruises or other physical signs of abuse (adapted from Sapey *et al.*, 2004, p. 32).Do you think the Practice Educator is acting *reasonably*in refusing to take the student before the pre-placement visit? Provide the reasons for your decision.The Practice Learning Co-ordinator persuades the Practice Educator to reconsider and go ahead with the pre-placement visit. What*reasonable adjustments* could be considered to enable Jason to take up the placement? What factors might influence whether or not these adjustments are considered *reasonable*?

This question serves a number of purposes. Students need to understand and demonstrate their understanding of key legal concepts such as what might be considered 'reasonable' and how this will vary dependent on the context and other factors. Also, it forces students to consider the accessibility of their chosen profession to disabled people because, as a representative of the British Association of Social Workers makes clear:

If we can't adhere to supporting people from diverse backgrounds in social work, then there is something desperately wrong in a profession that champions equal opportunities. (Cited in Lovell, 2008, unpaged)

This approach to assessment has worked well. Students are able to mirror the good range of marks achieved when the paper involved a greater degree of rote learning. More significantly, this assessment helps to identify those students who are presenting a 'ritualised performance' (Cousin, 2006a); for example, in response to a similar question to that in the example above, an MA student suggested that a blind student could spend their time on placement answering phones and stuffing envelopes without any apparent awareness that this might be problematic. Similarly, other students will demonstrate very fixed ideas about how social work might or should be practised without reference to the ableist (Campbell, 2009) attitudes that underpin this.

Concluding Reflection

The purpose of this article was to interrogate practice on a social work programme where a commitment to social model based practice is explicit

and embedded with the aim of identifying—in these evidence-based times—what works. The notion of threshold concepts, and particularly of troublesome knowledge, has proved extremely useful in interrogating precisely what it is we want students to 'get' and in beginning to address why they sometimes get stuck in liminal spaces where mimicry has the potential to leave them vulnerable to plagiarism and more importantly to result in 'ritualised performances'.

This discussion raises a number of on-going questions for those of us seeking to integrate disability studies within social work education. First, have we identified and do we agree about what the threshold concepts in disability studies are? As debates about the social model become more nuanced and *critical disability studies* (cf. Goodley, 2010) emerges as a form of second wave disability studies, how do we hold on to the accessibility and transformative nature of the social model?

Second, questions remain about whether, as disability studies educators in social work education, we are 'leaning on an open door' (Read, 2009)? Findings from a recent review of the teaching of human growth and development on qualifying programmes in England, Northern Ireland and Wales (Boushel *et al.*, 2010) suggest that disability (however it is conceived) receives 'variable attention' (p. viii) and is often 'associated with difference and even deviance rather than diversity' (p. 4). Therefore, we need to continue to ask is social work education receptive and inclusive of disability studies and its implications for practice? This is a crucial question at a time of reform for social work education in the UK. There are fundamental questions about the future role of social work in the lives of disabled people in the personalisation era and about whether statutory social work can meet the wider needs and entitlements of disabled people. I end by returning to Oliver's (2004) announcement of the demise of social work with disabled people. While I think it remains pertinent to borrow from Mark Twain in suggesting that the reports of social work's demise in relation to disability are premature, it continues to be a possibility. The twin-pronged attack from other statutory social care staff and from user-led professions aligned to the community (Finkelstein, 1999) means that social work and social work education need to provide an articulate and convincing argument about what social work can offer disabled people in the twenty-first century.

Notes

(1) The biennial international disability studies conference held at Lancaster University regularly attracts over 230 delegates and papers from a wide range of disciplinary backgrounds.

(2) IIn this approach practice is driven by compliance with legislation or policy directives rather than a commitment to values or principles. It is characterised by a tick box or task-orientated approach that does little more than meet basic standards.

(3) Social work has an ambiguous and contested status (Young and Burgess, 2005, p. 1) as an academic discipline with debate about whether it constitutes a discipline or a multi-disciplinary field of study. Similar debates continue in relation to disability studies (Goodley, 2010).

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Introduction

This chapter considers the place and purpose of research evidence when working with disabled people. A central concern of the disabled people's movement and of its academic partner disability studies has been to highlight the way in which disabled people have been excluded from the production of research and other forms of evidence, except as passive subjects of research or as recipients of policy and practice based on that exclusionary research. This means that any discussion of evidence to inform practice with disabled people must start with fundamental questions about how disability is understood, how this informs the production of research and therefore what the purpose of social work practice with disabled people is (Morgan and Roulstone, 2012; Oliver, 1983; Sapey, 2004).

Disability, disabled people and research

The research used to inform policy and practice with disabled people has been subject to a sustained critique by disabled people and by academics working in disability studies since disabled activist Paul Hunt (1981) labelled researchers Eric Miller and Geraldine Gwynne 'parasite people'. Hunt's paper 'Settling Accounts with the Parasite People' was a response to a research study on residential care for disabled people undertaken by Miller and Gwynne in the late 1960s. Residents of the Le Court Cheshire Home had invited Miller and Gwynne to research their experiences as part of a campaign for greater resident participation in the

management of the home. There was sense of 'horror' and a feeling they had been 'badly let down by social science research' (Finkelstein, 2001, p. 6) when in their 1972 book, *A Life Apart: A Pilot Study of Residential Institutions for the Physically Handicapped and Young Chronically Sick*, Miller and Gwynne argued that:

by the very fact of committing people to institutions of this type, society is defining them as, in effect, socially dead, then the essential task to be carried out is to help the inmates make their transition from social death to physical death (Miller and Gwynne, 1972, p. 89).

While the residents and other disability activists agreed that the outcome of residential care was 'social death' for residents, as Vic Finkelstein (2001) put it 'The issue seemed not so much whether we are or are not 'socially dead', but what we can do about it?' (p.7). According to Hunt (1981) the problem with this type of evidence was that the researchers were:

profoundly biased and committed against the residents interests from the start…[this was] evident in their whole conception of the issues, and therefore in their chosen research methods, and in all their analyses, conclusions and recommendations (p. 45).

The research was based on disablist assumptions about what it meant to be disabled and on what appropriate responses were to the predicament of many disabled people.

This critique emerged while the UK disabled people's movement was starting to radically rethink the way in which disability is understood. The Union of the Physically Impaired Against Segregation (UPIAS, 1976) argued that rather than disability being inevitably created by impairment, instead disablement was a form of social oppression imposed on top of impairments. This approach was developed by Mike Oliver (1983) as the 'social model of disability', which made a clear distinction between a person's condition or impairment (such as spinal cord injury

or learning difficulties) and the socially imposed restrictions and disadvantage they experienced (for example inaccessible buildings or presumptions about capacity).

A central element in the development of *disability studies* as an inter-disciplinary area of academic study and research was disenchantment with traditional forms of disability research such as that conducted by Miller and Gwynne. Barton (1992) summarised the criticisms that were made which included: their misunderstanding of the nature of disability, their distortion of the experience of disability, their failure to involve disabled people and the lack of any real improvements in the quality of life of disabled people that they have produced (p. 99).

An often cited example of this type of research were the surveys conducted in the 1980s by the Office of Population, Census and Survey (OPCS). Oliver (1990) highlighted the assumptions that underpinned the surveys by contrasting questions used by the OPCS with alternatives that are based on a social model understanding of disability (box 12.1).

[Open box here…

Box 12.1 Questions based on social model of disability

OPCS 1986 survey questions	Alternative questions
Can you tell me what is wrong with you?	Can you tell me what is wrong with society?
What complaint causes your difficulty in holding, gripping or turning things?	What defects in the design of everyday equipment like jars, bottles and tins causes you difficulty in holding, gripping or turning them?
Are your difficulties in understanding people mainly due to a hearing problem?	Are your difficulties in understanding people mainly due to their inabilities to communicate with you?

Have you attended a special school because of a long term health problem or disability?	Have you attended a special school because of your education authority's policy of sending people with your health problem or disability to such places?
Does your health problem/disability mean that you need to live with relatives or someone else who can help look after you?	Are community services so poor that you need to rely on relatives or someone else to provide you with the right level of personal assistance?
How difficult is it for you to get about your immediate neighbourhood on your own?	What are the environmental constraints which make it difficult for you to get about in your immediate neighbourhood?

(Adapted from tables 1.1 and 1.2,Oliver, 1990, pp. 7-8)

…close box here]

The insight provided by a social model understanding of disability enabled disability studies writers to question the apparently 'common sense' nature of the questions in the OPCS surveys. Oliver's alternative formulation of the questions demonstrates how a different understanding of what creates disability changes how the problem is constructed or framed. The significance here is the impact that such research had on public policy responses to disabled people because as Harlan Hahn (1985) concluded 'fundamentally disability is defined by public policy. In other words, disability is whatever policy says it is' (p. 94). Thus if the research underpinning policy development and practice implementation is based on an individualised personal tragedy understanding of disability that viewed disadvantage as created by impairment (Oliver, 1990) then policy and practice will perpetuate this.

In *Handicapped by Numbers – A Critique of the OPCS Surveys* Paul Abberley (1991) highlighted the significant and frequently negative implications of the ways in which such 'official statistics' were compiled. He noted that

It is a political decision, conscious or otherwise, to employ questions of the first type rather than the second. Since state researchers, whatever party is in power, have consistently asked individualising rather than socialising questions on a whole range of subjects it should come as no surprise that they do this on disability, which is as political a subject as any other' (p. 4)

Thus as Oliver (1992) contends:

Disability research should not be seen as a set of technical objective procedures carried out by 'experts' but part of the struggle by disabled people to challenge the oppression they currently experience in their lives (p. 102).

Disability research should therefore be 'openly partisan and politically committed' (Barnes and Mercer, 1997, p. 5) with researchers being explicit about 'which side they are on'.

Towards an emancipatory research paradigm

There was considerable discussion within disability studies and the wider disabled people's movement about how this new approach to research should be constructed with many of the key arguments and proposals brought together in a special issue of the journal *Disability, Handicap and Society* (now *Disability & Society*) in 1992. Here Oliver (1992) called for a new approach to disability research that he termed 'emancipatory disability research'.

Barnes (2014) summarises the core characteristics of this approach as accountability, the social model of disability, data collection and empowerment.

Barnes argues that researchers should develop on-going relationships with disability organisations so they can 'learn how to put their knowledge and skills at the disposal of disabled people' (p. 39). This requires researchers to work in ways that are accessible and inclusive for disabled people and that enable a meaningful and honest dialogue about the potential and limitations of research. In particular, Barnes highlights the difficulties raised by the 'market-led environment' in which many researchers work which can mitigate against small scale user-led research projects that may be viewed as 'political' in nature.

Adopting a social model understanding of disability is frequently viewed as a necessary precursor to emancipatory research. However, there are two key challenges to this. The first advanced by some within disability studies, notably Shakespeare (1996), relates to the first two principles which for Barnes are inevitably related. Shakespeare makes a persuasive argument that a commitment to a political understanding of disability and accountability to research participants should not automatically translate into formal accountability to disabled people's organisations. He contends disability academics and researchers can produce emancipatory knowledge out with this relationship. However, he makes a distinction between having the intellectual and academic freedom to pursue unpopular or marginalised ideas and presenting such work as 'being neutral or being objective' (Shakespeare, 1996, p. 117).

A second challenge is the now ubiquitous nature of the social model of disability which has the potential to undermine its effectiveness. It is difficult to find a government department, local authority or disability organisation that doesn't express a commitment to the social model, as Oliver (2004) put it 'it is tempting to suggest that we are all social modellists now' (p. 18). However, there is a tendency for organisations and researchers to ape the language of the model without fully adopting its principles (Morgan, 2014; Roulstone and Morgan, 2009).

This can make it difficult for user-led organisations and their research allies to compete for research funding with large disability charities and established research institutes who profess a commitment to the social model but without an accompanying transfer of power to disabled people.

Approaches to data collection methods within an emancipatory paradigm are varied. There has been an assumption that qualitative research is inherently more emancipatory because it allows the voices and narratives of disabled people to be heard. However, Barnes (2014) cautions against such assumptions reminding us of the potentially damaging nature of 'sentimental biography' that is grounded in individualised accounts of disability. The crucial defining element of emancipatory forms of research lies in a political commitment to challenging oppression rather than in any particular forms of or approaches to data collection, as Barnes (1996) argues elsewhere, academics and researchers can only be with the oppressors or with the oppressed.

Finally in response to criticisms that traditional disability research failed to improve the lives of disabled people, Barnes (2014) argues that 'to be truly emancipatory, disability research must be empowering' (p. 42). Research must have – the potential at least – to generate positive outcomes for disabled people. Barnes and some other disability studies writers contend this is only possible when disabled people's organisations formulate and steer the research agenda although this remains contested within disability studies. However, these debates should be located within wider discussions about what has been termed 'user-led' research.

User-led disability research

The development of the disabled people's movement took place at the same time and often in parallel with the self-organisation of people who use social care and other welfare services, many of whom are disabled. The claim for greater user

involvement in and control of research mirrors those made by the disabled people's movement and are summarised by Beresford and Croft (2012) as:

- social rather than medicalised individual approaches and understandings;
- the rejection of positivist claims to 'objectivity'; and
- a commitment to personal, social and political change (p. i)

As Beresford and Croft acknowledge there is great diversity and variation in the levels and extent of user participation in research. Initiatives such Involve (http://www.invo.org.uk/) which was established in 1996 to promote public (user involvement in its widest conception) involvement in medical, health and social care research, have had a significant impact on mainstream research activities which much more routinely involve service users. Alongside this a small but influential body of user-led research has developed. Notable examples include large national projects such as that undertaken on behalf of BCODP (then the British Council of Disabled People) *Independent Futures: Creating User Led Services in a Disabling Society* (Barnes and Mercer, 2006) and *Supporting People: Towards a Person-Centred Approach* which was funded by the Joseph Rowntree Foundation (Beresford *et al*., 2011). There are also numerous small scale local projects undertaken by disability and other user-led organisations, an example of which is presented later in this chapter.

As the majority of user-led research has sought to embody the emancipatory principles outlined above it has been subject to a counter-critique from some quarters. The overtly political nature of this work and its rejection of objectivity and neutrality has resulted in 'problems of credibility and discrimination' (Beresford and Croft, 2012, p. iii). There remains a suspicion that research commissioned or undertaken by user-led organisations will be partisan and lack the necessary rigour of more 'objective' research. This response fails to acknowledge

the strong commitment to transparency demonstrated by user-led research. Such research 'wears its heart on its sleeve' in terms of political commitment and projects like *Independent Futures* and *Supporting People* provide great detail about their methods of involvement and decisions about research strategy and design. It is also important to bear in mind the relative infancy of such research. As Roulstone (2012) notes social work education and practice is still dominated by research

produced for non-disabled professionals by non-disabled researchers

each benefiting from the study of 'disabled others'. This picture of a

world of 'solutions' created for disabled people by predominantly non-

disabled people is noteworthy in the early twenty-first century (p. 146)

The request from disabled people's organisations is not that they should control all research but rather that research produced by user-led organisations is accepted on equal terms and valued for the particular contribution it can make to the value base for practice. The development of tools such as the TAPUPAS framework for assessing the quality of knowledge for practice by Pawson *et al*. (2003) for the Social Care Institute for Excellence (SCIE), provides the opportunity to assess different types of knowledge and research within a privileging of particular standpoints or approaches.

[Open box here…

Practice Reflection 12.1: Is it TAPUPAS?

As discussed elsewhere in this book, Pawson *et al*. (2003) suggest knowledge can be assessed using the following framework:

Transparency - are the reasons for it clear?

Accuracy - is it honestly based on relevant evidence?

Purposivity - is the method used suitable for the aims of the work?

Utility - does it provide answers to the questions it set?

Propriety - is it legal and ethical?

Accessibility - can you understand it?

Specificity - does it meet the quality standards already used for this type of knowledge?

Revisit some of the research you have considered and ask 'is it TAPUPAS'? How easy is it to answer these questions based on the format or presentation of the research you are reading?

...end box here]

Research to inform work with disabled people

One of the greatest successes of the disabled people's movement has been to translate its 'big idea' (Hasler, 1993) – the social model of disability – into a rallying cry for change and into innovative mechanisms and practices to support independent living. This included the establishment of user-led disability organisations that provided a focus for campaigning and a location for developing radical new forms of support (Barnes and Mercer, 2006). Many of these initiatives have subsequently been translated into mainstream social care practice under the banner of personalisation.

The impact of the social model of disability has been discussed in some detail already and in key texts such as *Disabling Barriers – Enabling Environments* (Swain *et al.*, 2014) and *Disability Policy and Practice: Applying the Social Model* (Barnes and Mercer, 2004). A significant challenge for policy makers and practitioners is how to translate the principles of the model into practice. There is no single blueprint or handbook for social model services or practice. Instead there

needs to be on-going evaluation of the extent to which these principles have been embedded. As this chapter will go on to consider, there is a considerable body of research that emerged to evaluate the effectiveness and efficiency of many of the initiatives associated with the social model of disability. However, there remains less research conducted to assess the extent to which statutory agencies and other service providers have embedded their formal commitment to the social model.

Oliver and Bailey were commissioned by Birmingham City Council to evaluate the impact of its formal adoption of the social model in its services for disabled people (Oliver, 2004). The research sought to evaluate the extent to which this commitment had become embedded in the authority's policies, process and professional practice. They noted that the implementation of the model was varied within the local authority and identified three broad approaches to service provision – humanitarian, compliance and citizenship (box 12.2). These are not mutually exclusive, different elements of the same organisation or service may embody all or none of the approaches.

[Open box here...

Box 12.2 Approaches to welfare (adapted from Oliver, 2004)

Humanitarian	Compliance	Citizenship
Providers • We know best • Individual/medical model – whereby the older / disabled person is the problem • Doing clients a favour • Clients should be grateful	Providers • Meet laws, rules and regulations • Check list approach • Minimum standards • Lack of commitment or partnership	This approach requires older/disabled people to be seen as full citizens with all the rights and responsibilities that are implied • Older/disabled people are seen as contributing members of society both as workers and

Older/Disabled People	Older/Disabled People	valued customers (users)
• Don't like being patronised • Reject individual / medical model • Not valued as people • Services not reliable	• Rights not fully met • Going through the motions • Still service rather than needs led • Staff tend to own the task not the aim of the service	• Older/disabled people are recognised as empowered individuals (voters) • Older/disabled people are seen as active citizens with all that implies in terms of rights and responsibilities • Only when all three dimensions are met will the relationship between providers and users of services be a truly harmonious one.
Result • Conflict • Lack of trust • Inadequate services • Poor levels of satisfaction	**Result** • Conflict • Denial of entitlements and expectations • Inadequate services • Poor levels of satisfaction	

…close box here]

[Open box here…

Practice Reflection 12.2

The typology of welfare provision produced by Oliver provides a framework for evaluating the extent to which organisations are operating in accordance with their commitment a social model of disability.

Consider a welfare organisation you are familiar with whether as a user of that service, as a student on placement or as a practitioner. To what extent does the organisation and the services it provide embody the different elements of

Oliver's typology of welfare provision? How might it change to adopt a citizenship approach?

The typology can also be used as a template for critically appraising studies that are researching services and other forms of support that claim to adhere to social model principles.

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One of the most influential pieces of disability research undertaken was Colin Barnes' (1991) *Disabled People in Britain and Discrimination: A Case for Anti-Discrimination Legislation*. The study was devised by the BCODP and sought to collate existing evidence about the nature and extent of discrimination experienced by disabled people. There was considerable anecdotal evidence about this discrimination but until that point it had not been brought together, nor had it been analysed using a social model understanding of disability. The importance of this research was that it provided an empirical basis for the analysis provided by social model writers. As Barnes notes in his 1994 foreword to the second impression of the book:

although today there is no dispute about the extent of discrimination

against disabled people, this was not the case two and half years ago. At

the start of 1992 the British Government still denied that discrimination

against disabled people was a major problem…[after the book's launch at

the House of Commons]… the Minister for Disabled People.. admitted for

the first time: 'Discrimination against disabled people is widespread'.

The chapter on *The Health and Social Support Services* summarised the ways in which social care services were structured around traditional understandings of disability that assumed 'disabled people are unable to take charge of their own lives' (Barnes, 1991, p. 147), provision was focused on

segregated residential settings and that assessment was a professional activity to be undertaken upon, rather than in partnership with, disabled people. Barnes concluded that without significant reform social care services would remain a barrier to independent living in the community and to disabled people exerting control over their lives. This research provided undisputed evidence that services for disabled people – social care amongst them – was failing to meet the needs of disabled people and that practice would need to look the emerging body of research that was capturing the evolution of new forms of support.

The most influential innovation that emerged from disabled people's organisations is direct payments. Direct payments – in essence a cash payment in lieu of services – were promoted by disabled people's organisations as a way of transferring power to individual disabled people and enabling them to purchase more personalised and responsive forms of support than the rigid and inflexible services provided by local authorities. *Cashing In On Independence* (Zarb and Nadash, 1994) was commissioned by BCODP to demonstrate the cost effectiveness of direct payments schemes as part of a campaign for legislation to enable local authorities to make cash payments to service users. The study demonstrated that the use of direct payments enabled greater choice and control and therefore resulted in higher levels of service user satisfaction. The study also showed that a perceived disadvantage of the schemes was the time taken to administer them and the additional responsibility taken on by the service user, particularly in relation to becoming an employer. What is significant about these findings is that they have been reiterated by all the major studies of direct payments and more recent iterations of personalised forms of support such as personal budgets.

Personalisation has subsequently become the dominant idea in social care. It draws on elements of the ideas and approaches developed by disabled people and other service user groups, particularly the emphasis on independent living and

a commitment to greater choice and control for those who use services. These appear uncontentious aims for intervention. However, there is a growing critique emerging from disability studies (Roulstone and Morgan, 2009) and radical social work (Ferguson and Lavalette, 2014; Glasby, 2014) that there are considerable differences and variations in the ways in which these concepts are being utilised and applied. It is also important that a clear distinction is drawn between the principles that underpin the personalisation agenda and the mechanisms that have been deployed to implement them (Gardner, 2012). There has been a tendency in policy and practice contexts to view them as synonymous, that delivery mechanisms such as direct payments or personal budgets are forms of personalisation or independent living rather than as means to these ends (Beresford, 2014).

There have been two large scale evaluations of the implementation of personal budgets, the primary delivery mechanism for delivering personalised forms of support (details about direct payments, personal budgets and other delivery mechanisms can be found in Carr, 2012). The IBSEN project (Glendinning *et al.*, 2008) was a national evaluation of the Individual Budgets Pilot Programme (2006-8). The project was unusual in using a randomised controlled trial to consider the costs, outcomes and cost-effectiveness of individual budgets in the 13 pilot local authorities. A key finding of the evaluation was the differentiated outcomes for various service user groups with people with physical impairments recording the highest levels of satisfaction and that there significant 'practical, organisational and cultural challenges' for local authority staff.

The Personal Outcomes Evaluation Tool (POET) was devised by the social enterprise In Control and the Centre for Disability Research at Lancaster University. It seeks to provide a national benchmark on the impact of personal budgets. To date two surveys have been undertaken using the tool in 2011(Hatton and Waters,

2011) and 2013 (Hatton and Waters, 2013). The surveys reiterated the high levels of satisfaction and positive outcomes for disabled people identified by IBSEN. Similarly it highlighted the implementation difficulties experienced by local authorities.

While it is clear both these projects have had considerable impact on government policy there has been concern about the extent to which less positive findings have been addressed. While there was a strong evidence base to support the closure or 'modernisation' of traditional forms of social care provision, particularly segregated institutions like long-stay hospitals or day centres (Roulstone and Morgan, 2009) research that evaluates new forms of provision has not kept pace with the scale of change. As Beresford asserts, 'the government made the policy move and large-scale associated investment before it had the results of its own research, such as the IBSEN study' (Beresford, 2014, p. 8). Similarly, Glasby acknowledges that in 'a rapidly evolving policy context, the issues involved are always likely to be far in advance of the evidence base, which has inevitably had to struggle to keep up with such a rapid pace of change' (Glasby, 2014, p. 4).

There are two important messages to take from this. First, we should question the primacy afforded to 'what works' or evidence-based practice by government when, where it is politically expedient, policy is implemented without this supporting evidence or in the face of conflicting or disputed evidence. Second, and most importantly in a context of work with disabled people, our starting point should be on embedding values rather than mechanisms. There is significance evidence that what matters to those who use services and what ensures effective practice is 'a value-based approach to practice and support'(Beresford *et al.*, 2011, p. 48). There is a very real danger that language of these values – adopting a social model of disability, framing services as independent living – has become ritualised

rather than real (Morgan, 2012). Adopting Oliver's citizenship approach to welfare provision requires practitioners to adopt a critical perspective on their practice and the research and other evidence that underpins it.

In spite of this, there is a growing recognition that when policy makers, practitioners and disabled people talk about the social model, about independent living and about personalisation they are not always talking about the same thing (Roulstone and Morgan, 2009). The apparent ubiquity of the social model discussed earlier masks its still limited impact on social work education and practice (Beresford and Boxall, 2012; Morgan, 2012; Sapey and Pearson, 2004). Therefore a key task for any practitioner is to establish what these concepts mean and to understand the implications of the different methods and mechanisms that have been devised to implement them in practice.

[Open box here…

Case Scenario 12.1: Mary and Jane

Mary and Jane are both from a large town in the North of England. They both lived in a segregated hospital for people with the label of learning difficulty for over twenty years. The hospital was in a rural area and at least three times a year, Mary managed to reach a local shop or pub, trying to escape back to the town she was from. Each time, she was returned to the hospital.

The hospital was eventually assessed for closure, after unacceptable restraint practices, sexual assault and lack of privacy were cited in an Inspector's Report. Risk assessments showed some residents to be at worst risk of death and others at risk of severe distress and mental health service need, given their levels of institutionalisation and the speed of the move that was necessary.

A user-led organisation of disabled people was contracted by the Adult Social Care department to assist with the social well-being of residents, before,

during and after the move. Over the next eight months, it put in place support plans with each of the residents to gradually improve options available to the residents.

Members of local self-advocacy groups visited the hospital and residents of the hospital had personal assistants with them and transport to visit the group members in the community centre. The residents began to take an interest in what they would want in the places they might live. Mary asked for her bedside cabinet from the ward where she had stayed to go with her and asked to share a room with her friend in their new supported accommodation. They asked for their curtains in their new room to be made out of the material from the bay curtains in the ward where they had lived. They also took a tea pot and biscuit tray from the hospital. They began to stay in their new homes for short (gradually increasing) periods of time and eventually overnight and at weekends. Some of their favourite staff from the hospital transitioned with them to the new accommodation and they helped to recruit their own new support workers.

The advocate who helped facilitate their support plans, realised that the choices of food, clothing, activities and relationships generated by self-advocates and the residents, represented many indicators of what was good, not so good and poor in housing and community services. These plans were made into check lists and the residents and self-advocates used them to assess the places they wanted to live. The team leader in the social work department took the checklists and added some more questions, so that she could ask residents to use them as part of her inspections of supported accommodation.

Four years later… Mary is engaged to her partner, who lives in another supported home and they will be married next year. She is part of a Reality Checker group, using the checklists that were developed as part of her move to

supported living and leisure venues, to assess the suitability and standards of other accommodation for disabled people.

Jane's family were traced through social services and her cousin was delighted to have her join the family for Sunday lunch each week, as long as her PA came to help. Jane formed a bond with her cousin's daughter and learned to read and write so that she can help her to read too.

Mary still shields her plate with her hand when she is eating to ensure no-one steals it, a behaviour she learned in the hospital. Mary and Jane still share a house, but have their own rooms in a smaller supported accommodation house.

Mary hopes to get a house with her partner when they marry, but is frustrated when doctors won't give her information about her fiancé when he is in hospital, because they think she will not understand, even though she is listed as his next of kin. Jane has completed a level one childcare course (which was made accessible in Easy Words and Pictures) and now works two mornings a week in the local nursery. She travels all over on the local bus and campaigns to stop disablist hate crime.

...close box here]

Applying research in social work practice

This case scenario provides an opportunity to reflect upon the preceding discussion about the nature of evidence about disabled people and policies and practices that seek to support them. Sapey (2004), in his discussion of the place of evidence-based social work practice, reminds us that the use of evidence should be prefaced by a questioning of the nature of the understanding of disability that underpins that evidence and of the aims of the intervention being evaluated. The particular value of this case scenario is that it demonstrates the multi-faceted relationship practice can and should have with research. The work undertaken by a user-led

disability organisation was grounded in a social model understanding of disability and in research either generated by disabled people's organisations or that evaluating their work. Practitioners recognised and acknowledged the value of the knowledge produced by Mary, Jane and their peers, and through their participation in a 'Reality Checking' group developed tools for practice and evaluation.

The commissioning of a user-led organisation to support Mary, Jane and the other residents acknowledges the value and contribution user-led organisations make to supporting disabled people. The *Creating Independent Futures* project (Barnes and Mercer, 2006) found that user-led services, that is those devised and delivered by organisations of disabled people, were more accountable to service users. Additionally, a project that mapped the capacity of user-led organisations in England in 2007 highlighted the specific expertise these organisations have which include *peer support, mentoring and empowerment* (Maynard-Campbell *et al*., 2007).

An evaluation undertaken by the National Centre for Independent Living (NCIL) (2008) for the Department of Health reviewed the existing literature on peer support. The report cites a range of research that highlights the importance of access to peer support as a crucial element in the effective and sustainable uptake of direct payments. This is supported by the detailed findings of the *Supporting People* project which emphasises the 'value of learning from other people's successes' (Beresford *et al*., 2011, p. 165) and that 'making choices requires self-confidence' (Beresford *et al*., 2011, p. 161). The NCIL (2008) review concluded that peer support was an

essential element in giving people opportunities to control their own

lives and, moreover, where such support does not exist this has had a

negative impact on the implementation of self-directed support (p. 32).

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Practice Reflection 12.3

Despite the emphasis on closing institutions and supporting disabled people to live in their communities, a considerable number of disabled people continue to live in institutional settings where experiences akin to 'social death' persist.

Watch *Working with lesbian, gay, bisexual and transgendered people - people with physical disabilities: Doug's story* (SCIE Social Care TV: http://www.scie.org.uk/socialcaretv/video-player.asp?guid=7506DEAA-E24E-4ECC-9CFE-BDCF0149F26A

Then read the SCIE (2011) *Personalisation briefing: Implications for lesbian, gay, bisexual and transgendered (LGBT) people* which reviews a range of research into the experiences of LGBT people.

What are the particular barriers experienced by people living in residential settings and how might they be addressed?

What positive lessons can social workers take from Doug's story and the research summarised in the review? How could these positive lessons be translated into practice?

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Peer support is particularly significant for those disabled people who have been subject to institutionalisation, whether in large scale institutions such as the hospital described in the case study or by community based services that have perpetuated the negative elements of institutionalisation outlined by the *Supporting People* project as:

- People's rigid categorisation

- Being segregated

- Being lumped together

- The provision of merely physical maintenance

- Group living

- Standardised routines (Beresford *et al.*, 2011, p. 156).

The outcome of which is that they tend to be marginalised from their communities and wider networks of support which can limit individuals' aspirations for the future. Providing support that went beyond simply physically relocating the former hospital residents in the community enabled Jane and Mary to explore other options for their life and to broaden what can at times be a limited 'menu of choices' (Hollomotz, 2012) for those with personal budgets to choose from.

Recommended Reading

Beresford, P. Fleming, J. Glynn, M. Bewley, C., Croft, S., Branfield, F., and Postle, K. (2011) *Supporting People: Towards a Person-Centred Approach* (Bristol, The Policy Press)
This text provides rich detail about what matters to people who use adult social care services and how this can effectively be translated into practice.

Carr. S. (2012) *Personalisation: A Rough Guide. SCIE Guide 47* (London, SCIE)
This regularly updated report provides an introduction to personalisation and a summary of much of the research that has been undertaken.

Harris, J and Roulstone, A. (2011) *Disability, Policy and Professional Practice* (London, Sage)
Roulstone, A. and Prideaux, S. (2012) *Understanding Disability Policy* (Bristol, The Policy Press)

Both these books are core to understanding more about working with disabled people.

The Disability Archive UK is an on-line collection of material produced by disabled people and disability studies writers: http://disability-studies.leeds.ac.uk/library/

The Social Care Institute for Excellence (SCIE) website has a wide range of resources to support research informed practice: http://www.scie.org.uk/

Blogs provide immediate, powerful and often intimate access to the lived experience of disabled people using adult social care services.

My Daft Life. This blog is written by disability studies researcher Sara Ryan whose son 'LB' died while in an assessment and treatment unit for young people with learning difficulties. http://mydaftlife.wordpress.com/

Mark Neary's blog provides anecdotes and often fiercely critical analysis of his and his son Steven's experiences of personalisation: http://markneary1dotcom1.wordpress.com/

Kaliya Franklin (http://benefitscroungingscum.blogspot.co.uk/) and Sue Marsh's (http://diaryofabenefitscrounger.blogspot.co.uk/) blogs detail their personal and political disability activism.

You can access the Reach Standards for Supported Accommodation here: http://www.paradigm-uk.org/articles/SALE__Reach__Standards_in_Supported_Living_/2946/42.aspx

You can access a training pack to stop disablist hate crime here, which includes the DVD for Holocaust Memorial Day that the group made about the value of disabled people's lives:

http://arcuk.org.uk/safetynet/files/2012/08/Hate-Crime-Learning-Together-Training-Pack.pdf

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Abstract

In 2016, the Department of Health in England announced that it would pilot the role of a Named Social Worker, building on the current body of knowledge about the role of social work in improving the quality of life of learning disabled people. We have chosen to be a part of the pilot as we regularly witness too many people's lives being defined by restrictions imposed by professionals. Erroneous associations between the concepts of risk and danger have become the norm in how learning disabled people's decision making is perceived and managed. However, we believe social workers educated in the social model of disability and grounded more generally in disability studies offer an alternative perspective. The pilot is an opportunity to test our hypothesis that social work practice rooted in social model thinking can successfully challenge oppressive practice and disabling barriers, thus providing the opportunity for social workers to genuinely be 'servants not masters' in the lives of disabled people.

Introduction

In 2016, the Department of Health in England announced that it would be piloting the role of a Named Social Worker to support learning disabled people inviting applications from local authorities wanted to test innovative ways of practice that enable people to lead as 'fulfilling and independent lives as they can, and have the support to make choices that are right for them'. The ambition for the pilot is to build on the 'established values, knowledge, skills and ethics of social work - holistic, person-centred and proactive in co-opting awareness and support from other services' to ensure support for people where their dignity is respected and their rights are upheld (Romeo, 2016a). We (Calderdale Adult Social Care working with

Lancaster University) applied, in partnership with Lead the Way self-advocacy group to contribute to the pilot as we believe that too many learning disabled people are living lives confined by restrictions placed on them by health and social care professionals. Our application wanted to test our hypothesis that a reimagined social work role, as an applied social scientist (Croisdale-Appleby 2014) steeped in the social model of disability and as an expert in equality, mental capacity and human rights law , could act as a challenge to other professional voices within the health and social care system

Insert Figure 1 about here

Learning disabled people experience prejudice and discrimination (Mansell 2010) which manifests within the health and social care system as endemic low expectations and a lack of ambition for people's futures. The impact of the unjust nature (Whitehead, 1992) of the experience of the health and social care system by learning disabled people in England is observed in their over representation in long stay hospital beds and on registers of people living in the community who healthcare professionals perceive to be a risk to themselves and others (James et al forthcoming). In doing so, an erroneous association is being made on the part of health and social care professionals between ideas of risk and danger, resulting in paternalistic responses to disabled people, in particular people who exhibit behaviours which challenge professionals. The response of the majority of health and social care professionals of commissioning restrictive services to manage perceived levels of risk has been aptly described as wrapping people in "forensic cotton wool" in a recent Court of Protection judgement (A NHS Trust v P (2013 EWHC 50 (COP)). This tendency of professionals to impose colourless, restrictive lives was observed by Justice Hedley in his judgement which also shone a light on the assumptions made by professionals about the

extent of their legal powers to mitigate perceived risk through imposing restrictions on the lives of learning disabled people:

"A person is not to be treated as unable to make a decision merely because he makes an unwise decision…. the intention of the Act is not to dress an incapacitous person in forensic cotton wool but to allow them as far as possible to make the same mistakes that all other human beings are at liberty to make and not infrequently do."

The impact of such imposed restriction on the lives of people and their families can be devastating as seen in the abuse experienced by Steven Neary (LB Hillingdon vs Neary 2011); the routinised abuse exposed at Winterbourne View care home (DH 2012); the death through neglect of Connor Sparrowhawk whilst supposedly in the care of NHS Southern Health (NHS Southern Health 2016); and the stories told by families during the 2016 7 Days of Action campaigns (James et al 2016).   There is still limited systematic evaluation of the impact (or more often not/or absence of social work) has on avoiding such tragic outcomes. However, the stories told by the families who have experienced the health care system at its most restrictive and controlling are generating an emerging evidence base marked by consistent themes:

- People and families not being listened to and their views are not taken into account when decisions are taken by professionals about them;

- The most restrictive option being taken by professionals – usually the removal of the person from their family and admitted to a hospital or care home - in response to a presenting crisis when people and their families are asking for help;

- The purpose and effectiveness of assessment, care and treatment (the specified purpose of forensic settings (RCP 2014)) once the person was removed from their family ranging from ineffectively unclear to compromising of their dignity, rights and in the case of Connor Sparrowhawk his right to life; and

- Insufficient attention given to working with the person and their family members to plan an end to the treatment and for a sustainable return home (James et al 2016).

Writing from a user perspective grounded in disability studies Beresford & Boxall (2012) argue that for social work to be heard and make a better contribution to ensuring people experience their full range of rights as citizens, it needs to strengthen its intellectual nature and evidence base. We agree with this argument and welcome Croisdale-Appleby's revisioning of social workers as social scientists (2014:14) and the Chief Social Worker for Adults in England, Lyn Romeo's commitment description of social work as 'all about human rights' (Romeo 2016b). The culture of social work, at the deepest level of values in action, is critical to changing how people experience their lives. If social workers are to genuinely make a positive difference, standing alongside the person, they need to really believe that their role is one of a servant, not a master (Munby 2011). Good social work is professional practice which is both grounded in the social model of disability (Morgan 2012) and in mental capacity and human rights legal literacy expertise (BASW 2014).

From the early 1980s, when proposals to move to a more holistic approach towards providing community care for learning disabled people were articulated (Stevens 2004), UK policy makers have proposed a role for social workers in meeting the wider needs and aspirations of learning disabled people as citizens by acting as a source of advice and connecting people to wider circles of support. However laudable as a direction for social work this ambition may be, it will fail to meet learning disabled people's hopes, wishes and needs if social workers do not first have a strong understanding of the social model of disability, independent living and the forces of institutionalised disablism which they will need to overcome. It is over 30 years since Oliver developed the social model of disability however, social work still has a chequered relationship with the model and the challenge it brings of truly giving up professional power and devolving it back to people (Morgan & Roulstone 2012).

Insert Figure 2 about here

The vision for adult social work (DH 2016) is the most recent attempt to define the role of Named Social Worker as an advocate within the professions for the social model of disability. In keeping with wider policy goals to transform care and support (DH 2012) the initial pilot of the role of Named Social Worker has focused on the impact the role could and should have on the lives of learning disabled people. Whilst we remain concerned that the pilot may inadvertently result in reinforcing a view of professional dominance, the "expert" Named Social Worker with capitals in their title, we remain hopeful that our involvement may provide evidence that there is

another way. Our involvement in the pilot is demonstrating that social workers can make a difference in challenging the dominance of professional functionalist, reductionist perspectives of learning disabled people as being a risk and danger to themselves and others who require protection through restrictions.

Insert Figure 3 about here

Conclusion

Whilst it is too early to draw firm conclusions from the pilot, we are learning that a reimagined social work role could be a positive development. *Most social workers hold values which drive them towards a belief that their intervention will help the person they are there to support. However, the endemic low ambition and expectations with which too many professionals devalue the lives of learning disabled people mean this approach is insufficient. Social workers educated in the social model of disability, with its theoretical underpinnings in disability studies, holds promise to support a rights based approach which could challenge deep held values and assumptions. We are hopeful that over time this approach may resulted in learning disabled people experiencing better social work which enables them to access their full range of their rights as citizens.*

Disclosure statement

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Figures

Figure 1 Imagining a new future for social work co-produced with Lead the Way self-advocates

Figure 2 Co-designing a new approach for social work with Lead the Way self-advocates
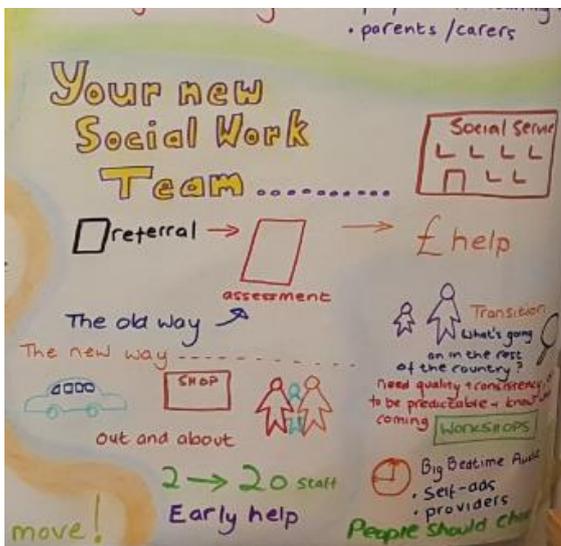
Figure 3 Co-evaluating progress in piloting the role of a Named Social Worker with Lead the Way self-advocates

Introduction

2003 was a significant year for disabled people in the European Union (EU).It marked the tenth anniversary of the United Nations' *Standard Rules on the Equalisation of Opportunities for Disabled People* (UN 1993) which gave international recognition for a social model or rights based approach to disability. The *Standard Rules* provided impetus for a more social modeloriented EU disability strategy, the language of which is dominated by a focus on citizenship, accessibility and barrier-removal. Furthermore, the year was designated European Year of Disabled People with the clear aim of raising awareness of disability issues in general and particularly of the environmental, social, economic, procedural and attitudinal barriers disabled people face. The intention was to generate a more concrete political commitment to promote disabled people's inclusion within mainstream European law and policy.

Central to the mainstreaming of disability issues has been a focus on the extent to which disabled Europeans can actively apply and develop their Union Citizenship. Disabled people, their organisations and allies have argued strongly that disabled people are in effect 'invisible citizens' within the EU, absent from European legislation and without adequate protection from discrimination by substantive EU law (EDF 1995).While more recent developments such as the 1997 Treaty of Amsterdam (which extended the protection of EU nationals against nationality-based discrimination to a range of other grounds, including race, sexual orientation, age, religious beliefs and disability (Article 13 EC)), mark an important advancement in the formal status of disabled citizens, concern still exists around the accessibility and scope of the rights and obligations implicit in the notion of Citizenship of the Union.

In order to frame our discussion of disabled people's status at Community level, it is important, to identify from the outset what, exactly, we mean by Citizenship of the Union, both in a formal legal as well as a practical sense.

Defining Citizenship of the European Union

Citizenship in a national context is traditionally allied with the exercise, to varying degrees, of civil, political and social rights. It also commonly denotes the legal and social relationship between individuals within a community and their relationship with the State. To what extent, therefore, does EU citizenship espouse these notions? Moreover, how many of us would really celebrate our status as a citizen of the Union? What, if anything, makes us identify and engage as individuals with EU membership? And to what extent does disability alter our conception and experience of EU membership? In responding to these questions, it is useful to consider, first of all, the formal legal definition of Union citizenship.

The concept of Citizenship of the Union attained formal constitutional status following the 1992 Treaty of Maastricht. This stated quite simply that all nationals of the current 15 Member States are to be regarded as citizens of the Union by virtue of Article 17 (formerly Article 8) of the EC Treaty. But how does the status of the EU citizen differ from the actual practise of EU citizenship - in other words, to what does this status give rise in terms of substantive rights? Very generally, the EC Treaty provides that all EU nationals 'shall enjoy the rights conferred by this Treaty and shall be subject to the duties imposed thereby' (Article 17(2)). This includes a set of (albeit modest) political rights and, more significantly, 'the right to move and reside freely within the territory of the Member States'(Article 18 EC).

The link between active EU citizenship and the exercise of free movement between Member States is, therefore, firmly established in this provision and has been pivotal to the development of substantive rights under Community law over the past thirty years, opening up access to a range of welfare and employment-related rights for those who migrate to other Member States (D'Oliveira 1995;Ackers 1998; Shaw 1998). This led one commentator to suggest that free movement is 'the central element around which our other rights crystallise' (D'Oliveira 1995:65).

The symbiotic relationship between EU citizenship and the free movement provisions implies that our rights as citizens of the Union are only really meaningful in the context of intra-union mobility making it for many European citizens a 'hollow concept'. As Ackers and Dwyer assert:

in the absence of mobility, Citizenship of the Union contributes little to the social status and day-to-day experience of Community nationals (2002:3).

This conception of EU citizenship is particularly exclusive of those with neither the means nor the inclination to move to another Member State, for example, because of disabling barriers. Even if an individual does wish to move, they must satisfy certain criteria in order to qualify under the free

movement provisions and obtain access to the panoply of social rights in another Member State. These criteria can be summarised as follows: you have to be an EU national and you have to be economically active (i.e. in work) or economically self-sufficient (that is, not dependent on welfare benefits). If you are neither of these, you can migrate as a dependent family member (that is, as the spouse, child or parent) of the migrant worker.

The limitations inherent in these criteria have, by now, been well documented, particularly in respect of their disproportionate marginalisation of women and children (Scheiwe 1994; Lundström 1996; Moebius and Szyszczak 1998; McGlynn 2000; Ackers and Stalford 2004) same-sex and cohabiting couples (Stychin 2000;Wintemute and Andenaes 2001) and third country nationals (Peers 1996).The more recent lobbying efforts of national bodies, network NGOs and Commission-affiliated organisations such as the European Disability Forum (EDF) have stimulated more critical discussion on the deficiencies of free movement legislation and wider EU-policies in respect of disabled people. However, there is relatively little academic discussion on this issue - one exception is the paper prepared by Waddington and van der Mei (1999) for the EDF - and very little literature challenging the accessibility of European Citizenship in this context.

We turn now to identify and critique the definition, scope and application of the free movement of persons provisions as the principal trigger of European social rights and, indeed, European citizenship. Specifically the paper will address the implications of the hierarchical nature of entitlement for disabled people with particular reference to debates around disability, dependency and work. This discussion will enable us to question the extent to which disabled people can enjoy active citizenship of the Union outside the context of free movement This concern has been recently re-articulated by the European Network on Independent Living (ENIL) (2003), the first European Congress on Independent Living held in Tenerife (2003) and the European Congress on Disability in Madrid (2003).

Disabling barriers to mobility

Waddington and van der Mei, in their discussion of the free movement provisions suggest that 'Community law does not (intentionally) seek to deny this right to people with disabilities' (1999: 8). In practice, however, the interpretation attached to concepts such as 'worker' and 'dependent family member', which are so central to accessing free movement rights, act as additional barriers to disabled people's mobility.This is quite apart from the physical barriers to migration and the impact of the disparity between disability related support available in different Member States. Let us look at these two concepts in more detail.

The concept of 'worker' under the free movement provisions

The concept of work under EU law is central to the operation and enjoyment of the free movement provisions but it is not clearly defined in any of the Treaties or secondary legislation. It has, instead, been left to the European Court of Justice (ECJ) to articulate and develop its meaning. The traditional rationale underpinning the mobility entitlement of workers was primarily economic: that they would be contributing to the development of the market economy by transporting valuable labour and skills resources between the Member States.

The essential criteria for qualifying as a Community worker under the free movement provisions have now been clearly established by the ECJ in Lawrie-Blum (1986) as entailing the performance of services, for or under the direction of another (separate rules govern the self-employed), in return for remuneration. While initially these criteria implied a full-time, male breadwinner who was making a discernible economic contribution to society, the ECJ has demonstrated an increasing readiness over the past twenty years to construe the term more broadly to encompass a wider range of working patterns. This has coincided with and, indeed, precipitated a gradual departure from a strict assessment of the tangible economic value of the activity towards one that is more subjective and looks at the value of the activity to the life of the individual him or herself.

As such, the ECJ has reaffirmed the right of all workers in all Member States to pursue the activity of their choice within the Community, irrespective of whether they are permanent, seasonal, temporary, part-time or full-time (Levin 1982),and regardless of whether they are supplementing their income by recourse to welfare benefits (Kempf 1986). The only limitation imposed is that the work must be 'genuine and effective' and cannot be carried out on such a small scale as to be regarded as marginal and ancillary to other activities carried out by the individual in the host state, such as studying or tourism, which are governed by different, more restrictive rules (Raulin 1992). One of the principal reasons behind these limitations on free movement entitlement is to protect Member States against the threat of so-called 'welfare tourism' whereby EU nationals may be motivated to move to other Member States under the pretext of carrying out 'work' but, in reality, in order to take advantage of more favourable welfare provision.

The expansion of the concept of work and worker has significant implications for disabled people, large numbers of whom are engaged in part-time, intermittent work (Sly 1996). According to recent EU figures, 15 per cent of the working age (16-64) population report disability, with 10 per cent reporting 'moderate disability' and 4.5 per cent 'severe disability' (Eurostat 2001). Within this group 46 per cent of 'moderately disabled'and

24 per cent of 'severely disabled' people are engaged in some form of work. However, as Barnes notes, disabled people's participation in the labour market tends to be characterised by their employment in 'poorly paid, low skilled, low status jobs which are both unrewarding and undemanding' (1991:65). Consequently, disabled people are more likely to experience lower levels of career advancement and under-utilisation of their skills and training when in work (Thornton and Lunt 1995:2).Thus, while the free movement provisions may open up to a greater proportion of disabled people of working age the prospect of working and living in other Member States they by no means represent a panacea for existing inequalities at national level.

The status of job-seekers

Case law also exists in relation to the status of unemployed Community migrants in pursuit of employment. In Antonissen (1991), for instance, the Court stated that jobseekers retain the status of worker and the right to move to another Member State to seek employment but that this right is not unlimited. For example in Lebon (1987) the ECJ held that 'those who move in search of employment qualify for equal treatment only as regards access to employment'. In other words, they can move to another country in order to look for work but will not enjoy all the social and tax advantages attached to the status of worker until they have actually found work. This finding is problematic for those disabled people who require support systems (which may include statutory support or benefits) to be in place to enable them to seek and obtain employment. This dilemma is mitigated to a certain degree by the existence of EU legislation (Regulation 1408/71 supplemented by Regulation 574/72) which entitles jobseekers to maintain benefits in their country of origin for up to three months while they are abroad looking for work, although certain benefits such as the provision of equipment may be restricted. A further disincentive for potential disabled migrants is that, on returning to their 'home' Member State, they may have to undergo a new assessment before they can recover any further benefits or forms of social support.

The status of voluntary workers

Some forms of voluntary work are held to constitute 'work' under Community law. In Steymann (1988) a German national, resident in the Netherlands, was refused a residence permit by the relevant authorities on the basis that his contribution to the life of a religious community could not be regarded as 'economic' for the purposes of Community law. In return for his contribution, the community provided him with accommodation and 'pocket money'. The ECJ concluded that Steymann did, in effect, provide services of value to the religious community which would otherwise have to

be performed by someone else (and presumably paid for) and, on that basis, he qualified as a worker.

The ECJ found that Steymann's contribution to the community via some plumbing work, general housework and participation in the external economic activities of the community (running a disco and laundry service) were indirectly remunerated through the provision of accommodation and modest living expenses.T his decision is significant for the increasing number of disabled people engaged in user-involvement, in-service provision or in the organisation and running of user-led service providers, where they may be involved in irregular or less formalised types of consultation and training for which some sort of remuneration other than cash is made (Barnes 2003).

While decisions such as that of Steymann advance disabled people's opportunities and status as Community migrants, it is interesting to note that the majority of ECJ cases considering the concept of work and the definition of 'Community worker' do not explicitly refer to disability take account of the specific barriers disabled people encounter when seeking to participate in the labour market. In one of the few cases concerning a disabled person's claim, that of Bettray (1989), the Court rejected the claim of a disabled German man employed in a sheltered environment to be considered as a Community worker. Bettray was employed by a special Dutch scheme which aimed to 'maintain, restore or develop the capacity for work' of those who able to undertake some form of economic activity but who are not in a position to undertake regular employment either because of disability or substance misuse. The ECJ held that such schemes could not constitute 'genuine and effective' work as the activities were tailored to fit the individual and were specifically aimed at rehabilitation and reintegration into the mainstream labour market. The ruling in Bettray, therefore, significantly enhances the worker status of over 300,000 disabled people in sheltered employment (Samoy 1992), because as Waddington and van dei Mei (1999) point out, contrary to the image of sheltered employment depicted in Bettray, the work of most sheltered workshops can be considered equally as 'genuine and effective' as that of most mainstream jobs.

While the extension of the Community concept of work and the definition of what constitutes a Community worker to include less traditional forms and patterns of work often undertaken by disabled people is to be welcomed, a sizeable proportion of disabled people are not, for various reasons, active in the labour market in any sense. In fact, according to 2001 Eurostat figures, 46 per cent of 'moderate' and 61 per cent of 'severe' disabled people are reported as being economically 'inactive'. This begs questions as to the

availability of an alternative status that triggers access to the freedom of movement provisions: the status of a dependent family member.

The status of 'dependent' family members under the free movement provisions

The second group to enjoy certain rights by virtue of the free movement provisions is the families of Community migrant workers. This group encompasses many disabled family members who do not, for various reasons, undertake paid employment, such as disabled children and young people, and (increasing numbers of) older disabled people. Family members who move with a migrant worker can access the same welfare-related (including disability benefits) and other social benefits in the host state as the worker and, in that sense, derive a highly privileged status from their relationship with the worker (Michel S 1973). However, limitations are placed on who may claim these derived rights by the way in which Community law defines who and what constitutes 'family' and 'dependency'. Again, in much the same way as the definition of work and 'worker' has evolved, these definitions and, perhaps more noteworthy, the ideologies and presumptions underpinning them have significant implications for disabled people.

The Community definition of 'family' under the free movement provisions

Currently, Community law specifies that the only family members who are entitled to move with the migrant worker and have access to the range of social and tax benefits in another Member State are: the worker's spouse (legally married, heterosexual); their children who are under the age of 21; any other children who are over the 21 but who are dependent; and dependent relatives in the ascending line (Regulation 1612/68, Article 10). It is the interpretation attached to dependency that impacts most significantly on disabled people generally.

Defining 'dependency' under the free movement provisions

A dependent relationship is, to a large degree, presumed in relation to children under the age of 21 and to the older parents of Community workers. However, the ECJ has so far failed to provide any clear guidelines as to what exactly constitutes dependency. It mostly clearly associates the state of dependency with financial dependency. For example in the case of Inzirillo (1976), the ECJ ruled that the son of an Italian migrant worker was entitled to claim a French disability benefit based solely on his financial dependency on his parent. However, financial dependency is not taken to require residence with the migrant worker. The ruling in Diatta (1985) held that a 'dependent' family member is not required to live in the same

household as the migrant worker as long as some form (however superficial) of financial dependency can be demonstrated. Ironically, the financial dependency required for a family member to claim social entitlement may be extinguished once that claim is realised, making dependency 'a matter of initial [qualifying] fact' (Ackers and Dwyer 2002:44).

More appropriate in the context of disability would be a broader interpretation of dependency by the ECJ to encompass relationships of physical and emotional support, which are often of greater significance to those concerned than financial support, as this would open up derived rights to a large number of disabled (and non-disabled) family members.

The way in which dependency is construed within this context is particularly problematic from a social model perspective. A central tenet of the disabled people's movement has been a rejection of a presumed automatic link between impairment and dependency with a focus instead on less physically based notions of independence (Morris 1993; Shakespeare 2000).This is encapsulated in the philosophy of independent living which distinguishes between the physical doing of an act for oneself (such as dressing or feeding) and exercising choice and control over how these activities are undertaken. Adopting an independent living approach to dependency involves recognising that:

no one in a modern industrial society is completely independent, for we live in a state of mutual interdependence. The dependency of disabled people, therefore, is not a feature which marks them out as different in kind from the rest of the population but as different in degree (Oliver 1989: 83-4).

Defining 'family' (and indeed 'work') to account for the interdependence between family members (and therefore the contribution that all family members make however financially or physically dependent they may be perceived to be) would have significant implications for the accessibility of the free movement provisions. It may also have implications for the hierarchical nature of entitlement as it would be difficult to sustain a privileged position for workers if other aspects of family life were recognised as equal to the breadwinning role.

Adopting a rights-based approach to European Citizenship

While the free movement of persons provisions, and particularly the extension of the concept of worker, have achieved much in enhancing the migration potential of disabled people, it is important to note their limitations. First of all, the social and economic rights arising out of free movement are based firmly on an ethic of non-discrimination. In that sense, they do not create additional social rights but merely provide migrants with access to these rights under the same conditions as nationals in the Member

State to which they migrate. Consequently, the nature and level of benefits (for example, those yielded by social welfare systems) are only as good as those already available to disabled nationals within the host state. Attaining EU migrant worker or family status does not, in that sense, address the inequalities already inherent in national laws and policies affecting disabled people.

A second limitation of the free movement provisions is their emphasis on economic contribution as a basis for entitlement. Essentially, the extent to which disabled people enjoy rights in this context bears direct relation to their level of economic activity. Feminist and, more recently, children's rights critiques of EU citizenship have in particular challenged EU law's devaluation and, thus, marginalisation of economically subordinate groups in its allocation of tangible entitlement (Ackers and Stalford 2004).

These limitations suggest that a shift towards a more coherent rights-based approach to EU citizenship could effectively address the deficiencies of free movement-based conceptions of citizenship. Indeed, citizenship is not just about securing access to social entitlement. It provides an important oratory for enhancing individuals' sense of autonomy and agency and for promoting effective participation. A broader, rights-based approach to citizenship incorporates these more ideological notions of participation, inclusion and equality while acknowledging individuals' contributions as everyday social actors (Cockburn 1998). Lister notes in this respect:

social citizenship rights also promote the 'de-commodification of labour' by decoupling the living standards of individual citizens from their 'market value' so they are not totally dependent on selling their labour power in the market (1997: 17).

Much remains to be achieved, however, to translate these ideologies into more inclusive, tangible entitlement for disabled people. So far, the EU has stopped short of implementing any binding law on Member States in respect of disability issues, opting instead for less controversial, aspirational, non-binding (or 'soft law') initiatives aimed primarily at facilitating the professional integration of disabled people. Even Article 13 of the EC Treaty, by which the 1997 Treaty of Amsterdam extended the long-standing prohibition of discrimination on grounds of nationality to other grounds including disability, has yet to be fully exploited as a legal basis on which to address the specific needs of EU nationals with impairments. Indeed, the European Disability Forum did submit proposals in 1999 for a specific disability directive based on Article 13, similar to that already implemented in the context of race equality. This recommended imposing specific obligations on Member States to take into account the impact of all laws and

policies on disabled people, not only in an employment context, but also in relation to housing, education, welfare and environmental initiatives.

It was not until the end of 2003, however, that the Commission made any real political commitment to act on the proposals put forward by the EDF and other lobbying organisations. On 30 October, it presented an Action Plan to improve and facilitate the economic and social integration of disabled people in an enlarged Europe. The first two-year phase of this six-year plan, which started in 2004, focuses on creating the conditions for disabled people to access the mainstream labour market. This is accompanied by a commitment from the Commission to issue bi-annual reports on the overall situation of disabled people in the enlarged EU as a means of identifying new priorities for subsequent phases of the Action Plan.

Notwithstanding the fact that these measures are targeted primarily at those who have the capacity to engage in full-time, paid employment, it is with some optimism that we might forecast the direction of the wider EU disability agenda, particularly in view of recent constitutional developments. Perhaps one of the most promising portents in this regard is the increasing prominence of human rights at EU law-making level, most notably through the introduction in December 2000 of the Charter of Fundamental Rights in the European Union (CEC 2000). This document sets out, for the first time in the European Union's history, the institutions' commitment to upholding and advancing a range of civil, political, economic and social rights in favour of all persons resident in the EU. Most of the 54 provisions contained in the Charter (which are heavily inspired by the provisions of the 1950 European Convention on Human Rights) are of direct or indirect relevance to disability with Article 26 of the Charter explicitly stating that:

The Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community.

These measures concern education, vocational training, ergonomics, accessibility, mobility, means of transport and housing as well as access to cultural and leisure activities, giving it a much wider scope than many of the other employment-related initiatives presented previously.

The Charter is currently only of declaratory (non-binding) force, although it has been incorporated in its entirety into Part II of the draft EU Constitution currently under negotiation. The new Article 26 is now enshrined in Title III of Part II (entitled 'Equality') and is supported by other provisions such as Article 20: 'Everyone is equal before the law'; and Article 21 (1):

Any discrimination based on any ground such as sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation shall be prohibited.

These measures, which reflect the spirit of Article 13 EC, are further reiterated in Part III Title I of the draft constitution entitled 'The Policies and Functioning of the Union'. Specifically ,Article 3 states that:

In defining and implementing the policies and activities referred to in this Part, the Union shall aim to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation.

Finally, Part III,Title II acknowledges the institutions' capacity to enact binding laws with a view to combating discrimination on these grounds:

Article 8 (1): Without prejudice to the other provisions of the Constitution and within the limits of the powers conferred by it upon the Union, a European law or framework law of the Council of Ministers may establish the measures needed to combat discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation. The Council of Ministers shall act unanimously after obtaining the consent of the European Parliament.

While institutional activity is restricted to the areas of competence articulated by the constitution, if adopted, and implemented, these provisions will provide an important template on which to enact more tailored initiatives in favour of disabled people, thereby detaching tangible rights from the economic imperative of the free movement provisions.

Conclusion

In this chapter, we have aimed to illustrate the way in which Community definitions of the concepts of work, family and dependency have significant implications for the citizenship of disabled people. The evolution of the concept of work to include new forms and different working patterns has opened up the status of Community worker to a larger percentage of disabled people. This ignores, however, the growing tension within disability studies and the disabled people's movement about the priority afforded to inclusion in the labour market (Barnes 2004).Early social model thinking clearly linked disablement with exclusion from the labour market (Oliver 1990) and therefore argued that reintegration was a precursor to disabled people's full participation and citizenship. Alongside this the independent living movement has adopted a different focus. The movement emerged largely from attempts to replace large-scale residential institutional care with services and support required for disabled people to live independently

while emphasising the importance of acknowledging individuals' interdependence.

Furthermore, focusing solely upon paid employment as the precondition for the full exercise of citizenship rights provides a narrow view of contribution. In an economy driven by consumption the consumer plays a 'productive' role. This is particularly pertinent for disabled people around whom a vast 'disability industry' has emerged employing thousands in the direct provision of care and medical support as well as indirectly through the production of aids and adaptations. Likewise, as feminist writers have suggested (Ackers 1998; Lister 2002), unpaid or informal 'care' work undertaken largely by women (including disabled women) plays an important role in both supporting the traditional notion of a single family breadwinner and of dispersing much of the societal costs associated with supporting children, disabled and older people.

Quite aside from these ideological debates, we have identified a range of additional barriers that restrict disabled people's ability to effectively exercise free movement. The disparity between social security systems and welfare provision in different Member States acts as a deterrent to mobility. Moving between Member States may result in the loss of existing benefits in the sending state and there are often qualifying periods before new claims can be made in the receiving state. Moreover, the conditions under which disabled people can export certain benefits are decidedly restrictive. Non-legal barriers include barriers to physical movement especially in terms of inaccessible public transport; in addition to well-documented discrimination in employment, housing, public support, and assistance (Waddington and van dei Mei 1999).

Thus while there may be a growing formal commitment at EU-level to extend full citizenship and its accompanying free movement rights to disabled people (on the basis of non-discrimination), considerable obstacles still exist at national level which hamper their enjoyment and for which the EU cannot currently claim legislative competency. In order to engage disabled people in a more meaningful way in the EU polity, therefore, active citizenship requires a departure from traditional free movement based interpretations which, through their elevation of formal employment, inevitably and consistently exclude a large proportion of them.

It is in this respect that a broader rights-based approach to citizenship becomes an important means by which to extend disabled EU nationals' rights beyond the economic imperative of the free movement provisions towards a more inclusive and positive declaration of their specific needs and value. As well as seeking to promote the substance of tangible entitlement, a rights-based model of citizenship provides an important platform not only

for promoting individual autonomy and agency but for exposing and crediting disabled people's contribution to society through their formal and informal, direct and indirect participation in the labour market.

The EU has certainly started to adopt a more proactive stance on disability issues in the past decade or so, manifested in a number of subtle budgetary, institutional and legislative developments. However, if European citizenship is to be regarded as more than simply a showcase for modest rights available primarily to economic actors under the free movement provisions, there is an urgent need for a more enforceable and confident declaration of disabled people's status at this level.

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Introduction

The European project, currently realised in the *European Union* (EU), has it foundations in the economic and inherently capitalist imperatives of the initial European Economic Community (EEC) established by the Treaty of Rome in 1957. The primary focus of the embryonic community was on facilitating economic integration, with wider social issues considered only insofar as they were deemed necessary to achieve the functioning of the common market. Thus, it is in this context that an employment-based disability policy emerged.

In the fifty years since its inception the rationale of this project has evolved both in scope and scale to a state that would be almost unrecognisable to its founders. The Union could now be viewed as being primarily concerned with constructing what Castells describes as a 'project identity' whereby its democratic deficit and lack of popular mandate is addressed by the development of a 'blueprint of social values and institutional goals that appeal to a majority of citizens without excluding anyone in principle' (1998:333).

This chapter will discuss the shifting paradigms that have emerged in European debates about employment, social policy and disability during this most recent period of identity and consensus building. Furthermore, it will suggest that the aims and objectives of these often overlapping areas of policy are characterised by tensions between competing and perhaps increasingly divergent, drivers in this process of identity production. The replacement of the concept of citizen-the-

worker (and the parasitic rights of dependent family members) with a more inclusive notion of citizenship based on nationality provides for the first time the opportunity for a comprehensive rights based disability paradigm (Morgan, 20014; Morgan and Stalford, 2005). The aim here, therefore, will be to discuss the development of this paradigm and to offer pointers to its future development.

Background and Context

Disabled people make up a significant percentage - about 10% (CEC, 2001a) - of the current EU population, a proportion likely to increase with enlargement and over time. However, the experience of disabled citizens of the Union has been characterised by an absence of their collective concerns and aspirations from agenda setting and decision making processes resulting in the marginalisation of issues relating to disability from the mainstream of EU policy and legislation. This led to the charge that disabled people became in effect 'invisible citizens' (EDF, 1995) without adequate protection in law or provision through policy.

The publication in 1993 of the United Nations Standard Rules of Equalization of Opportunities for Persons with Disabilities (UN 1993) gave international recognition to a rights based approach to disability and provided the impetus for a more social model orientated European Union disability strategy. The intervening period, marked annually by a European Day of Disabled People and, with much fanfare, in 2003 by the European Year of Disabled People (EYDP), has seen a clear attempt by the institutions of the EU to reorientate their disability policy and to respond to charges and claims levelled against them by disabled people and their allies.

Organisations of and for disabled people are choosing to mobilise to an unprecedented extent at an EU and pan-European level, evidenced by establishment of organisations such as the European Network on Independent Living (ENIL) in 1989, the European branch of Disabled People International (DPI-Europe) in 1992 and, in 1996, the creation of the European Disability Forum (EDF) to provide an

'independent voice in the political debate at European Union level which is truly representative of the whole spectrum of disabled people and parents of disabled people unable to represent themselves' (EDF, n.d.).

In addition, wider networks of local, regional, national and supra-national disability groups have begun organising collectively to articulate their concerns about the status of disabled citizens, for example via the recent Tenerife Declaration produced by the first European Congress on Independent Living (ECIL, 2003), the Strasbourg Freedom Drive (ENIL, 2003) and European Parliament of Disabled People held in November 2003 as part of the EYDP (EPDP, 2003). The broad agenda that emerges is one concerned with issues of rights, non-discrimination, independent living and the mainstreaming of disability, encapsulated in a focus on the degree to which disabled people can actively apply and develop their Union citizenship (Morgan and Stalford 2004).

The Emerging European Union Disability Policy

The development of a European disability policy can be broadly divided into three phases mirroring to some extent the more general development of the social dimension of the Union. First, a period of 'benign neglect' (Mosley 1995) from the founding treaty in 1958 until the early 1980s. This was followed by a more focused attempt by the Commission to 'creep softly' towards to the establishment of a Disability Strategy in 1996 and finally the adoption of a more radical rights-based approach in the mid-1990s. The aim here is not to provide a comprehensive overview of the development of EU policy in relation to disability (for a more detailed review of the development of disability policy see Geyer, 2000a and Mabbett and Bolderson 2001), but rather to point to key influences and trends, particularly the relationship between disability policy and the wider concerns of employment policy.

Benign neglect 1958-81

Very little attention was paid to the needs and concerns of disabled people during the early years of the European Community, indeed Community disability policy during this period can be described as 'virtually non-existent' (Geyer 2000a:187). The Treaties of Paris and Rome were silent on the subject of disability and the majority of disabled people – those who did not gain entitlement to the worker's

rights established by the Treaties – were only indirectly the concern of the Community and the beneficiaries of the creation of the common market (Geyer 2000a; Hantrais 2000). Thus, disabled people were 'left out of the master plan' (Waddington 1999).

For much of this period broader 'social policy' concerns remained subjugated to economic ones concentrated at the member state level. As a result social and disability policy – such as it was – were subsumed within a broader employment policy concerned predominantly with the free movement of labour, health and safety and other measures designed to complement economic integration.

Creeping softly 1981-96

The impetus for developing the 'social dimension' of the Community came from a concern in the 1980s that 'the European project would be seen as benefiting big business, bankers and politicians, while ignoring the needs of workers and citizens' (Kleinman, 2002:86). To this end Jacque Delors, as President of the Commission, proposed the 'creation of a European social area' as a pre-requisite of economic integration (1986 cited in Neilsen and Szyszczak 1991: 32). However, as Article 5 establishes, the institutions of the Community may only act within the competences assigned to them by the Treaties (for fuller discussion relating to Commission competence and disability see Waddington 1997). In addition, there remained substantial resistance in the Council and at member state level to the development of a fully-fledged EC social policy separate from the concerns of economic integration, illustrated by the United Kingdom's opt-out from the 1989 Social Charter. Despite these restrictions, the Commission made substantial progress in developing a range of social policy initiatives during this period via a process known a 'competence creep' which utilises 'soft law' measures such as non-binding (less controversial and often aspirational) resolutions, communications and guidelines to facilitate action in areas not explicitly mentioned in treaties and to build 'new constituencies of support' for EU action (Wendon, 1996:8 cited in Mabbett and Bolderson 2001:15).

A key element in this process in relation to disability was the creation of two successive Community Action Plans– Helios I (1988-91) and Helios II (1993-6). The central aim of the Helios programmes was to 'promote the social integration and independent lifestyle' of disabled people and as such represented a shift in community thinking about disability away from a somewhat blinkered focus on employment and labour market participation and a gradual reorientation of policy objectives towards wider areas of concern. Indeed, Hurst asserts that before 1993 the European institutions viewed disability solely as 'an issue of rehabilitation and social care and provision' (2004:300).

The process of pan-Community exchange fostered by the programmes precipitated a growing awareness amongst disability (and other) organisations of the potential of EU Treaty law (Quinn 1999:304) that was shared by the EC's recognition that:

people with disabilities undoubtedly face a wide range of obstacles which prevent them from achieving full economic and social integration. There is therefore a need to build the fundamental right to equal opportunities into Union policies' (CEC 1993a)

Consequently, the EC proposed

at the next opportunity to revise the Treaties, serious consideration must be given to the introduction of a specific reference to combating discrimination on the grounds …of disability (CEC 1993b).

A rights-based strategy 1996-present

Considerable attention has been paid to the reorientation of Commission thinking in line with a rights or social model based approach to disability (cf. Quinn 1999; Waddington 1997, 1999). The Commission itself points to the 1996 Council Resolution *Equality of Opportunities for People with Disabilities* as an endorsement of an approach concerned with barriers and participation at the highest levels of the European project (CEC, 1996). The resolution encouraged member states to 'empower' disabled people's participation, to remove barriers to this participation and to open up 'various spheres of society' although the focus remained on participation in employment.

The culmination of this 'sea change in attitude' (Quinn 1999:310) was the inclusion of disability in the anti-discrimination clause of the Treaty of European Union. (1997). The adoption of Article 13 EC was highly symbolic, for the first-time disabled people were explicitly recognised at the heart of the European project. However, the Treaty does not confer additional rights for disabled citizens. The granting of new competencies to the Community is not a guarantee of action, but rather leave to act should the Community choose (EDF, 1998:23), Moreover, action requires the unanimous approval of (the more circumspect) Council. Furthermore, the potential impact of action is constrained by the continued exclusion of areas of paramount importance in tackling disablement such as education and housing from Community competence. Nonetheless, the changes to the Treaty do have a significant practical impact. It provides a legal basis which Community institutions can utilise for new legislation and action to ensure better account is taken of the needs of disabled people across the whole community programme.

Mainstreaming Disability

Mainstreaming particularly around equalities issues is now common practice at both the member state and European level. In essence it is the consideration of the needs of a particular group at all stages of policy and decision making processes and complements rather than replaces specific action targeted designated groups. Mainstreaming also involves assessing whether a policy or action will have a different impact on different group. The process of mainstreaming in social policy was adopted at the European level first in relation to gender and race and latterly to older people and disability (Geyer 2000b). More recently it has been extended to the areas of human rights (CEC, 2002) and children's rights (Stalford ref). In the context of disability policy the EC described it thus:

Mainstreaming requires well-informed policy-making and wide participation
in the policy making process to ensure that disabled people, and their
diverse needs and experiences, are at the heart of policy-making each time
it has an impact, directly or indirectly, on their lives (CEC 2003:6).

An example is the EC's recent work to encourage member states to consider disability within each of the 10 Employment Guidelines of the European Employment Strategy rather than simply addressing issues of disability as part of the guideline on disadvantaged groups (Social Dialogue.net 2004).

The shift towards mainstreaming disability is viewed by the EC as a central plank of a rights-based response to disability which it signalled in the 1993 Green Paper on social policy -

special facilities, institutions and legal rights are obviously necessary, but
they should not be an obstacle or an alternative to the principle of
mainstreaming, that is to say, acceptance of people as full members of
society (CEC 1993b:48)

This was formally adopted in the 1996 Council Resolution *Equality of opportunity for people with disabilities* (CEC 1996). In his analysis of mainstreaming in three areas of EU social policy Geyer (2000b) rates the success of this strategy as 'partial' (in comparison to 'successful' in relation to gender and failure in the field of older people). Geyer points to the Treaty provision for gender equality and the strength of the women's lobby as the key factors in ensuring gender has been effectively mainstreamed in EU policy. Thus, the lack of a formal and forceful legal base that empowers Commission action remains a significant barrier. The increasing political impetus around disability issues is countered by 'mainstreaming competition' and 'overload' as well as concern about the resource implications of such a policy.

As suggested earlier in this chapter the requirement for unanimous agreement by the Council of Ministers, permission for action is a considerable constraint on the development of disability policy leading the Commission to utilise 'soft law' as a method of consensus and momentum building. This practice of 'competence creep' can be viewed as a key element of project identity creation whereby 'social values and institutional goals' are constructed through an incremental process of consensus building. This aspect of the European project has been termed 'europeanization' and can be summarised thus:

the concept of Europeanization refers to a set of processes through
which the EU political, social and economic dynamics become part of the
logic of domestic discourse, identities, political structures and public

policies (Radaelli 2000:4).

The Europeanization of Disability Policy Paradigms?

The exact extent of EU influence on approaches and responses to disability in the member states is hard to pinpoint for a number of reasons. First, the EU has drawn extensively on supranational, national and subnational discussions and debates in the development of its Disability Strategy making it difficult to establish which direction influence is flowing in. The EU was clearly inspired and given a certain degree of legitimacy by the development on universal instruments such as UN Standard Rules and the European Declaration on Human Rights to which most member states are signatories. Furthermore, the trend from welfare-based rehabilitation orientated policies towards an approach grounded in rights is an international one embraced in responses based in constitutional, civil and criminal law (Waddington, 2001). Indeed Waddington suggests that far from leading this trend Europe – whether the EU or its member states – 'is lagging behind other parts of the world' such as North America and Australia and has developed its rights based disability policy 'more or less simultaneously' with many other countries and regions (2001:162).

Second, the EU is essentially collectivist and consensual in its nature, what Bulmer and Radaelli term 'governance by negotiation' (2004) whereby the institutional structure of the Community means that policy is usually the result of a process of negotiation between the different EU institutions, member state governments, social partners and other interest groups. In addition, commitment to the subsidiarity principle – where decision making, and action takes place at the lowest effective level - remains strong. Furthermore, the emphasis in Commission guidance tends to be on securing specific outcomes or harmonizing approaches rather than stipulating particular policy tools or methods.

Third, as Hvinden (2003) suggests there are a number of other factors that influence the development of similar policy across member states. He points to the common challenges faced by European governments such as globalisation and changing demographics, the emergence of 'epistemic communities' among experts and policy

makers (Deacon 1999)' and finally he notes the impact of the development of an increasingly vocal and co-ordinated disability movement bringing considerable pressure to bear on both member states and the institutions of the Union. However, despite these influences there remains 'much cross-national divergence in the objectives and instruments of disability policy of Western European countries' (Hvinden 2003:610). This reflects a broader trend across social policy in which 'similar concerns and approaches by EU countries do not necessarily translate into similar decisions and outputs by member states' (Morento and Palier 2004:4).

Equal Citizens: An emerging EU policy paradigm?

Citizenship of the Union was formally established by the 1992 Treaty of Maastricht which granted the status to all nationals of the member states (Article 17 ex 8 EC). The EC Treaty provided a set of modest political rights (such as the right to vote and be a candidate in municipal and European elections) and more significantly 'the right to move and reside freely within the territory of the member states' (Article 18 EC). This opens up access to a range of welfare and employment related rights for those who migrate within the Union. There is symbiotic relationship between European citizenship and the free movement provisions with the result that citizenship is only really meaningful in the context of intra-union migration.

The (disabling) barriers to mobility that exist for many Europeans have the potential to make this status a 'hollow concept'. Moreover, even if an individual wishes to migrate they must satisfy certain criteria to qualify under the provisions and obtain access to the panoply of social rights available in another member state which can be summarised as follows: You must be an EU national and either economically active (that is a worker) or, economically self-sufficient (i.e. not dependent on welfare benefits). Certain family members such as spouse, child or parent, enjoy these rights parasitically (based on their 'dependency' on the worker).

The limitations inherent in these criteria are well documented in relation to their disproportionate marginalisation of women and children (Scheiwe 1994; Lundstrom

1996; Moebius and Szyszczak 1998; McGlynn; Ackers and Stalford, 2004), same-sex and cohabiting couples (Stychin 2000; Wintemute and Adenæs 2001) and third country nationals (Peers 1996). More recently attention has been paid to the deficiencies of the free movement provisions in respect of disabled people (Waddington and van dei Mei 1999; Morgan and Stalford 2004; Morgan 2004). While it has been suggested that 'Community law does not (intentionally) seek to deny this right to people with disabilities' (Waddington and van dei Mei 1999:8), in practice a range of factors limit the accessibility of Union citizenship for disabled people. These include the interpretation of concepts such as 'worker' and 'dependent family member' (which is explored in detail in Morgan and Stalford, 2004), disparity between social security systems and welfare provisions in different member states, the current restrictions on exporting benefits as well as a variety of non-legal barriers in fields such as transport, employment and housing.

Two key limitations further inhibit the utility of Union citizenship for disabled people. First, the rights that arise through free movement are based on an ethic of non-discrimination which only provides access to those rights and entitlements available to nationals in the member state to which they migrate. Additional social rights are not created nor are the inequalities inherent in national policies and laws affecting disabled people address. Second, and more fundamentally, is the narrow interpretation of contribution embodied in the Treaty (Morgan and Stalford, 2004). The development of the European project as primarily an economic one has resulted in the evolution of a citizenship and social policy centred around citizen-worker, someone who contributes via the paid labour market thereby excluding those contribute by non-economic means such as the provision of informal care (Ackers 1998; Ackers and Dwyer 2002; Ackers and Stalford 2004;) or voluntary or community based activity (Barnes 2004).

The development of a more coherent rights-based approach to EU citizenship could address the deficiencies of a free-movement based conception of citizenship. Indeed, particularly in the context of disability, citizenship is not just about securing access to social entitlement, a broader, rights-based approach to citizenship incorporates more ideological notions of participation, inclusion and equality (Barton 1993) while acknowledging individuals' contributions as everyday social actors (Cockburn 1998).

Conclusion

While the continued development of a European social model based upon shared 'social values and institutional goals' but achieved through a variety of policy, legislative and legal mechanisms should consolidate the hegemony of a rights based approach to disability within the EU it appears likely that further extension of the European project will be centred on a process of formalising the status of its citizens illustrated by the commitment to a European Constitution that includes the Charter of Fundamental Rights initially published in 2000 (CEC 2000). This broader rights-based approach to citizenship is a significant means by which to extend EU nationals' rights beyond the economic imperative of the free movement provisions to a more inclusive and positive declaration of their specific needs and values.

As well as seeking to promote the substance of tangible entitlement, a rights based model of citizenship provides an important platform not only for promoting individual autonomy and agency but for exposing and crediting disabled people's contribution to society through their formal and informal, direct and indirect participation in the labour market.

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Abstract: This article explores recent developments in the modernisation of adult social care through the lens of changes to English day services. Drawing on wider policy debates, it argues that Disabled Peoples' Movement and governmental ideas on self-directed support, although superficially similar, are growing increasingly apart. It is argued that in the absence of adequate funding and exposure to organisations of disabled people, day service recipients risk moving from a position of enforced collectivism to an enforced individualism characteristic of neo-liberal constructions of economic life.

Introduction and scope

This article explores the challenges of effecting self-directed support policies in English day services for disabled people. The article is based on a research project in a large English city completed in late 2006. The challenges identified are not unique to the city context being studied (Gordon *et al.*, 2006) and raise much broader issues of how modernised day services can be established and maintained (DoH, 2005). Arguably, the very language of 'day services' conveys the depth of the paternalist tradition in day centre contexts (Barnes, 1990; Whittaker and McIntosh, 2000) and the need for greater choices and rights for disabled people. However, the article identifies barriers to day service modernisation as well as discursive inconsistencies around some disabled peoples' self directed options in the context of straitened adult social care budgets. A philosophical question inheres in the future relationship between individualised and collective lives for disabled people. Day centre users have historically not had access to wider disability forums within which to build the self identities and confidence which are often assumed to be the sine qua non of self-directed support. Until 2005, day centre users did not feature strongly in discussions of self-directed support, but have recently been seen as eligible, in principle, for such policy and programme intervention. Can an individual choices discourse contained in the modernisation agenda be applied unproblematically to disabled people who have had no prior exposure to rights-based opportunities?

Modernisation of adult social care: promoting independence wellbeing, and choice

The apparent convergence of statutory and Disabled Peoples' Movement thinking on individual self determination provides a unique opportunity in furthering the convergence of governmental and Disabled Peoples' Movement developments towards choices and rights. However, the history of past social care policy can be viewed as unpropitious and as missing opportunities to liberate disabled people from the yoke of paternalism. Notably, the NHS and Community Care Act of 1990, whilst viewed positively by its statutory architects in the Department of Health as ending institutional care and bringing care closer to the individual and community (Griffiths, 1988; House of Lords Select Committee on Health, 2007), was roundly criticised by disability and mental health organisations. Critics pointed to erroneous assumptions of 'imagined communities', cost saving imperatives of community care policy and policy leaving many 'beneficiaries' with few economic and social resources (Bornat *et al.*, 1993; Beresford *et al.*, 2005). The failure to fully fund such a major social care policy was coupled with suspicions that overt policy objectives of providing greater choices masked underlying Treasury-driven cost saving imperatives. That similar dynamics might attach to aspects of recent social care policy has to be taken seriously. What is novel in more recent policy and programme debates is the borrowing by the English government of the language of radical disability politics, which makes criticism of its key precepts seems misplaced and 'unreasonable'. However, critical policy analysis is required to account for the range of dynamics underpinning modernised social care.

The recent convergence of views is significant, with a more generalised governmental championing of self-directed support to a wider range of disabled people. The earliest application of ideas of what are now termed self-directed support, dates back to the 1996 Community Care (Direct Payments Act), and the first disability-led Centre for Integrated Living (now Centres for Inclusive Living) based on a philosophy of 'choices and rights' was established in the mid 1980s (Barnes and Mercer, 2006). Choices and rights summed up the aspirations of the UK Disabled Peoples' Movement that disabled people should have greater control over their lives underpinned by a political struggle that fostered enabling services and a 'sense of pride and collective awareness among the disabled community' (Campbell and Oliver, 1996: ix). Such developments, although important, were not widespread; indeed even some ten years after the Act, less than 5% of the eligible population were receiving direct payments – a key benchmark of self-directed support (Davey *et al.*, 2006). In part because of this poor take up of direct payments, the UK government redoubled its efforts to support a range of self-directed social care policies and a further reduction in traditional services, such as day centres. These ideas have converged since the mid 2000s with earlier ideas from the UK Disabled Peoples' Movement around 'choices and rights', which in concrete terms favoured direct payments, joined-up financial support and the closure of institutional 'care settings' (Barnes and Mercer, 2006). However, concern is beginning to be raised that the Department of Health may be promoting

self-directed options to previously overlooked groups of disabled people, whilst failing to underwrite commitments with the additional money required to effect seismic changes in adult social care. In turn, this could lead to a rationing of funding for meaningful self direction. Without such financial commitment, current day centre users could risk being moved from a position of enforced collectivity to one of enforced individualism. The cost of adult social care and risks of unaffordable adult care in an 'ageing society', whilst a legitimate policy concern, has become inextricably linked with notions of choices and self determination:

Indeed we don't simply want to embrace individual choices but in financial terms we have to in balancing the books . . . We are unlikely to raise the revenue needed to fund the needs of an ageing population using traditional approaches to adult services. (Care Services Improvement Partnership, 2008: 2)

Questions might be raised in policy terms as to why choices and rights remain a funding problem as opposed to social and moral imperatives. Two recent reports published by the Office for Disability Issues (Henwood and Hudson, 2007; Hurstfield *et al.*, 2007) also emphasised the social and economic imperative of promoting independent living:

there are likely to be dynamic, long-term benefits to the exchequer and society in the form of reduced reliance on health and social care services and a reduction in overall dependency on informal support. (Hurstfield *et al.*, 2007: 49)

The ease with which cost savings in health and social care sit alongside reduced reliance on informal care is noteworthy. The transcending of reliance on unpaid informal support suggests more rather than less spending on day services. Similarly a recent policy document makes clear the financial and demographic imperative for ending institutional provision:

Demography means an increasing number of people are living longer, but with more complex conditions such as dementia and chronic illnesses. By 2022, 20% of the English population will be over 65. By 2027, the number of over 85 year-olds will have increased by 60%. (DoH,2007a: 1)

However, the projected costs of expanded self-directed support are nowhere delineated and policy visions for self direction are based on extrapolating previous self-directed activity where recipients received higher than average support packages (PSSRU,2006) and were often close to disabled peoples' organisations (Riddell *et al.*, 2005). If the engendering of real choices, personal empowerment and financial savings can be squared through self-directed support, then concerns will have proved to be unfounded. However, the weight of projected cutbacks in adult social care budgets emanating from central government continues to raise real anxiety amongst mainstream service and standards organisations (Commission for Social Care Inspection, 2008; Local Government Association, 2008). As Liz Sayce, chief executive of RADAR recently noted:

When over 70% of local authorities have restricted their eligibility criteria for support to those in 'critical or substantial need' social care budgets are clearly squeezed to breaking point. This stops preventive work – help comes too late – and severely limits support to enable people to participate in social and economic life. It also means the post-code lottery between different local areas is all too likely to continue. (NCIL, 2007: 1)

It is noteworthy that whilst most key policy statements on 'adult social care' emanating from government emphasise cost savings and demographic 'risks', statements from writers close to the disabled peoples' movement emphasise the social or moral imperative for offering greater choices (Barnes and Mercer, 2006). Organisations at the forefront of modernised service delivery and user-led policy have begun to register their concerns on the gap between rhetoric and reality in service provision:

Many of our member groups find themselves increasingly inundated with local disabled people who are struggling to keep their lives together and to stay independent in the face of adult social care service restrictions. It seems for many people that independent living is slipping further away. At the same time, national Government rhetoric consistently advocates empowerment, choice, control and personalisation. (NCIL, 2006: 1)

This is supported by evidence published in the Commission for Social Care Inspection (CSCI) report *The State of Social Care in England 2006–7* (CSCI, 2008) which acknowledged that increasing numbers of disabled people are no longer eligible for statutory funded social care and that access to support resembles a 'national lottery'.

Policy background
The arrival of the Green Paper, *Independence, Wellbeing and Choice* (DoH, 2005) has been seen by some to mark a watershed in the UK Government's approach to future adult social care (Morris, 2008). This Green Paper, alongside theWhite Paper *Our Health, Our Care, Our Say: A New Direction for Community Services* (DoH, 2006) and the guidance contained in *Fair Access to Care* (DoH, 2003), all emphasise individual choices in preventive approaches to inappropriate care options, maintaining independence and support tailored to individual needs (DoH, 2005). Most recently *Putting People First* (DoH, 2007a) and *Independence, Choice and Risk* (2007b) have added to the message that social care solutions should be personalised, that money should follow individual disabled people and foster the 'self management of risk' (DoH, 2007b). In tangible terms, greater choice making will be facilitated by both more supportive Professional values and practice, and specifically through the greater use of Individual Budgets and Direct Payments. Similarly, the widespread consultation that fed into the 2005 *White Paper Our Health, Our Care Our Say* (DoH, 2006) also emphasises the importance of choice, joined-up working, the widest use of community resources, preventing health deterioration, wellbeing strategies, more flexible and reflexive service delivery. In day-to-day terms, the modernisation agenda has arrived at a number of key self determination and

personalised mechanisms best captured in 'Person Centred Planning' (DoH, 2002), direct payments (Glasby and Littlechild, 2002; HM Government, 2003; Woodin, 2006) and individual budgets (Ibsen Consortium, 2007).

The rise of direct payments and individual budgets over time has led some writers to use the term 'self-directed support' to sum up disabled peoples' greater control of their support package. This rapid shift towards self direction has predictably led to diversity of response, with evidence pointing to a lottery of provisions of direct payments and some professional ambivalence towards the implications of greater 'choice' (Sapey and Pearson, 2004; Henwood and Hudson, 2007), particularly in relation to those identified as 'vulnerable adults' (Glendinning *et al.*, 2008) . Evidence suggests that people with learning difficulties often require additional support in direct payment use via brokerage services, whilst some applicants are deemed ineligible, as they do not meet basic eligibility thresholds (Glasby and Littlechild, 2006). Notably, Holman and Collins (1997) made early observations that pre-existing provisions, such as Independent Living Schemes and Trusts, needed to be able to connect fully with new direct payment approaches to empower disabled people.

What the above literature displays is a broad agreement that direct payments and individualised choice are inherently welcome and suited to disabled peoples' lives. It is unclear, however, how broader policy shifts emphasising the central role of user-led organisations (Office for Disability Issues, 2008), which in the guise of Centres for independent or inclusive living have historically been rooted in collective philosophical roots (Driedger, 1989), can connect with the categorical shift towards individual choice making? Writing about mental health day services Bates (2007) emphasises the way in which provision offers 'safe spaces' and an opportunity for both solidarity and sanctuary for service users from often inaccessible and disabling mainstream spaces and locations. This however is a far cry from the Disabled Peoples' Movement's construction of collective struggle.

Collective identities
In relation to collective identity Finkelstein notes:

it is essential that all disabled people join together in our own organisations so that there is a creative interaction between disabled people. (Finkelstein, 1987: 4)

The question of a collective 'disabled identity' as illustrated in Finkelstein's assertion above, although contested (Shakespeare, 2006), might be seen as in philosophical opposition to individual budgets. However, the potential to connect individual control and disabled identity could inhere in the growth of CILs (Centres for Inclusive Living). This was given a boost in the Life Chances report recommendation that a CIL was required in every local authority area:

By 2010, each locality (defined as that area covered by a Council with social services responsibilities) should have a user-led organisation modelled on existing Centres for Independent Living. (Prime Minister's Strategy Unit, 2005: 77)

However, the Green Paper on adult social care makes no such commitment, although it is flagged up in the Putting People First concordat and the Department of Health is leading on implementation. Moreover, there is growing concern within the disabled people's movement about the approach being taken by government in what it terms the 'disability movement' (Ivory, 2008; Oliver and Barnes, 2008). User-led organisations are increasingly struggling to be awarded service contracts and to remain financially viable in the face of
a myriad of local and national organisations 'not led, managed or controlled by disabled people [who] will find it relatively easy to adopt the phrase in order to secure funding' (Barnes and Mercer, 2006 :177).

Advocacy groups such as Values into Action and People First also clearly have a key role in supporting people with learning difficulties through the labyrinth of social care funding. The reality for many disabled people however is that they have little or no contact with activist or advocacy organisations (PMSU, 2005) and for some their sources of collective identity, however dilute, are gleaned through contexts that are rejected by the Disabled Peoples' Movement. The challenge of responding to the majority of disabled peoples' needs and the establishment of new solidarities and identities is easily under-estimated. To do this we need to reflect on different forms of collectivities and their potential to counter neo-liberal individualisation.

Disabled collectivities
The disabled peoples' movement in the UK (Campbell and Oliver, 1996) and globally (Driedger, 1989) has been founded on what might be dubbed collectivities of identity and a contestation of a range of social barriers to disabled peoples' social participation. There are clearly significant economic facets to this struggle (Shakespeare, 1996), however the disabled peoples' movement is characterised as being concerned with a range of barriers – environmental, economic and cultural – which serve to oppress disabled people. In line with Inglehart's classic formulation, the disabled peoples' movement is concerned with reconceptualising social ideologies (Ingelhart, 1990). Inglehart characterised new social movements as post-materialist. This best captures new social movements in their concern with issue-based projects, such as environmentalism, new age religion, sexual politics and of course disability rights. The above diversity of focus and broader redefining role is embodied in Centres for Inclusive Living (CILs). CILs are seen both governmentally and by some disabled people as the focus for delivering future disability services (Prime Minister's Strategy Unit, 2005), for advancing new ways of viewing disability and one could argue new sites of solidarity. Whilst the above provides the ideal conception for many of enabling collective identity, many disabled people remain distant from or unaware of the 'Movement' and constituent organisations. It would

be inaccurate however to see such disabled peoples' lives as untouched by collective experience, indeed many have experienced what might be dubbed 'enforced collectivities'. Enforced collectivities are typified in now reduced segregated long-stay, residential and day centre contexts. Critical commentary highlights the negative categorical impulses to segregate disabled people based on assumptions of sub-normality (Barnes, 1990). More generous interpretations point to paternalist impulses to 'protect' vulnerable sub-populations. It is noteworthy and not a little ironic that experiences of enforced collectiivities may afford friendships, exposure to new ideas and personal empowerment (Linton, 2007). It is reasonable to assume that collectivised lives can be experienced positively *and* negatively and as potentially empowering and profoundly disempowering. It is also conceivable that aspects of our lives be influenced by collective and individual influences. What then of individualism?

On individualism
It was the French sociologist Emile Durkheim who provided the starting point in our understanding of the rise of 'organic solidarity' in a complex social division of labour. Individualism was perceived as a functional prerequisite of complex, flexible and geographically mobile social systems (Durkheim, 1893). Of note, Durkheim viewed paid work as the currency of individualism, something questioned recently in critiques
of work-first agendas at the heart of neo-Durkheimean projects (Malholtra, 2005). Marx of course viewed individualism as the result of competitive capitalism, with its requirement for impersonal social actors who could best embrace the raw cash nexus that characterised industrial capitalism (Marx and Engels, 1848[1992]). Lukes' more recent (1973) appraisal however makes clear that individualism is deeply ambivalent and thus amenable to a range of ideological ends, both reaffirming and also challenging social hierarchies:

Individualism . . . forms the basis for a particular ideological view of a certain society and its social relations. But I have also suggested that this way of constructing the individual has been historically progressive as a crucial weapon in the breaking down of traditional privilege and hierarchies. (Lukes, 1973: 122)

Lukes of course makes clear in his later writings the perception that individualism has been used by neo-liberal governments to support anti-interventionist ideas. More recently, Mike Oliver's classic *Politics of Disablement* (1990) updated Marx in providing a fundamental critique of individualism as a key ideological starting point and one inimical to an a liberatory politics of disablement. It is therefore a challenge to envision the individualisation of adult social care without individualism. Clearly the 'self direction' and 'self management' which have grown out of radical critiques of liberalism and neoliberalism risk being distorted to equate more fully to 'responsibilisation' and victim blaming discourses (Dean, 2007) . The need for parallel collective contexts with which to comprehend and understand shared experiences and identity alongside enhanced individual control is then very real.

Reflecting on the needs of a globalised economy, Beck *et al.*'s celebration of 'reflexive modernisation' (Beck *et al.*, 1994) is typical of work which envisions the reflexive self as the essential building block of complex and responsive economies. As they note there are implications for individuals and social collectivities as in reflexive modernisation:

A process of self-organization emerges, drawing upon economic, community, and political activities. (Beck *et al.*, 1994: 39).

What is unclear in this and similar formulations are how self organisation and community can cohere. At no point do such arguments acknowledge that self and community ideas might conflict where individualism is promoted as the basis of social and economic efficiency. Komter provides a more critical approach in his appraisal of new 'segmented solidarities' which emerge partly in response to rapid social and institutional change (Komter, 2005).Whilst (rightly) arguing for greater collective strength, the Disabled Peoples' Movement in the UK (Campbell and Oliver, 1996) and US (Charlton, 2000) has not been able to safeguard these ideas for all disabled people in an increasingly individualised and marketised social care context. The ability to articulate needs, or locate and use advocacy in gaining control, seems pivotal in engaging in a reflexively modernised adult care model based on self management. If we fail to build in these supports and safeguards, issues of access, equity and isolation may arise needlessly. We need to be honest in facing up to the reality of many disabled people being far removed from disability organisations and sources of collective solidarity and/or identity. The following aims to provide examples of the lived experience of these current policy contradictions.

The need for greater control : service user views of current services
The following provides highlighted findings of a study of Day Services modernisation in a large English city (population 0.4 million). The fieldwork for this study was completed in the North district of the City in late 2006. In total, over 30 participants were interviewed ranging from the Director of Adult Social Care, frontline managers, informal carers and day service users. Day service users (*n* = 20) were interviewed in day centre contexts. Day service users were purposively sampled using maximum variation principles to include respondents with a range of impairments including physical impairments, learning disabilities and mental health problems. A range of ages, ethnicities, sex and length of time in day services was reflected in the interview sample. The lead researcher had previously completed work on day centre attendees in the south district of the city, and the profile and experiences of this group, once selected, was not untypical of the wider city experience of day centre changes wrought by modernisation.

Findings
Overall, despite the efforts of the city council, current service users had little working knowledge of what the modernisation agenda meant for them in practical terms and most could not envision what a self-directed daily life would feel like. Of the 20 day service users interviewed, only two had any links with disability organisations (both with People First). By definition,

most day centre users' social and spatial worlds were largely focused on day centre contexts, although four of those interviewed were also working outside in a paid or voluntary capacity. It was important therefore to briefly explore experiences of current services. The following typifies responses to questions about current choices. There were in reality few choices made available to day centre users adding to the perception of the need to reduce day centre dependency:

If it's a pub lunch, you get to choose where you want to go, you know a few choices. Sometimes you get a choice as to whether to go out and what you want to do . . . at others they may just say we are going to the shops, and if you want to go. But they decide where . . . you just tag along like. (Jim, 28, day centre user for 12 years)

However, the following comment from a family carer of a day centre user highlights the inherent challenges of engendering responsive adult services per se and the reality of adult services for some disabled people:

Anna is not a shrinking violet by any means, by and large my observation has been that together we used to be able to speak up for her better when she was younger; they seemed more interested. When you meet professionals in adult services, you seem to be just another 'case' really. So the idea of being in control, as you say, is less nowadays. (Jenny, mother of Anna, 26, day centre user for eight years)

The respondent also later refers to the cash-strapped environment which pervades adult services in the locality; this reflects policy evidence presented earlier (National Centre for Independent Living, 2006; Commission for Social Care Inspection, 2008; Local Government Association, 2008). The gaps in day service provision and the aspiration to do activities currently not made available was a recurring theme in the study findings. At the same time, many day service users also wanted to hang on to what they had known for some time as it was currently the best option they had. There was evident a pervasive tension between what might be dubbed idealised and pragmatic 'here and now' appraisals of options beyond day centres.

Enforced collectivism: lost years or stepping stones to collective empowerment?
Although often displaying mixed sentiments, there were many comments that supported the value of Day Centres. Many acknowledged that they had been placed together with other disabled people simply because that was the 'done thing'. However, this enforced collectivism turned out serendipitously to be an important collective identity for some centre users:

Day centres in my mind are a place to get together, most people in the city and that are mindin' their own business, by themselves like, that's the way of the world, I mean I've been at work – but since then have enjoyed the thing of being with others, I wouldn't want to lose that – also I met [current partner] through the Day Centre. I understand people with physical disabilities – wouldn't turn my nose up to people with disability as I know

what it is like to be disabled-somethin' in common. (Billy, 32, day centre user for four years)

The exact value then of current day centres as expressed by service users depended on the perceived current options, the range of activities on offer and on the age, outlook and impairment of the service user. This offers some clues as to future policy options for self-directed lives into the twenty-first century. As the modernisation agenda aims to afford greater choices and to review the value of day centres, service users were asked to reflect on recent changes in day centres. Interestingly, many service users refer to the reduction in certain forms of day centre activity over time due to cost savings:

We take the Centre bus, they take me for a run out. I used to go for pub lunches and packed lunches, the pub lunches stopped, I don't know why they stopped. We got mixed messages as to why we go out less often and less far, not sure why there are limits. (Colette, 25, day centre user for three years)

It was perhaps predictable that some day centre users who had been placed in day centres without a process of choice, who had witnessed service cutbacks over a number of years, should be somewhat suspicious of proposed mainstreaming of daily lives; as one service user notes:

I'd like to go out more and that, but I would need someone wid' me. One day I might be able to do everythin' myself, but at the moment that scares me. Dunno what I'd do all day, do you? (Dierdre, 53, day centre user for seven years)

This begs a question as to the nature and substance of choice on offer. Of note, none of the research participants had received the more substantial forms of self-directed support such as direct payments during the lifetime of the project and were therefore prey the rhetoric of self-directed support without receiving the quantity of financial support required to engage with other disabled people and wider society in a safe and genuinely freely chosen way. Exhortation to seek options outside of day centres often translated into equally 'safe' activities of painting and craft making in contexts identified by centre staff and key workers. Life in the mainstream was beginning to feature more strongly in daily activities, but often took the form of visits to town centres with key workers or where possible individual disabled people spending short periods of time in the 'high street' but a great deal of former centre-based time was beginning to be spent at home. This did not square well with notions of self-directed support and reduced informal care spending being predicted by the DoH (Hurstfield *et al.*, 2007).

Choices and rights: who's choices, whose rights?
Some comments focused on the principles of choice as outlined in *Independence, Wellbeing, and Choice* (DoH, 2005) and *Our Health, Our Care, Our Say* (Doh, 2006). The majority of day centre users (16/20)

concentrated, as might be expected, on the likely impact on service users of feared centre closures:

I'm not sure how closing the Centre is givin' us more choice, we need time to think and get used to the idea of being out by ourselves. Have heard [Centre Name] will close-I dunno where that leaves me and that-need time to think an' try things out an that. Am not ready just yet. (Mark, 24, day centre user five years)

Similarly:

D'ya want my honest view? I don't think they've [council] thought it through really – the only certain thing is they want to save money – we are the price for that really. In my case I might get out sometimes, but I get ill and me mum's going to pick up the tab I suppose – and that's not fair as she is in her 70s. (Clare, 48, day centre user for six years)

A final reflection is provided by a carer of a current day centre user. Whilst not denying the values of choices and rights, the carer notes the reality of moving quickly beyond current day centre provision and the requirement for intensive transition planning:

I worry about too much emphasis on being 'out and about', as I've said she [daughter] is very active work wise and to a lesser extent at the Centre, but she looks different to others and she has been taught by her support worker to be friendly and confident with people, but I worry that by herself that could be misread, put her at risk. How could I hand her to someone I don't know, have never met. I would never forgive myself if anything happened. (Bridget, mother of Catherine, 33 day centre user for 8 years)

Conclusions

The advent of a choices agenda around self-directed support is rightly welcomed by the UK Disabled Peoples' Movement and UK Government alike. The notion of greater self determination will be welcomed by many disabled people where adequately supported. The concerns highlighted in this study suggest that modernisation policy has to account for a diversity of disabled people who may be at very different vantage points in terms of their readiness for self determination. Ironically, in moving away from the enforced collectivities of day services and in the absence of a CIL or user-led organisation in every locality, there is a risk of individual support solutions fostering enforced individualism and isolation. Dependency could shift from day centre to family carer contexts more fully. There is a need to acknowledge the value of collective contexts and identities for disabled people and the urgent need to plan and fully fund transition policy towards greater choice. The recent decision by many local authorities to only fund major self-directed packages to those in 'critical' need (CSCI, 2008) seems at odds with the spirit of the modernisation agenda. Without that financial and organisational support, self direction takes on distinctly neo-liberal characteristics.

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Introduction

That there has been a proliferation of organisations controlled and run by disabled people across the United Kingdom since the early 1980s is 'an indicator that the disability movement has come of age' (Harris and Roulstone 2011:119). These include centres for independent/inclusive living (CILs), local coalitions of disabled people, service user organisations and, more latterly, social enterprises and community interest companies. What unites these diverse organisations is a commitment to the social model of disability and to having a constitutional structure that ensures control rests with disabled people. The movement has been bolstered by successive government's commitments to greater choice and control for disabled people and to promoting the development of user-led organisations encapsulated in the (still unmet) 2005 commitment that

"By 2010, each locality (defined as that area covered by a Council with social services responsibilities) should have a user-led organisation modelled on existing CILs". (Cabinet Office, 2005:91)

The language used to describe disabled people's organisations has, and continues, to evolve. The terminology used varies and some terms are used interchangeably. Different documents refer to DPOs (Disabled People's Organisations), ULOs (User Led Organisations) and increasingly to DPULOs (Disabled People's User Led Organisations). The following definitions capture the essence of the way in which both terms are used:

- A disabled people's organisation is 'an organisation whose constitution requires it to have a membership and management board with a majority of disabled people and who objectives are the rights and equality of disabled people' (Disability Listen Include Build 2008:11)

- A user-led organisation *is* 'one where the people the organisation represents (or provides a service to) have a majority on the Management Committee or Board, and where there is clear accountability to members and/or service users' (Morris 2006:3)

Some organisations will be both a ULO and a DPO, while others such as *Shaping Our Lives* which is a national network of service users and disabled people draws in non-disabled people who uses services such as children and young people in the care system. The term DPULO is used throughout this chapter to refer to organisations that are controlled and run by disabled people

This chapter begins by outlining what independent living has come to mean in the United Kingdom before moving onto consider why it has been viewed as essential by the disabled people's movement that the practical application of this approach should be controlled and implemented by disabled people. There is then an overview of the nature, scope and purpose of DPULOs focusing especially on what distinguishes them from other ostensibly similar organisations. The discussion focuses on the distinctive contribution DPULOs make to the lives of disabled people and to challenging disablism on a wider scale. The chapter ends by considering the current position of the ULO community and in particular on the challenges they face at a time when many in the wider disability field are appropriating the language and style of the disabled people's movement.

Independent Living

Life is more than just a house and getting up and going to bed. Independent Living is about the whole of life and it encompasses everything. We want equal opportunities. We want citizenship. These are the issues that drive the independent living movement. It is philosophical, it is political, it is about integration and disabled people becoming a part of this world and not separate, segregated and second class. That is what we are actually after and that is why independent living is so important.

(Evans 1993:63)

As this quote from John Evans, one of the leaders of the Independent Living Movement suggest, independent living is a way of combatting the oppression and discrimination disabled people endure. Independent living can be viewed as both a philosophy and a practice. As a philosophy it shares many of the central tenets of the social model of disability and questions the way in which an individualistic understanding of 'independence', meaning people have to be able to do everything themselves, has come to dominate policy and practice in Western industrial societies.

Understandings of disability which assume that disabled people are inherently and inevitably dependent and requiring 'care' to meet their needs have been so dominant that the resulting *hegemony of care* has pervaded policy and practice cultures. This has meant that the ways in which services and other forms of support are organised have created and perpetuated the physical, financial and psychological dependency of large numbers of disabled people in a way that would be unacceptable to non-disabled people. This has usually occurred through the

provision of 'special' and usually segregated services that take disabled people's dependency for granted and view it unproblematically. The result is that disabled people are excluded from exercising many of the rights and responsibilities that most non-disabled people take for granted, such as having a job or raising a family.

The alternative understanding of disability provided by a social model analysis enables disabled people and their allies to turn traditional and taken for granted assumptions about disability on their heads. As a result independent living groups have pioneered innovative and effective ways of working to enable disabled people to exercise choice and control in their lives and to allow them to participate within society on equal terms with non-disabled people.

In contrast to the Independent Living Movement in the United States where the focus was more on the individual and on self-help, in the UK independent living 'entailed collective responsibilities for each other and a collective organisation. Independent Living wasn't about individual empowerment; it was about individuals helping one another' (Campbell and Oliver 1996:204). Thus, DPULOs have tended to focus on collective forms of action such as campaigning and placed a particular emphasis on peer support. Peer (or peer to peer) support is where one disabled person draws on their own experience, knowledge and skills to support another disabled person. Peer support recognises the value of sharing the lived experience of disability and the contribution disabled people can make to one another. A review of peer support undertaken for the Department of Health found that it is frequently 'an effective method of achieving a range of goals' especially in relation to making choices about support needs where 'Such support would appear to be an essential element in giving people opportunities to control their own lives' (NCIL, 2008). Peer support has been at the heart of all DPULOs.

Defining characteristics of disabled people's user-led organisations

The most essential characteristic of a DPULO is that is an organisation *of* rather than *for* disabled people. There has been a sustained and successful critique of the dominance of organisations for disabled people, often large well-funded charities such as SCOPE and MENCAP, who seek to both represent disabled people in policy discussions and to provide services to meet their needs. Until relatively recently these organisations adopted what Oliver (2004) termed a *humanitarian approach* to the welfare of disabled people. This approach privileged the knowledge and expertise of professionals who provided services to disabled people on the basis of individualised and medical understandings of disability. Disabled people became dependent on services over which they had no control, that frequently did not meet their needs and which were contingent on the assessment of professionals. Inherent in this approach was a paternalistic 'we know best' assumption about the needs and aspirations of disabled people, an assumption that has been refuted by disabled people since the early work of Paul Hunt (1966).

There is consensus that DPULOs should be social model organisations, that is they have a formal commitment to the principles of the social model and are controlled

by disabled people (Barnes & Mercer 2006:83). Participants in an evaluation of DPULOs identified five criteria that they should aspire to meet:

- adopt a social model approach to the development and operation of services;

- provide disabled people with meaningful choice and control;

- be flexible and responsive to the needs and wishes of local disabled people;

- be inclusive and offer services based on the common experience of disability;

- A range of core services were identified, but it was agreed CILs should also respond to local needs.(Barnes et al 2000:8)

The way in which this is implemented on the ground varies considerably with DPULOs providing a diverse array of services and campaigning on a wide range of topics at a local and national level.

Derbyshire CIL produced a list of *seven needs* that need to be met if disabled people are to achieve independent living:

- Information;

- Counselling / peer support;

- Housing;

- Technical aids and equipment;

- Personal assistance;

- Transport;

- Access to the built environment (Davis 1990).

Hampshire and Southampton CILs added a further five areas, which they termed *basic rights*

- Inclusive education and training;

- Adequate income;

- Equal opportunities for employment;

- Advocacy

- Appropriate health care provision (Woodin 2006).

These combined lists have been adopted by many DPULOs as the framework for their activities. Writing in 2007 as the result of a project that mapped the capacity

of ULOs in England Maynard et al identified a range of expertise contained within the ULO community that includes

- Peer support, mentoring and empowerment
- Direct payments advice and support
- Knowing what accessible features, environments and facilities are required for participation to be physically inclusive to all
- Support for consultation and involvement
- Providing interpreting and transcription services
- Employment and education support
- Access auditing
- Disability Equality and diversity training
- Knowledge of the Disability Discrimination Act and other disability specific legislation
- Accessible housing and transport
- Delivering research, consultancy and training. (2007:8)

The manifold services and facilities provided by DPULOs span the whole gamut of disabled people's lives from promoting inclusive education, providing support to disabled people and their families seeking to navigate the complex health and welfare terrain, assisting mainstream providers of services meet their obligations to disabled customers and being a proactive voice of disabled people in policy discussions. DPULOs now occupy, formally at least, a central and influential position in shaping and leading disability policy and the provision of services seeking to meet the needs and aspirations of disabled people.

Threats and Challenges facing DPULOs

However, while DPULOs enjoy significant levels of support particularly at a national and policy level, their position often remains precarious (Barnes & Mercer, 2006; Maynard-Campbell et al 2007). As with the social model of disability the concept of independent living has been adopted as a goal by many disability organisations. A wide range of service providers in the public, voluntary and private sectors claim that independent living for disabled people is now their guiding principle. However, there is often a gap between the aspirations of disabled people to be in control and the ways in which some 'independent living' services have been implemented. Jenny Morris (2011), amongst others, warns of the dangers of the language and ideas of the disabled people's movement being appropriated by policy makers and service providers.

This creates a tension at the heart of the DPULO movement. As more local authorities and traditional service providers and charities adopt the formal trappings of a DPULO (such as commitment to the social model and a majority of disabled people on the management committee) it is becoming increasingly difficult to tell them apart. The result is frequently to the detriment of genuinely user-led organisations who rarely attract the levels of funding and high level policy

access enjoyed by the large disability charities (Barnes & Mercer 2006). The result is that 'these organizational wolves in sheep's clothing are then able to complete with DPOs for scarce resources, threating the very existence of some DPOs' (Maynard et al 2007). While as Morris argues 'adjusting one's language to suit the prevailing discourse' may be a pragmatic and often effective strategy to adopt it does leave the ULO community and wider disability movement vulnerable to colonisation.

Gibbs, formerly an influential member of staff at DCIL, asserts that social model services provided by statutory and traditional providers are an oxymoron, that is a contradiction in terms. He contends that such providers are locked into an approach that is at odds with the philosophy and principles of independent living. He goes onto argue that

'the social model is non-reducible, it cannot be implemented by any programme of services that is separate from other functions. Even within the disabled people's movement, it is commonly believed that 'service provider' and 'lobbying' functions are incompatible in a single organisation. To the contrary, the social model cannot be applied by either on its own. (2004:158)

This is illustrated by the way in which one of the original Centres for Independent Living in Derbyshire has evolved (DCIL, undated). Derbyshire Coalition of Disabled People was established in 1981 as a democratic representative organisation of disabled people. It received funding from the county council and focused on campaigning and peer support. The Coalition worked in collaboration with the local authority to set up a Centre for Integrated Living (CIL) in 1986 with a commitment to the social model and the seven needs of disabled people underpinning the venture. The CIL provided a range of services including the training and provision of peer counselors, direct payment support, an employment service as well as providing employment and volunteering opportunities for local disabled people.

The functions of the two organisations were separate although the membership overlapped; the Coalition was a campaigning organization while the CIL developed 'practical applications' of a social model perspective. This arrangement was felt to give the Coalition freedom to pursue campaigns that targeted the local authority while also allowing the CIL to develop the more formal structures required of a service provider. A review was undertaken in 1996 when it became clear the funding and political landscape was making it difficult to 'safeguard the original wide-ranging objectives and community emphasis' of the organisations (DCIL, undated). The result was the formation of Derbyshire Coalition for Inclusive Living, a title that was felt to be a more accurate description of the county wide work of the organization while the shift from integrated to inclusive was seen to resonate more closely with a social model emphasis on challenging disablism rather than integrating disabled people into society (Barnes & Mercer,2006:78). DCIL describes itself as a DPULO and is run by a board of directors elected by members.

While the value and contribution of DPULOs has been acknowledged in key policy documents and in independent evaluations of DPULOs (such as Barnes & Mercer 2006) providing formal evidence of the added value provided by DPULOs has been

less easy. Methods such as calculating the 'social return on investment' explored by Lewis & Roulstone (2010) have the potential to capture the less tangible benefits created by DPULOs in a format funders and commissioners understand. Becoming increasing 'savvy' in terms of their engagement with policy makers and commissioners may run the risk of incorporation or neturalisation, however, without it DPULOs are in danger of appearing marginal, amateurish or too overtly political.

Conclusion: The future of DPULOs in an age of austerity

While the emphasis on the 'big society' and the priority afforded to DPULOs by government appears to offer great potential to the DPULOs, disabled people have been amongst the hardest hit by the swingeing cuts to public sector services and implementation of 'welfare reform' by the Coalition Government (Wood 2012). There is a contradiction between policy rhetoric that says DPULOs have a vital role to play and the still relatively minor funding they secure compared to the traditional disability charities. Moreover, austerity creates very real threats for disabled people and their organisations, mostly obviously in relation to a crises in funding opportunities. However it also has the potential to open up new opportunities. The resistance to the cuts offered by disabled people has reinvigorated the campaigning element of DPULOs and their allies (see Disabled People Against the Cuts www.dpac.uk.net for example). Local and national government are having to think much more creatively about how to 'do more with less' and this provides the scope for DPULOs who have an established track record in providing innovative and effective solutions.

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Introduction

Geographies of disability and spatial geographies have rightly taken their
place in the wider canon of disability research and disability studies. That
disablement is a spatial issue seems at one level a truism; however a key
driver for this edited collection is the perception that the wider panoply of
geographical insights on disability, embodiment and the emplaced body has
not been applied that systematically to the forms of policy and legal
exclusions experienced by disabled people in contemporary society. Indeed
notions of policy and space rarely sit together save for a small number of
descriptive readings of building regulations and anti-discrimination
legislation and guidance. Policy has not to date been conceptualised as a
spatial phenomenon. Policy is often reified as natural and fixed, at least
once it is formulated. We argue that policy spaces and their relationship to
physical, psycho-social and ontological spaces afforded to disabled people
needs to be central to our understanding of social space and
enabling/disabled society. Social policy both emanates from and continually
remakes the spaces or constraints that directly influence disabled people's
life opportunities. To reflect such new insights we aim to respond to such an
absence of critical attention and to engage more fully notions of disability,
policy and space. Both policy and law embody constructions of 'right' bodies
and minds and thus frame current and future social possibilities for disabled
people. Space, for example, being able to occupy freely certain public,
private or even 'taboo' spaces, is heavily inscribed with disablist notions of
just what is possible given disabled people's capability, capacity and reason.

In the chapters that follow we draw on the commissioned writings of
geographers, sociologists, policy and disability studies academics to provide
a range of insights into the nature, reproduction and challenge to the spatial
and policy inscribed exclusion of disabled people. We take as our cue a
number of important preceding works that have been published in what
might be framed as disability geographies, and which help set the scene for
the work that follows. Such works focus on matters as diverse as physicality
and commodification (Gleeson, 1999 ; Hansen, 2002), disability and spatial

justice (Butler and Parr, 1999 ; Kitchin, 1998), the spatial dynamism and boundaries of disabled bodies (Haraway, 1991), ableism (Imrie, 1996 ; Kumari-Campbell, 2009), and the fluid biographical identity that negotiates, traverses and navigates a range of complex social spaces, places and landscapes (Chouinard et al. , 2010 ; Crooks et al. , 2008 ; Imrie, 2007 ; Maddern and Stewart, 2010). The chapters that follow aim to expand the current geographical frame of reference operating within the realm of disability; intersecting three critical, yet often contrasting, ideas, of disability, space and place, and social policy regimes. Through critical conceptual analysis and based on empirical insights, the chapters explore how current policy and legal regimes re/map, re/frame and re/shape divergent spatial relations and realities for disabled people. In this context, the spatial is not confined to the material and structural alone. A key feature of a number of chapters that follow are their attempts to disclose the diverse ways disability and spatial relations are constructed symbolically, culturally and materially. Thus, the book challenges readers to consider the 'multifaceted spatial dimension' of social policy for disabled people and the imposition of altering policy regimes that confine, override or disguise the spatial dimension of social life for disabled people. For example, changing welfare regimes not only have profound consequences in terms of their financial settlements for disabled people, but represent a profound reframing of belonging, legitimacy and selfhood.

The chapters included within this volume therefore provide a critical and comprehensive examination of disability and spatial processes and their impact on the contemporary exclusion or inclusion of disabled people. While this reflects the growing increase in academic attention on issues of disability and critical policy and practice (Oliver and Barnes, 2012 ; Roulstone and Prideaux, 2012), the book extends current theoretical and empirical discussions and debates in the area via pivoting this analysis around 'the spatial' and 'the geographical' and their links to and from policy systems. As the chapters together suggest, there is now a compelling need to critically review, conceptualise and explore the ways in which policy and spatial constructions re/shape and re/frame disabled people's experience of the social world in a number of country contexts internationally. To distil the uneven and differentiated effects of the inter-relationship of these dynamics upon disabled people, a number of empirical spheres are explored, such as the law, policy and programmes from countries as diverse as Australia, Canada, Guatemala, UK and Ireland. The chapters explore public and private space as typically conceptualised within the realm of disability geographies as differing spheres of social life, whilst engaging with policy and law that shape sexual, personal, economic and legal choices across a range of varying scales. Each of the chapters reveal

how these social policy domains are challenged or undermined by the spatial realities faced by disabled people.

Space then is not simply the end product of, or a material challenge to, policy; policy-making itself attempts to construct spaces and places via opportunities that may previously have been closed off to disabled people individually or as a social category. A good example of such processes are the Disability Discrimination Acts developed in the United States, UK and Australia – these statutes were in part bound up with both the potential redefinition of spatial options (adjustments to environments for example) and the reshaping of policy space (such as the involving of disabled people within the disability policy process). Yet, in turn, these progressive initiatives can be undermined by pre-existing, enduring or new/emerging spatial barriers to environments (structural, cultural and material) and the policy process. Rather than see policy as a process or quantum of social imperatives, the spatial dimension facilitates the connection of innovative disability studies' ideas that explore policy as spatial redefinition and as a space of contested social priorities.

The chapters contained within Part II of the book draw upon recent empirical research that has sought to explore the interstice of disability, policy change and spatial relations. These rich empirical chapters provide a window into disabled people's experiences of changing relations of space and place with the onset of policy changes that govern these spatial settings. The chapters distil the ways in which disabled people negotiate and traverse these varying environments, and the resultant impacts and effects upon disabled people's lives materially, discursively and symbolically. The insights emerging from Part II of the book highlight to the readership that while disability policies may appear to have as their target the category of people known as disabled people, in fact, these policies have a broader lived reality in the way they transform the spatial dimension of disability.

The compilation of the work presented within this volume aims to locate discussions about disability, disablism/disablement and disabled people within the wider spatial turn occurring within the social sciences, acknowledging the disability lacuna within existing spatial discussions and debates, and the limited emphasis on space and place in mainstream disability studies.

The book structure and chapters explained

The book is made up of two parts. First, Part I, a conceptual section, aims to provide a state-of-the-art picture of the ways in which disability is constructed and reconstructed in policy assumptions. This part will provide

the reader with critical and searching appraisals of space and disability in a way that better underpins a reading of Part II of the book. Part II aims to draw on recent empirical evidence from a range of country contexts on how policy is premised on certain constructions of disability and how policy serves to constrain or support disabled people in their daily lives. It explores how space is experienced in given policy contexts. This introductory chapter provides a general overview and orientation to the book and rehearses a range of theoretical, conceptual and empirical issues to arise in the wider chapters. Chapter 1 by Imrie explores the multiple intersections between disability, public policy and geography. Its overarching observation is that there is limited explication about the interrelationships between the lives of disabled people and the geographies of public policy, or the intrinsically spatialised nature of state policy regimes. The chapter explores how fruitful lines of inquiry, between geography, social policy and disability studies, may be the basis for enhancing understanding of the impact of policy regimes on disabled people. The chapter begins by recognising the significance of changes in the nature of contemporary citizenship, underpinned by the re/evaluation of what productive bodies are or ought to be. Developing Ong's (2006) observation, that people's citizenship is based upon their marketable skills, the chapter suggests that the human worthiness of disabled people is, increasingly, being discredited in a context whereby welfare policy reform is placing the onus on self-active and self-starting individuals as the basis of a 'good' society. The techniques and technologies of governing, that seek to re/shape the nature of citizenship, are part of the formation of policy regimes that are unstable and malleable. These characteristics of policy regimes are shaped by their inherently geographical nature, in which, as Imrie argues, the fortunes of disabled people have to be understood as indissoluble from the interstices between space, place and policy.

In Chapter 2 , Edwards provides a searing critique of the way in which sexual offences legislation delimits personal and spatial freedoms for people with learning difficulties in Ireland. She draws on debates emanating from the subdiscipline of 'legal geography' to explore how law shapes understandings of disabled people as victims of (sexual) crime by regulating disabled bodies and their interaction with public/private space. It draws on contestation over a particular piece of criminal law in Ireland, Section 5 of the Criminal Law (Sexual Offences) Act 1993, which in seeking to protect people with learning disabilities from sexual abuse also places restrictions on people with learning disabilities to engage in consenting sexual relationships. Through examining this legislation, the chapter unpicks the 'law-space nexus' (Blomley, 1989) by illustrating how law engages in boundary work to imagine victim and offender identities in different spaces, and seeks to regulate the spaces where disabled people are deemed to be 'at risk'. In so

doing, Edwards draws on an analysis which acknowledges that both space and law are socially constructed entities, a product of social, cultural and political processes rather than value-free 'givens'. In this way disabled people, those framed as 'incapable minds' are seen to have 'regulated' and 'troublesome' sexual identities, and as victims and potential perpetrators of inappropriate sexual behaviour.

In Chapter 3, Grech responds to a number of concerns emerging from disability geographers based within the global South. Disability in the global South is often not contemplated in Western disability studies as a topic of analysis. When disability in the global South does become a subject of analytical inquiry, research discourse and strategies are transferred indiscriminately from the West to the rest. This is most clearly marked in discussions surrounding the word 'poverty' and its relationship to disability. Too often, references to southern disability poverty and the disabled people's experience of it is opportunistically used as the central reference to disability in the majority world, but rarely is it considered epistemologically. Drawing from ethnographic work in rural Guatemala, Grech seeks to critically engage with dominant understandings of disability poverty by arguing that disability is constructed and lived differently within specific spaces and places of poverty. Poverty is thus spatially stratified and differentiated, imbued with local situated meanings and understandings. These are dynamic spaces where the meaning of disability is fluid and constantly re/negotiated, subverting attempts at homogenising both disability and the disability experience.

In Chapter 4 Roulstone and Morgan address the very topical issue of changing welfare policy constructions of disability and desert. To date there has been much writing about welfare and welfare-work reform, but most writings are concerned with the economic impact of reform on disabled people's lives. This chapter is concerned with the altered public climate that is engendered by wider welfare policy discourses that are actively repositioning social understandings of disability and welfare. Indeed, public space, even when considered within disability research, tends to be understood as a technical, physical measureable space external to the individual. Drawing on examples of changing public discourse, the chapter explores the space between disabled people's self-perceptions and the increasingly harsh welfare and media discourses around 'not genuinely disabled people'. In this sense enabling or disabling space is part physical, part social and part psychological transaction. The increasingly political emphasis on sifting the 'real' disabled people from the army of 'malingering opportunists' ignores the complex relationship between the individual, the environment and the economy. It also ignores medical, welfare and wider social constructions of just who counts as disabled. Disabled people can feel

they are genuinely disabled in one definition and context and not another. In this chapter Roulstone and Morgan problematise space and acceptance/jeopardy to think about space as contested terrain, both imagined and real, where lives are constructed as more or less acceptable in a new corporeal (bodily) economy. The chapter suggests that this has led to a number of major jeopardies, especially for those disabled people who no longer fit stereotyped images of disability with the onset of new welfare discourses of disability and desert. Risks are mapped out which are countered through the new forms of resistance being practised by some disabled people's organisations as repertories of action to counter the new moral economy of neoliberal welfare.

Chapter 5 makes a marked conceptual turn to the previous chapters. Grover and Soldatic undertake a comparative analysis of the complex temporalities operating within Australian and UK spaces of social (in)security as the central mechanisms giving legitimacy to retracting disability welfare regimes. Like Edwards before them, Grover and Soldatic conceptualise the space of social security law as a space in and of itself that adopts a range of discursive, symbolic and material strategies to shift the boundaries of who can now legitimately count as disabled. Whilst the analysis seeks to comparatively differentiate those local practices of reshaping disability welfare regimes at the national scale, Grover and Soldatic elucidate the ways in which disability geographers need to overcome the desire to focus solely on the spatial, at the risk of marginalising the role of the temporal in reshaping disability social security regimes. The chapter examines key departures and differences between the two nations, encouraging readers to critically engage with the local particularisms of how neoliberal restructuring affects disabled people. Spaces of affordance in welfare, who counts as eligible and the shifting of the disability category (Stone, 1984) is central to our understanding of the temporal-spatiality of these reforms.

In Chapter 6, Reeve explores the limits to environmental improvements at the heart of reasonable adjustments or accommodations. As in previous chapters that have explored legal and spatial issues, Reeve notes how the law not only fails to adjust in an enabling way, but by making reasonableness a province of nondisabled designers and arbiters, may lead to negative and disabling social and psychological consequences. Although disabled people in the UK had the right to use services and access goods in 1995, it was only in 2004 that the Disability Discrimination Act (now the Equality Act 2010) was extended to demand that service providers make 'reasonable adjustments' to physical features which otherwise made it difficult for disabled people to access their services. Reeve discusses how indirect psycho-emotional disablism, a form of social oppression which impacts on emotional well-being and self-confidence, can arise from moving

within 'landscapes of exclusion' (Kitchin, 1998 : 351) caused by poorly thought through 'reasonable adjustments' (Titchcosky, 2012). Whilst adjustments to the environment facilitate independence through the provision of physical access, this is often at the cost of disabled people's self-esteem and dignity. If the reasonable adjustment is too demeaning to use, then ironically the 'solution' to a physical barrier reinforces ablest practices of psycho-emotional disablism which is in some ways worse than no provision at all.

Warren and Garthwaite in Chapter 7 assert that place, space and identity are often closely intertwined. Based on their research on regional change and long-term impairment and health conditions, they ask why do some localities have much higher incidence of impairment and chronic illness than others? They also ask why do social policy initiatives and health interventions work in some areas and make little impact elsewhere? Warren and Garthwaite argue that critical disability studies perspectives are required in order to confront official spatial constructions of illness and disability. Their chapter argues that this will challenge the way in which public health researchers and geographers have tended to focus on composition or contextual effects of ill health, paying little or no attention to regional economic, psycho-social and generational factors in social understandings of disability and ill health (Macintyre et al., 2002). They argue that it is only by situating constructions of disability, health and opportunity in spatial terms that a more integrated understanding of spaces, place, body and identity can emerge. The chapter argues that there is a need to understand places as entities with specific identities which are more than the sum of their parts, and that spaces are constituted by many more factors than geographical boundaries alone. The discussion draws on Wright Mills' (1959) ideas about the relationship between biography, history and social reality, and empirically reveals the implications of such an approach via a case study of the former mining district of Easington in County Durham, north-east England.

Chapter 8 explores a very tangible example of how spatial impacts of policy change can begin to afford greater policy choices in the lives of disabled people. Using the example of Scotland, a country which has successfully fostered devolved powers for certain policy areas, Hall notes how such devolution of governance is a powerful contemporary policy process. The chapter argues that aspirations for the reform of social care/support and growing disillusionment with English policy developments, has been central to the case for and practice of such devolution. The chapter examines how the new scales and networks of social care policymaking have produced a model that is distinctly different to and challenges the individualised model of personalisation, so dominant in neoliberal welfare states including

England. Further, the chapter argues that the 'double devolution' to the local authority scale in Scotland offers an opportunity for a more positive and progressive interpretation of the widely critiqued notion of 'localism'. The chapter sees this further local devolution as a recognition of the centrality of local contexts, networks, organisations, and disabled people and families, for the provision of ethically-informed practices and relationships of 'care' and 'caring'.

Other chapters in this book have helpfully documented the fact that disabled people are at times excluded from public spaces, resulting in many spending a disproportionate amount of their time in segregated social care and domestic settings or when in public space facing environmental and economic barriers to both 'being' and 'doing'. To begin, Hollomotz and Roulstone in Chapter 9 explore the less well-trodden territory of sexual citizenship for some disabled people, most especially those with learning difficulties (referred to as intellectual disabilities in many countries and as learning disabilities by official governmental authorities in England) by looking at denial of intimacy in group home contexts. Prior to moving onto the disabled people's lived experience of sexual citizenship within the context of group homes, Hollomotz and Roulstone first undertake a detailed, critical review of the broader literature on space, power and citizenship and show how this is related to disabled people's sexual citizenship. The latter half of the chapter then moves to explore these themes in the lives of people with learning difficulties through in-depth interviews with people with learning difficulties and focus groups with a self-advocacy group. The chapter concludes that the right to 'privacy' so that disabled people can fully explore and engage in practices of sexual citizenship must be formally acknowledged and enforced in social policy, and in enabling practices of support staff who have extensive authority over the lives of people with learning difficulties within their own homes. The chapter notes how pre-existing assumptions of learning difficulty have tended to err on the side of constructing sex and sexual choices for people with learning difficulties as secondary to protection from risk and the effects of 'innate vulnerability' (see Chapter 2 in this volume and Roulstone et al. in Roulstone and Mason-Bish, 2012). Sexual activity and desire for people with learning difficulties continues to be constructed as risky, deviant or asexual (O'Callaghan and Murphy, 2007).

Power's chapter, the final chapter in Part II, is concerned with the increasingly placeless but personalised nature of social support for people with learning difficulties. Drawing on empirical research in Ireland and Canada, Power's chapter makes clear the role of new professional support workers in the form of community connectors and social interpreters who have a role of linking disabled people with novel and uncliched social

opportunities. Power's analysis illuminates the ways in which this is no longer fixed spatially and within institutional settings and requires a detailed and critical reflexive knowledge of communities and natural supports that could be identified in these fluid locations. Power makes clear that although there are some clear strides being made towards greater living options, the shortage of funding and often anti-statist nature of the wider policy reforms could risk stopping off choices, especially those for collective lifestyles options that many disabled people still wish to pursue (Roulstone and Morgan, 2009). However, with the right funding and a genuine ethic of choice, such facilitative professional roles could mark a clear step forward in aiding independence and choice for disabled people.

The discussions in this book make plain that although space and disability are being more carefully and critically connected as ideas, there is still some distance to travel in making those connections substantial and enduring. The spotlight on policy, its spatial role and influence is however seen as a very important development, as are robust empirical and cross-national evidence. To understand space and disability we clearly need to draw on the wide array of insights the book provides, connecting the overlapping ways in which they shape the lived experience of disability. We hope you enjoy reading the book.

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Background and context

The specific prompts for this chapter are changing and increasingly critical discourses of public space, participation and legitimacy and their implications for disabled people. Ironically these discourses, rather than view the problem as disabled people being excluded from public space, instead increasingly construct the problem, or at least a policy preoccupation, as disabled people being disengaged from public and economic space (Gregg, 2008). Not only do we see these discourses as negating policy objectives in making space and economic opportunity available, but also see the harsh content of these discourses such as 'shirkers and scroungers' (Briant et al., 2011; Garthwaite, 2011), as de facto confirming 'sick and disabled' people's marginalisation. In that vein, we aim to explore the space between disabled people's self-perceptions, internalised and potentially jeopardised selfhoods and the increasingly harsh welfare policy and media discourses, and most especially, for those who are presented as 'not genuinely disabled people'. In this sense we argue that enabling or disabling space has to be viewed as part physical, part social and part psychological phenomenon. We also contend that policy and political ideology as inscribed in public space are constitutive of the disabled and failed-disabled identity. Our work derives largely from developments in the UK, but we feel the neo-liberal dynamics that sit behind the increasing jeopardisation of space is likely to characterise other 'advanced' economies that have seen welfare growth and fiscal crises.

The material, physical and social basis of public space

Public space tends to be understood even within academic debates as a technical, physical measureable space, one characterised as external to the individual (Imrie and Kumar, 1998). Technologies similarly are often constructed as new technical means to afford or limit access to those environments (Gleeson, 1999). Policy constructions of space tend to equate the notion with access (BSI, 2005; DRC, 2000, 2002, 2004; Disability Rights Taskforce, 1999; ODPM, 2000). Even critical sociological accounts equate public space with the birth of the democratic principle and see its defining characteristics as shared not owned, a counter to bourgeois capitalism's tendency to translate social goods into marketable and privatised commodities (Habermas, 1989). Across the Western high-income economies at least, public space has been symbolic of greater social equity and

decommodification, as for example in the public accessibility components of Roosevelt's New Deal (Leighninger, 1996). The involvement of the public in the design of public space also points up the shift historically towards the democratisation of space (Davidoff, 1965). From protesters from the large conurbations who undertook mass trespasses such as the Kinder Scout Trespass in 1932 as part of a campaign to open up private land for walkers (McKay, 2012) through to the recent mass global 'Occupy movement', occupying, reclaiming or subverting often restricted spaces has been a frequent tactic of many social movements. The disabled people's movement has frequently used public demonstrations, often in spaces of symbolic exclusion, to highlight the lack of access to public space that non-disabled people take for granted (Finkelstein, 1975; Zarb, 1995).

Disability studies and critical geography has also spawned a large literature on exclusive public space and the role of policy in making those environments more or less accessible (Clarke and George, 2005; Gleeson in Butler and Parr, 1999; Gray et al., 2003; Hahn, 1986; Imrie and Kumar, 1998; Imrie and Wells, 1993). Perhaps closest to our own thinking on these issues is the work of Freund. In his article 'Bodies, disability and spaces' Freund (2001) makes the important point in stating:

Here I stress sociomaterial space. The social organisation of space is not merely a place in which social interaction occurs, it structures such interaction. Congregating, avoiding people, movement and other practices constitute spatial patterns.

He further goes on to note:

Sociomaterial space is not simply inert material – a confi guration of asphalt and concrete – but exposes and structure's social life. (2001: 694)

Freund is useful here in going beyond a simple material 'bricks and mortar' account of public space. Indeed by using the notion of disability as 'bodies in space' he counters critiques of the social model as being disembodied (Freund, 2001). Even helpful recent discourses as to spatial inclusion do however have their limitations. Freund's work for example views spatial exclusion as increasingly rooted in auto-centred living and poor transport infrastructure. In this sense, the social and political interactions between bodies, self and environment, construct jeopardies too narrowly to capture recent events (Freund and Martin, 2001). Disability, health and embodiment are also rather taken for granted in this approach to [il]legitimate selfhood. As with Freund, our objective is to go beyond a physico-spatial construction of public space, or as the end product of urban planning/access policy, to broaden the analyses in a way that accounts for the overt politicisation of the public realm and, in turn, public space. In this sense space is constructed, maintained and shapes social relations. This is especially poignant where space constructs and maintains social distance and difference, as is often the case where disability and difference emerge into public spaces. There are literatures that apply notions of space and exclusions to an exploration of disability of course. For example, Dyck (1995) in her work 'Hidden geographies: the changing lifeworlds of

women with disabilities', details the interaction of living with multiple sclerosis and the broader social, policy and environmental shaping of access, and notes:

The majority of women were found to experience shrinking social and geographical worlds which rendered their lives increasingly hidden from view as patterns of social interaction changed and use of public space diminished. (1995: 307)

The focus of Dyck's study on the spatio-temporal settings of the women's everyday lives reveals:

an interplay of biomedical discourse, policy structures, sociocultural norms and local sets of social relations that shape the strategies women used in re/constructing their lives. Participants showed a diversity of responses, but these were all characterized by a restructuring of home and neighbourhood space, a reordering of personal relationships and increasing interpenetration of the public sphere in their private lives. The findings suggest that attention to the body in its geographical as well as social context provides an avenue for investigating the links between subjective experience and the broader social relations and processes which shape the illness experience. (Dyck, 1995 :1)

Dyck's work is extremely helpful in aiding a socially and policy located notion of gendered space; however policy discourses are broadly inscribed via local influences and practices. Policy is merely one, albeit important, facet of Dyck's work. Perhaps closest to our construction and connection between disability and space is the work of Kitchin. Kitchin, in his article '"Out of place", "knowing one's place": space, power and the exclusion of disabled people', notes: space, as well as time, is instrumental in reproducing and sustaining disablist practices. Disability has distinct spatialities that work to exclude and oppress disabled people. Spaces are currently organised to keep disabled people 'in their place' and 'written' to convey to disabled people that they are 'out of place' … As a result, forms of oppression and their reproduction within ideologies leads to distinct spatialities with the creation of landscapes of exclusion, the boundaries of which are reinforced through a combination of the popularising of cultural representations and the creation of myths. (Kitchin, 1998 : 351).

Changing policy and remoralised corporeal economies

Space, or public space to be precise, is then more than the sum, of physical, technological space, but potent psycho-social environments created by public discourses that need to be understood if we are to understand disabling/enabling space. This is especially true where an impairment is 'hidden', contested or fluctuating. The increasingly political emphasis on sifting the 'real' disabled people from the army of 'malingering opportunists' (HM Government, 2012) ignores the complex relationship between the individual, the environment and the moral economy of contemporary competitive society (Soldatic and Meekosha, 2012). Such mainstream policy constructions ignore medical, welfare and wider social constructions of just who counts as disabled. In trying to remoralise, to forcibly reintegrate those reconstructed in policy terms as 'faux' disabled people, we argue policy and public spaces paradoxically make such reintegration less rather than

more likely (Roulstone and Prideaux, 2012). Of note, even key architects of the conditionality regime that underpins welfare and disability benefit reforms have now voiced their concern as to the harshness and levels of sophistication of the reassessment processes (Gregg, 2012). Recent official reports also point to national and governmental concerns over those reforms (Harrington, 2012; National Audit Office, 2012).

The debate as to who is, or is not, disabled has often been constructed using crude policy and representational (media) binaries (Briant et al., 2011), ones that assume disability is fixed, static, knowable and easily measured. Disability, unlike race, sex/gender, age and genetic profile, cannot of course be viewed unproblematically. Disabled people can feel they are genuinely disabled in one definition and context and not another. They may feel they are chronically ill but not disabled, or disabled but not sick (deWolfe, 2002, 2012). In this sense, we wish to problematise space and acceptance/jeopardy to think about space as a contested terrain, both imagined and real, where lives are constructed as more or less acceptable in a new corporeal (bodily) economy. This new corporeal economy, one arguably driven by the retraction of the welfare state, has led to a number of major jeopardies, especially for those people who do not fi t stereotyped images of disability (Boyd, 2012).

The social costs of such binary remoralisations are arguably not simply the potential loss of welfare, but, drawing on the valuable work of Thomas (1999) and Reeve's (2002) notion of psycho-emotional disablism, we can see the psycho-social costs of being deemed unfit for the new corporeal economy of space. According to Reeve for example, psycho-emotional disablism is the result of continued negative constructions and interactions which in turn create psycho- emotional barriers to future opportunity. In this context, barriers to being sit alongside and can be as powerful as barriers to doing, and have the potential to be more pervasive, persistent and disabling. Drawing on Reeve and Thomas' work then, there are likely to be emotional costs for some disabled people in 'moving through space' or failing to occupy economic space, even if through no fault of their own (Reeve, 2008). As we suggest below, the public realm may well have become much harsher, much more judgemental as to who counts as legitimately disabled, and just who 'belongs'. Experience of those with hidden impairments and who may experience pain and fatigue are especially important here. The already medically contested physical or psychological condition also enters an increasingly socially contested space where hidden or unseen impairment may sit badly with new policy constructions of desert and eligibility (Garthwaite et al., 2013). Psycho-social notions of disability can be defined as: the result of the interplay of physical, institutional, political and interpersonal constructions of 'desirable states'. Here, space is synonymous with 'locations' which welcome, exclude or other (Butler, 1990) disabled people. In this sense, space can be an object, a process, a project, an existential sense of belonging/exclusion.

Policy spaces and the changing environment for jeopardised selves

To the casual observer, the realm of say disability policy, interpreted as welfare and social care policy and that of access and anti-discrimination policy, sit in very different policy and spatial locations and have not been in meaningful dialogue. Indeed, the idea that certain policy developments might negate others seems anathema to mainstream policy analyses. However it could be argued that in emphasising fair and reasonable treatment in anti-discrimination policy (Disability Rights Taskforce, 1999) alongside increasingly harsh statements about disability welfare dependency (HM Government, 2012) helps unravel any potentially more progressive disability policy developments. Of note the failure to enforce key aspects of the DDA (1995) and the DDA Amendment Act (2005) leaves many barriers in place (Roberts et al., 2004) or perversely can lead to the assumption that barriers have already been removed. The attachment of welfare dependency to sick and disabled people had not been a characteristic of the welfare state or wider welfare discourse from 1945 to 1997 (Roulstone and Prideaux, 2012). The exact causes of a hardening of rhetoric and the growing 'link' between sickness/disability and dependency are fiercely debated (Connor, 2010 ; Deacon and Patrick, 2011 ; Garthwaite, 2011 ; Hirst, 2007), however a careful analyses of the changing rhetoric and detail of policy reform makes cost-savings and the avoiding of a growing welfare/social care budget clear explanatory favourites (Duncan-Smith, 2012a).

The general tenor of welfare reform was established by the New Labour government from 1997 (Prideaux, 2005); however the rhetoric has hardened yet further with the accession of the British Coalition government (merger of British right and centrist parties) in what might be seen as a consolidation of anti-welfarist and anti-dependency thinking. The following from the newly installed Chancellor George Osborne makes clear their resolve in battling a welfare system that is viewed as 'out of control':

I want to support the person who leaves their house at six or seven in the morning, goes out and does perhaps a low-paid job in order to provide for their family and is incredibly frustrated when they see on the other side of the street the blinds pulled down and someone sitting there and living on out-of-work benefits. (Osborne, 2010)

Public and economic space have here become the focus of increased scrutiny and top-down discourse in a manner that affords little right to reply for those affected. The stridency and the power of these messages arguably creates the broad backdrop of jeopardised public space for those unable or unwilling to work. Both the system of welfare and those whose behaviour has been distorted by welfarism is clear in the following assertion from the incoming Secretary of State for Work and Pensions which is unambiguous in its use of derogatory and disablist language:

the benefits system is "bust" and carries such disincentives to work that many people on benefits regard those who enter employment as 'bloody morons'. (Duncan Smith, 2010)

Such rhetoric has not however, at least since the days of the English Poor Law (1601, 1834) (Boyer, 1990; Topliss, 1975), connected disability, frailty, sickness and

bodily difficulty (or faux versions of these) with such harsh welfare narratives. Indeed a founding characteristic of the early welfare system was its concern for those who could not make a contribution via taxation or national insurance as they were too ill or faced too many barriers gaining access to production (as workers) and often consumption spaces (as consumers). Concern to help those who were outside the economic system of advanced capitalism also sat beneath the development of key facets of the welfare state, most notably the National Health Service (Topliss, 1975). Whether one sees this as perpetuating the view that disabled people should be cared for or given what the state felt was best (paternalism) is a moot point. However, there is risk in both right-ideology and a productivist form of disability studies (see Abberley, 1999) that they might both inadvertently overlook those who face the greatest social barriers, that is, sickness and impairment effects. Unlike the English Poor Law there are many sick and disabled people who cannot work but who are being told they can (Garthwaite et al., 2013) work in the new corporeal economy of welfare reform. Certainly the recent coupling of welfare reform with sickness and disability is perhaps the most important development of the last 60 years of UK social policy (Roulstone and Prideaux, 2012). The certainty of the cause, response and justification of welfare reform and the inclusion of disability/sickness is made clear in the following statement by the UK prime minister:

Politicians often overcomplicate their analysis, but actually, it's quite simple. It comes back to responsibility. When the welfare system was born, there was what we might call a collective culture of responsibility. More than today, people's self-image was not just about their personal status or success it was measured out by what sort of citizen they were; whether they did the decent thing … That meant that a standardised system of sickness and out-of-work benefits – with limited conditions – was effective. It reached the people who needed that support, and not those who didn't, in part because fiddling the system would have brought not just public outcry but private shame. In other words, personal responsibility acted as a brake on abuse of the system. And because the ethos of self-betterment was more wide-spread, the system supported aspiration rather than discouraging it. (Cameron, 2011)

The romanticising of a bygone welfare age and system of personal responsibility forms the basis of an ideological justification of the need for change. It is assumed that many people jumped on the sickness and disability bandwagon as a way to avoid paid work. The growth in benefits is attributed to worklessness and loss of citizen-impulse and not due to illness, impairment and barriers. Additionally, the argument is put that the disability benefits system is too easily manipulated due to vagaries in the system itself, for example the Disability Living Allowance (extra costs benefit) (DLA) system:

A lot of that is down to the way the benefit [DLA] was structured so that it was very loosely defined. (Duncan Smith, 2012b)

Both the presentation of a 'golden age' of welfare and the decline into dependency are each complementary but highly questionable in factual terms (Garthwaite,

2011). Indeed a veritable flood of critique, counter-evidence and activism has arisen to attempt to challenge this welfare reform project. However there is evidence of real, negative and possibly enduring hardship and divisiveness for many sick and disabled people (National Audit Office, 2012). The public domain, one where we can claim and reaffirm our sense of belonging, has arguably become a terrain of conflict and hostility towards the so-called 'not genuinely disabled' as the media portrayal and evidence of hate crime below attests. This is in spite of the acknowledgement that key components of welfare reform, such as alleged fraud, is now acknowledged by the UK government to be overstated:

The truth is quite a lot of what we here politically term constantly as fraud is often complexity error, which is very easy for us to then say this is fraud and people feel quite stigmatised by that … the truth is quite a lot is nothing to do with them, it's the system itself. It simply means they didn't understand what they were meant to be doing and now they are apparently committing fraud and a lot of them didn't know that was the case. (Duncan Smith, 2011)

The officially acknowledged fraud rate for disability benefits is 1.5 per cent (National Audit Office, 2009), whilst the real reasons for DLA growth is mostly to do with ageing on DLA with the growth of the over-65 claimant count and an increase in children surviving previously deadly impairments (DWP, 2012). These are images far from that of a burgeoning mass of scroungers with little or no sickness or impairment. Of note this is not the first time such policy claims of growth via fraud have bedevilled the disability benefits system, an earlier moral panic about DLA had taken place in 1998, whilst the final analyses led to similar paucity of evidence of fraud as a rather apologetic ministerial response to a parliamentary select committee made clear back in 1998:

I am not quite sure what you mean by robust. In terms of DLA [Disability Living Allowance], it is extremely difficult to identify quite whether it is fraud … I do think it is about correctness and we are sure that there is a high level of incorrectness there. (UK Parliament, 1998)

Despite the evidence of the thinness of argument behind the detail of welfare reform, the impact on sick and disabled is very real. Public space becomes saturated with daily stories of disability fraud and scrounging (Briant et al., 2011). Many of the stories afford little or no right to reply, many of the people highlighted have impairments but have been caught functioning in ways that are not congruent with disability benefit claims. This is noteworthy as the need to emphasise everything you cannot do (as opposed to objective medical assessments) characterises disability benefit claim processes (Beatty et al., 2009). The impact for many is a state of fear and apathy that whatever they say or do, the state will, they believe, arbitrarily decide on whether a person is 'legitimately' disabled or not (Soldatic, 2013). For example the recent target to get 0.5 million claimants off Disability Living Allowance (an extra costs benefit) makes clear that a number of disabled people who had been medically accredited to be 'disabled for life' would possibly be deemed not disabled enough for the new benefit – Personal Independence Payment (PIP) (Deacon and Patrick, 2011).

There is clear evidence that there has been a significant shift in the focus and tenor of media coverage of disability. In their recent report, Bad news for disabled people: how the newspapers are reporting disability, Briant et al. (2011) found there had been an increase of over 30 per cent in the number of articles concerned with disability between 2004-5 and 2010-1. While this increase is perhaps unsurprising given the growing awareness of disabled people in a range of forums and particularly as customers/consumers (ODI, 2012), what is of concern is the emphasis and tone of this coverage, much of which echoes the politicised and vitriolic nature of speeches by key government ministers we cite above. In particular there has been the presentation of disability status as a privileged and mis-used option for the 'faux' disabled.

There has been a significantly increased use of pejorative language to describe disabled people, including suggestions that life on incapacity benefit had become a 'Lifestyle Choice'. (Briant et al., 2011: 5)

This is well illustrated by the following diatribe by a well-known columnist in which he tastelessly suggests 'pretending' to be disabled enough to secure benefits is both fashionable and easy:

My New Year's resolution for 2012 was to become disabled. Nothing too serious, maybe just a bit of a bad back or one of those newly invented illnesses which make you a bit peaky for decades – fibromyalgia or M.E … And being disabled is incredibly fashionable. The number of people who claim to be disabled has doubled in the past ten years … It has become easier to claim those benefits, partly as a consequence of the disablement charities who, out of their own self-interest, insist than an ever-greater proportion of the population is disabled … I think we should all pretend to be disabled for a month or so, claim benefits and hope this persuades the authorities to sort out the mess. (Liddle, 2012)

The piece also echoes the report finding that while those with 'hidden' or socially 'unsympathetic' conditions were more likely to be described as 'undeserving' (11) while the attitudes of participants in the accompanying focus groups were summed up as 'disabled people are not fraudsters and fraudsters are not disabled people' (13) with clear implications for those who are either 'not-obviously' disabled or perceived not to be 'disabled enough'.

Moreover the report noted that claims in the media, and much repeated elsewhere, about extremely high levels of disability benefit fraud were 'made overwhelmingly without evidence' (Briant et al., 2011:12) and without a concurrent acknowledgement of the officially collated figures that document extremely low levels of fraud 0.3 per cent for Incapacity Benefit and 0.5 per cent for Disability Living Allowance (DWP, 2012 : 14). A particular feature of the coverage highlighted by the report was the way in which the explanations for benefit claims were personalised and pathologised as these fairly representative tweets by @thisisamy suggest:

Collectively, this government & certain media have made me feel that I am at fault for having a disability. That I choose it. (@thisisamy 2013a)

As a disabled person, I do feel persecuted & singled out. (@thisisamy 2013b)

This is part of a much wider discourse about all those who claim benefits captured in the phrase 'scroungers or strivers' that implies a false dichotomy between those who claim benefits and those in work that fails to acknowledge the barriers that many disabled people face in accessing the labour market or that benefits like the Disability Living Allowance enable significant numbers of disabled people to work. What is apparent from this analysis is that political and media discourses around disability and ('faux') disabled people have been effective in influencing popular perceptions. As Tyler notes social media is increasingly used to 'harden public opinion into consent' and that the 'symbolic violence' witnessed there 'is converted into forms of material violence that are embodied and lived' (2013 : 211– 12). This can be experienced as direct disablism, in acts of naked aggression and violence targeting disabled people or perhaps more invidiously as Reeve suggests in her chapter as indirect psycho-emotional disablism whereby disabled people's experiences of moving through public space are uncomfortable and inhospitable.

Responses to jeopardised space and demonised selfhood

Despite the harshness of policy space and the propagation of myriad stories about scrounging and faked disability, it would be wrong to portray disabled people as willing victims of these discourses and as lacking agency (Findlay-Williams, 2011). However the truly destructive development aspects of these new policy and public constructions is that no one quite knows who it is that deviates from acceptable definitions of disability and claimancy. Indeed a key aspect of jeopardised public space is that we cannot often know who has an impairment, who experiences pain, fatigue and social barriers. Apart from disabled people who are obviously akin to stereotypes of disabled people – wheelchair users, people with learning difficulties –the 'obviously' different; the preponderance of people with state accredited impairments have often unseen musculo-skeletal, heart, chest or neurological challenges (Department of Health, 2012). In fact, a number of people will be what might be called 'sick disabled' and have hard-to-manage and frequently fluctuating impairments/illnesses. These disabled people may arguably be at risk of being overlooked by new policy discourses built on visible stereotypes and have also been largely overlooked by disability studies where the emphasis has often been on playing down pain, fatigue and impairment effects (Mont, 2007).

 Because we often do not know who counts in a public context such spaces and equivalent policy spaces arguably draw on hunches, convictions, clues and revelatory news stories which unearth the 'truth' about impairment or pretence at a disability status. The result is akin to a form of mutual public paranoia, that any one individual may be a benefit cheat and be affecting disability status, whilst for sick and disabled people, some of whom who may have been reluctant to take on a disabled identity due to fear of stigma, may now fear being found 'not disabled' or not disabled enough to meet the threshold of state-accredited impairment. Frequently this is the result of changes to eligibility criteria rather than a change in a condition or level of impairment which further blurs the distinction between

genuine and faux disabled people (Grover and Soldatic, 2013). As we discuss above public perception of a reducing number of claimants is that individuals have withdrawn from claiming benefits to avoid being 'found out' rather than the result of heightened eligibility criteria and a harsh and dehumanising assessment process. Furthermore, there has been a disassociation in much popular discourse of the perceived 'perks' disabled people enjoy, such as the blue badge parking scheme or DLA.

These are new developments and the closest parallels in recent history are the psycho-dynamics of authoritarian states where unorthodox or unapproved thoughts and behaviours lead to informing and often very severe sanctions (Fitzpatrick, 1999). These ideas are not confi ned to policy and ideological pronouncements but it can be argued begin to pervade public space as powerful dynamics and behavioural forces which make life hugely conditional and fearful for many disabled people (Garthwaite, 2011). The recent shift from DLA to Personal Independence Payments (PIP) is a case in point. The higher rate threshold to establish a claimant's rights to have their independence supported is being reset to a point where a disabled person cannot walk more than 20 metres without risk of harm, danger or severe discomfort (Dunt, 2013). Many disabled people are querying how such a stipulation can form the basis of an independence-driven agenda. For example for those that can walk 50 metres (the previous threshold) their ready access to independence and support is stopped off, whilst those 'successful' in claiming higher rate PIP may be likely to fear being seen walking more than that distance (Dunt, 2013). Here then is an inadvertent extension of possible stigma and fear for those who have more obvious and visible impairments. Whether one takes the example of the person with an unseen impairment fearing exposure or an individual with a visible impairment afraid to be seen walking more than 20 metres, new welfare discourses will undoubtedly lead to increasingly jeopardised identities in public space. What then of the impact of these changes to public space?

There are many manifestations of disabled people's fears, for brevity, the following are typical of many thousands of statements that populate blogs and e-bulletins in 2013:

I don't think about what might happen to me if the government's proposed threats/changes actually materialise. I firmly push it to the back of my mind, burying it as deep as I can so not to be overwhelmed by panic and fear about a situation I can do nothing about … The kind of fear that is hard to describe. The type that sits, deep in the pit of your stomach and travels up in to your throat where if you let it will clench it's fi st and take hold starving you of breath. (Ouch! web blog 2008)

The following is a parent's letter to the editor of a well-known newspaper which supports an eye hospital wing where their daughter is being treated, whilst championing as the newspaper's editor alarmist and wildly inaccurate editorials on disability scrounging. The parent of the disabled child notes the irony of this apparent incongruity of approach:

Just over a year ago, my daughter Eve, then aged three, was diagnosed with chronic uveitis, an inflammation of the eyes that can cause blindness … I was shocked to discover she had no vision in one eye and the other was deteriorating … But it is another of your business interests that I find more difficult to square with your support for Moorfields [eye hospital]: the Daily Express – and its relentless war on sick and disabled benefit claimants. Recent front page stories include: 75% on sick are skiving – benefit cheats are taking us to the cleaners Blitz on Britain's benefits madness – scroungers use 500 scams to grab your cash Blitz on benefits: 887,000 fiddlers exposed So here's a novel idea. The next time a DWP briefing comes your way, instead of repeating it, scrutinise it. In these austere times it needn't cost your newsroom extra cash. The Express recently complained that, according to DWP figures, 'spots, indigestion and sunburn' were among the reasons claimants received benefit, while the Daily Mail mocked other ailments such as 'diarrhoea' and 'nail disorders'. But a glance at the DWP survey's footnotes would have revealed that these conditions were not necessarily the reason benefits were given. (Singer, 2011)

While one disabled person is using artistic expression to convey the degree to which a climate of fear places some disabled people in a twilight world: one where they are afraid to be seen doing anything that might be construed as at odds with benefit criteria. This is of course some distance from the objectives of independence and choice at the heart of wider disability policy reforms of the 1990s:

For some months, I have lain low for fear of being penalised, but instead of letting fear determine who I am, I'd rather stare it in the face … I want to make a twilight existence visible, but more than that, I want to show that what many people see as contradiction – what they describe as fraud – is only the complexity of real life. (Pring, 2011)

Conclusion: rights, wrongs and jeopardised public space

From the outset we have argued that space, or public space to be precise, is more than the sum, of physical, technological space – potent psycho-social environments created by public discourses need to be understood if we are to understand disabling/enabling space. What can we glean from the above exploration of media portrayal, new constructions of welfare dependency, behavioural distortions 'wrought' by the welfare state and our understanding of public space?

It is probably best to compare an idealised model of inclusion and belonging and to place that in parallel to the environment that is being (inadvertently or deliberately?) created by recent discourses on welfare and disability. The following aims to represent the difference between an idealised picture of citizenship by drawing on key principles of the UN Convention on the Rights of Disabled People (UN, 2006) whilst contrasting these with the increasingly jeopardised state that many disabled people find themselves in. Although the Convention does not operationalise rights to inclusive and humane spaces beyond an anti-discrimination legal construction of access, the spirit of the Convention captures well a range of

measures of enabled citizenship that many disabled people would aspire to (see Table 4.1).

Table 41 Public space, inclusion and jeopardy: a comparison with the UN Convention precepts (excerpted) (UN, 2006, www.un.org/disabilities/convention/conventionfull.shtml).

UN Convention Precepts	Risk that Inhere in Stigmatising Policy
Dignity, autonomy, independence	Jeopardised selfhoods, enforced behavioural norms
Full and effective participation and inclusion	Fear of participation, hostile public spaces in society; psycho-social exclusion
Respect for difference	Propagated fear of difference, hatred of difference
Humanity and diversity	Uncertainty, stigmatising or unseen or 'hidden' impairment
Equality of opportunity	Engrain and reinforce disablism, fear of disability, fear of being in public, fear of assault

The above makes clear the hardening rhetoric around disability and welfare dependency. Academic analyses to date have attempted to explore the nature, accuracy and purpose of such changing rhetoric. In this chapter we have entered into a new line of analysis in looking at the impact of these changing discourses on constructions of disability, legitimacy and selfhood. We argue that spaces are increasingly jeopardised for many disabled people. Living lives of fulfilment, rights and choices has been made harder in this climate. Only the future will tell us the longer-term impact of such new jeopardies.

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Disability and Neoliberal Statistical Panic

There has been a growing global statistical panic surrounding 'disability' over recent years. This disability anxiety has been couched around a discourse of *un*sustainability as governments use a particular set of disability statistics to argue that they can no longer afford disability welfare, that is, one of fiscal doom and gloom, 'looming in the horizon' (Woodward 2009, p. 197). Such concerns have been occurring across most OECD countries, and these statistical discourses of disability fiscal panic have become normalized with the onset of austerity measures since the financial crash in late 2007. Global policy institutions such as the OECD, World Bank and the IMF have situated disability within economic discourses of global restructuring (Grover and Soldatic 2013). Disability is thus now central to economic debates pertaining to the future 'health' of the nation that dominates debates of welfare retraction that aim to move people off welfare and into the world of work (Soldatic 2013).

Disability's shift from the fringes to the epicenter of economic policy emerged in the mid-1990s (Soldatic and Chapman 2010). Before this, disability was mostly positioned as a category of social welfare and medicine (Clear and Gleeson 2001). This changed with the emergence of two specific forces: the disability rights movement and the rise of neoliberalism as a policy orthodoxy

(Roulstone and Morgan 2009). As French and Swain contend (2008), while these two movements have disparate aims for disabled people, their focal point around disabled people's enduring exclusion from the labour market and the resultant effects of entrenched poverty and dependence on welfare has, at times, led to a precarious position of convergence.

The timing of the disability right's movement call for the 'right to work' emerges in concert with workfare. Peck (2001) suggests that workfare is the key domestic social project of neoliberal global restructuring as it seeks to re-regulate the relationship between the labour market and state welfare provisioning by making welfare supports dependent upon individualised economic contribution. This deepening of the market society via workfare regimes first surfaced in North America under the Reagan administration but came into full effect in the US during the Clinton Administration with the passage of the Personal Responsibility and Work Opportunity Reconciliation Act 1996 (Abramovitz 2006, p. 339). Workfare is now part of an international project promoted through global policy institutes such as the OECD and IMF (Grover and Soldatic 2013). In the last ten years, most Western nation states have undertaken some form of welfare restructuring to reflect the institutional requirements of a workfare state (Soldatic 2013). In the UK, the Blair Labour Government developed its 'making work pay' strategy and its *New Deal* policy (Peck 2001) which have been further consolidated under the Cameron Conservative-led Coalition Governments radical withdraw of any claim to citizenship entitlement, affecting a multitude of groups, and particularly disabled people (Roulstone and Morgan 2014).

The hegemony of neoliberalism has redefined ideas of citizenship, social inclusion and social mobility. The liberal social contract of 'rights and entitlements' and 'roughly equal' has radically shifted to the coercive authoritarian neoliberal logic of 'responsibilities and obligations'; often pitched in the populist mantra of 'no rights without responsibilities' (Fiske and Briskman 2007). This means that access to social entitlements is no longer

based on need or necessity alone. The discursive panic created by statistical repetition of doom and gloom creates public consent for an authoritarian logic that requires citizens to *earn* their social entitlements through performance of market behaviours in exchange for welfare benefits and supports. Work, labour market attachment and subordination to the imperatives of the market are thus promoted as the highest form of citizen responsibility (Lister 2001). Workfare is thus inherently contradictory, as it combines the imperative of market individualism of the New Right with the authoritarian obligations asserted by neo-conservatives.

Nearly all Western liberal democracies have undertaken large-scale disability policy restructuring in line with neoliberal welfare policy trends (Humpage 2007). While there is a multiplicity of local variations and deviations, international analysis suggests that neoliberal disability policy converge around the restructuring of disability social security entitlements with the primary aim of steering disabled people off disability pensions and into the open labour market (Roulstone and Barnes 2005; Grover and Soldatic 2013). Consistent across Australia, Britain, Canada and the USA has been the large-scale implementation of numerous governance technologies to 'activate' disabled people's labour-market participation (OECD 2009). These activation technologies concentrate on compelling disability social security recipients into a set of prescribed activity tests as a condition of maintaining access to benefits, such as individual compacts, participation plans, sanctioning regimes and in many instances, the straight denial of social security support (Grover & Piggott 2013; Soldatic 2013). These all aim to contain disability pension growth and curtail future fiscal outlays by making disabled people disappear from the welfare rolls (Grover & Soldatic 2013).

While major scholars in welfare studies often interrogate neoliberal workfare governance in the key centres of global power, such as the USA and the UK (Jessop 2002; Peck 2001), as Grover and Soldatic (2013) illustrate, it has been Australia that has been the experimental 'hot bed' of neoliberal workfare

restructuring, and, it has been the area of disability that has been central to its trialling of new forms of neoliberal governance under governments of either persuasion (Morris et al 2015). In fact, in recent years we have seen the active global transfer of neoliberal disability welfare restructuring as the Australian political elite are increasingly invited to remind their global political counterparts of the benefits of Australian neoliberal restructuring (see Hockey 2012). Thus, this inter-scalar transfer of neoliberal orthodoxy, spoken within intimate elite political networks, moves from the centre to the periphery and back again, in a continued dialogue of discursive privilege and power.

This global statistical panic, however, discloses little about the reproduction of neoliberal violence in the everyday experience of disability in a continually and rapidly changing polity where disability has become centre stage in economic policy deliberations (Soldatic & Pini 2012). Rarely are the voices of disabled people heard in these critical public policy debates (Gibilisco 2010) despite the impact of these policies on disabled people's subjectivities. Thus, there is the possibility of another reading of these statistics, a reading that critically focuses on the narratives of disabled people who have developed a range of strategies to sustain their emotional wellbeing to contend with the barrage of neoliberal workfare policies that shame them into compliance. In this chapter, we draw upon interviews conducted as part of two national studies in Australia and the UK with disabled people who have been experiencing first hand the effect affects of neoliberal workfare. Despite the differing socio-spatial contexts, these people's narratives reveal an intimate convergence - a highly masculine abled bodied project that denies subjects care for oneself and others, whilst having to perform 'care for the nation' via the realm of work.

Emotions, Disability and Neoliberal Governance

Emotions have had a contested and chequered history within scholarly research since the emergence of industrial capitalism. With the advance of

neoliberal capitalism, they have become, once again, prominent in work that seeks to critically illustrate the regulatory role of emotions with capitals ebbs and flows. Authors such as Ahmed (2004), Skeggs (2004) and Tyler (2013) are documenting the emotionality of neoliberalism as it increasing frames social citizenship via the emotional lens. This rich body of work identifies the ways in which emotions infuse the contested boundaries of the private and the public as an array of emotions are actively drawn upon by elite actors to socially shape new forms of neoliberal governance at the micro-scale of the 'self'. Emotions thus are not things that belong to an individual as a separate object, but are in fact, framed with moral meanings and sentiments that operate discursively at the macro scale to create nascent forms of social control that can become embodied as everyday practices of self-governance.

Disabled people have long been aware of the role of emotions in social regulating their daily lives (Marks 1999). Emotions have historically been powerful mechanisms to maintain disabled people's confinement within the asylum, clear them from the streets, and to hide them away from the public gaze (Schweik 2009). Latterly, Kolarova (2012) demonstrates how disabled people have had to take on 'handicap, social stigma, dependence, isolation and economic disadvantage' (Stone 1984: 4 cited in Kolarova 2012: 265) in exchange for the status of being a 'tolerated exception' from neoliberal requirements of citizenship. For disabled people, emotions are thus deeply political. This is both due to the direct and indirect affects it has on their lives, which are disabling, stigmatizing and extremely painful. As Reeve (2012) contends, the emotional sphere of disability social regulation operates in the ''most mundane words or deeds that exclude or invalidate' (Hughes, 2007, pp. 682)' a form of 'ontological invalidation [that] undermines psycho-social emotional well being' (Reeve, 2012: 79-80). The affect effects thus frames disabled people's intra-corporeal engagement, effectively reaffirming social processes of oppression as forms of internalized self-governance. Emotions for disabled people, are therefore, a key area of social life where they are required to manage other people's emotions, whilst simultaneously managing their own emotions all for the benefit of others.

Of all of the emotions, it is shame that dominates the everyday experience of disability. As Charlton (1998, p. 27) notes, 'shame and other manifestations of this process are devastating, for they prevent people with disabilities from knowing their real selves'. To have an unruly corporeality is one of great shame, signifying to the public a rejected body (Wendell 1996) and a corporeality that is in fact of 'no social value' (Siebers 2008, p.162). This negative social devaluation re-positions disability as *the* human spectacle, the ongoing invalidating gaze forces disabled people to adopt, practice and perform a tightly controlled performance to avoid the shaming gaze of the able-bodied public (Soldatic 2010). Most critically, for disabled people, the recurrent experience of shame, and the internalized practices of self-management to avoid public shaming, radically alters their own sense of self-dignity and self-respect (Reeve 2012). With each external repetition, these underlying structures of internalized shame reaffirm an internal dialogue of self-disrespect, which are durable and enduring (Siebers 2008).

For disabled people, these acts of shaming, through either public discursive depictions of disabled people through political or media discourse and representations coupled with the daily acts of staring they encounter in a multiplicity of spaces and places are a form of violence (Garland-Thomas 2009). This is captured in the burgeoning literature on disability 'hate crime' (Sherry, 2010; Roulstone & Mason-Bish 2013) where Sherry's apparently common-sense subtitle 'Does Anyone *Really* Hate Disabled People?' is in stark contrast to the level and intensity of everyday routinized violence disabled people experience. This generates a heightened sense of fear for disabled people when navigating the world due to the frequency, irregularity and randomness of this violence (Roulstone and Morgan 2014). These everyday forms of shaming experienced by disabled people are reflective of Young's (1990) definition of violence when she denotes that:

Members of some groups of people live with the knowledge that they must fear random, unprovoked attacks on their person or property,

which have no motive but to damage, humiliate or destroy the person. (Young 1990, p. 61)

The long lasting effects of such random attacks prohibits many disabled people from actively traversing and experiencing the outside world. As Roulstone and Morgan (2014) have argued, disabled people are frequently feeling this form of everyday routinised violence, directly and indirectly, as they are shamed by the political elite's attack on disability welfare with the ongoing intensification of neoliberal restructuring of welfare. It seems that increasingly, disabled people are shamed not just because they are disabled, but because of their potential association with the welfare system that disability suggests (Soldatic 2010). The implied profligate expansion of welfare provision that permitted too great a number of *exceptions* 'from the requirements of conscientious citizenship and individual responsibility' (Kolarova 2012, p. 265) is utilised as a way in which to '*justify* the channelling of public hostilities towards vulnerable and/or disadvantages populations' (Tyler 2013, p. 212). This reclassification of large numbers of disabled people from deserving to undeserving recipients of welfare provision transforms them in to 'symbolic and material scapegoats' (Tyler 2013, p. 211) for the economic crises and resultant austerity.

Shame is the emotion that 'makes you want to disappear, to hide away and to cover yourself' (Probyn 2004: 329). Roulstone and Morgan (2014) argue that many disabled people are now remaining 'in place', stuck within their homes with their curtains closed to avoid the public shaming and rise of direct acts of violence that has coincided with the political speak of disabled people as neoliberal welfare scroungers. In fact, as Roulstone and Mason-Bish (2012) have documented there has been a massive increase of violent hate crime against disabled people with the advent of neoliberal political speak to make them feel ashamed of their claim to social entitlements.

This everyday experience of internalising the affect effects of neoliberal shame both violates disabled people's sense of identity, and also their sense of security and safety when being 'out of place' (Soldatic 2013). The structural collective shaming of disabled people thus becomes embodied in the reproduction of everyday life, where disabled people are shamed by the performance of the non-market self. Neoliberalism is thus extremely mobile. Moving from the structural, the political and the group through to navigating down to the individual who is required to perform the market individual in everyday life. Shame performs this inter-scalar labour on its behalf.

Nussbaum suggests that shame is *the* social emotion (Nussbaum 2004). It is the emotion best known for keeping people *in their place* due to 'its everyday dependence on the proximities of others, of place, of routine, of biography and history' (Probyn 2004: 329). Primarily, its use as a subtle everyday mechanism to contain marginalized social groups, works to establish borders and boundaries around sets of bodies – dividing, sorting and classifying bodies-and-minds into a complex web of social regulating regimes (Sayer 2005). Nussbaum (2004) refers to this process as stigmatised shame, where the role of shame in public moral discourse is to stigmatise the class of people towards which it is targeted as a form of group subordination. The resultant feelings of shame associated with this type of public shaming leaves members who identify with the stigmatised group feeling unworthy; a feeling that disabled people can readily corroborate.

Therefore, it is not surprising that shame has a long-standing association with violence (Scheff & Retzinger 1991). Shame has been used throughout the establishment of modern liberal democracies to regulate the socio-spatial sphere (Nussbaum 2004) and yet, is most often exhibited as individual acts of violence in direct response to structural shame (Scheff & Retzinger 1991). Shame's power is hence its ability to become embodied and internalized as individual moral failure, as it subtlety oozes through a range of spaces and places to hide the structural effects of social inequality, exclusion and

deprivation (Sayer 2005). Shame is embedded in, and emerges from, our social existence and, therefore, it shapes, and is shaped by, the political sphere (Nussbaum 2004). It is actively used to individualise structural deprivation to re-situate the place of blame and entails the reimagining of the 'rational individual' or of 'homo economicus' as an *emotional* being. This emotional being is *irrational, unruly* and *resistant* to market behaviours, logics and norms.

It is these individualizing properties of shame and public acts of shaming that are incredibly significant in revealing the architecture of neoliberal workfare and the experience of neoliberal forms of everyday life. The targeting of individual behaviour as a moral public discourse has been prominent across Western liberal democracies implementing workfare strategies. For example, US President Reagan referred to single mothers on welfare as 'welfare queens' (Goodin 2002) and Prime Minister Tony Blair insisted that disabled people were using disability benefits 'as an excuse to never work again' (Lyall quoted in Galvin 2004, p. 126). In Australia and the United Kingdom the 'welfare scrounger' has become a powerful moral signifier across successive governments (Soldatic 2010; Roulstone & Morgan 2014). Wilson and Turnbull (2001: 384) argue that such strategies are a '*calculated political tactic*' of the New Right (original emphasis), personified around a 'politics of blame' that discursively constructs, poor working subjects as the primary cause of the welfare- fiscal crises (Haylett 2003). All of these efforts are thus designed to move public resentment away from neoliberal governments as growing numbers of their citizens are faced with a precarious existence, of high economic insecurity and of growing material deprivation with neoliberal global restructuring. Shame thus actively displaces political discontent; providing governments with a proxy to target one's anger for the downward spiral in social mobility experienced so much by the lower-middle classes (McRobbie 2013).

Shaming of welfare recipients also encourages an active process of forgetting, forgetting past injustices, past inequalities and past structural exclusions, hiding such structural marginalization through blaming and shaming. As Ranciere (2004) argues, this shifting political frame then creates a form of seeing of what was previously *un*seen. This key technique of neoliberal governance, lays the grounds for the political elite to build a new moral consensus of social norms, dominated by new meanings of citizenship that are framed around precarious forms of work in low wage casualised labour markets as the 'new norm' of participation. The desired effects of shaming are thus two fold – to build public consensus for neoliberal workfare restructuring, and also, to remove social entitlements as a right of citizenship and propel welfare recipients into the labour market.

As we illustrate throughout the next section, neoliberalism actively draws upon acts of shaming to force disabled people to comply with its coercive regulating regime (Bessant et al. 2006). As legitimising discourses, to advance the market logic of neoliberalism, the structural processes of neoliberal welfare restructuring not only individualise, but directly blame, disabled people suffering from structural disadvantage. Shame is used to articulate the lack of a job as a private moral failure. It is used to labour the inter-scalar moralisation of neoliberal intensification. Moralising structural disadvantage reinforces existing social divisions (Martin 2007), whilst re-constituting new social hierarchies. Most significantly, shaming has become a calculated political tactic to re-imagine the disability landscape; creating new divisions to separate the deserving from the *un*deserving disabled welfare recipient (Grover and Piggott 2013). With the emergence of a neoliberal workfare state, a new set of social norms are required; re-regulating and re-classifying disabled citizens into two classes – those so-called disabled people who are *un*deserving of social entitlements and plague the system by actively abdicating their responsibilities, and those *truly* deserving disabled citizens who are unable to contribute to the neoliberal project.

Repeated experience of shame within neoliberal workfare spaces undermined disabled people's sense of self and their ability to act in the world. The chapter combines two separate studies that occurred in Australia and the UK. The Australian study was part of Soldatic's PhD research that focused upon Australian disability income reform with the onset of neoliberalism and its intensification with the 2004 re-election of a majority Conservative Government (Soldatic 2010). The second study, completed in the UK during 2012, drew upon the learnings of Soldatic's Australian study, working in collaboration with researchers from Lancaster University. While the temporal moment of each set of interviews does not occur simultaneously, the structural transformations with the intensification of neoliberalism as policy hegemony are directly comparable (Grover and Soldatic 2013). Henceforth, the comparative analysis of the interviews confirm the global literature on the policy mobility of neoliberal welfare to work measures, that despite local contingencies, illustrates the transfer of international learnings, processes and practices to build consensus within the polity to achieve the structural, institutional and regulatory transformations that neoliberalism demands.

The interview transcripts reveal that the dominant experience of disabled people in Australia and the UK with neoliberal intensification is that of public shaming, through a diverse range of political discourses. The constant barrage of shame promoted an internalisation of the violation and disrespect embedded in institutionalised practices of shame. Public discourses and symbolic representations to promote neoliberal governance not only misrecognised disabled people's structural disadvantage, but actively worked to further stigmatise disabled people as a group in order to assure their compliance with the new workfare norms of neoliberal governance. Shame labours on neoliberalism's behalf, traversing the inter-scalar relations between the citizen and the state, transforming disabled people's subjectivity through everyday forms of violence. These everyday practices of violence become internalised, and yet, remain abstract and distance, critical components of the affect effects of shame. The discursive power of statistical

panic moves from the parliament, the financial market and the press, and then breadth, lived and negotiated in everyday life.

Neoliberalism and Disabled People's Songs of Shame

Shaming employs multiple strategies. Some acts of shaming are subtle, while others are deliberately overt, intended to signify to a group the set of power relations in which they are embedded (Barbalet 1998). Shaming occurs at all levels, from the macro-structural scale to the micro-spaces and places (Sayer 2005). Disabled people from Australia and the UK participating in these studies clearly understood neoliberal acts of shaming to reflect their marginalized position of power in workfare governance. Most significantly, they actively internalised the public shame of being unemployed and on welfare as a moral evaluation of the self. We first were alerted to this with Beatrice, a young women with a vision impairment living with her mother in Perth, Australia. Even though Beatrice has made multiple attempts to find work, actively seeking the support from workfare services Beatrice repeatedly disclosed the feelings of inferiority she experienced when explaining her experience putting in her best efforts to join the neoliberal labour market that has historically excluded disabled women. At the end of the interview, Beatrice told has how she no longer had the energy to pursue employment as "I was feeling I wasn't worth it, even though I had skills I thought I wasn't good enough anymore".

All the disabled people in the UK and Australia participating in these two studies expressed these individualized feelings of internalized shame. While Beatrice's shame is commonly expressed as a form of low-lying shame, revealed as ongoing feelings of inferiority, others expressed more overt forms of shame. In fact, it appeared that as neoliberal workfare intensified across the two countries, the everyday experience of shame was heightened for the research participants with their failure to gain employment, even though they actively worked hard to gain employment of any kind. To us, as researchers, it appeared that as the research participants intensified their efforts to gain

employment so did their experiences of internalized shame and feelings of unworthiness. The internalization of social forms of shaming had a transformative effect. For Beatrice she no longer wanted to "go out to try for another job" and therefore, she largely remained 'in place', isolated in her home with her mother. However, for others these effects were more direct and violent.

Rachel, a woman with cerebral palsy, reveals the extreme forms of hiding that disabled people may need to practice to escape neoliberal workfare strategies that aim to 'activate' disabled people's labour market participation. Rachel was forced to see a workfare employment provider and meet regularly with a case management to manage her transition to employment and off welfare. Eventually a job was found, however, this job was within a local library that was unpaid. The local library had stairs and no lift. Rachel was a wheelchair user. Additionally, this unpaid job, would force Rachel to spend money from her disability payment to get to and from work, which she could ill-afford. Even though Rachel explained this situation to the case worker, Rachel was forced to 'go to work'. Eventually, Rachel decided to actively exclude herself from the barrage of daily shaming that was experienced with having to work for free in an inaccessible workplace. In fact, Rachel took to hiding from the workfare case worker she was assigned, which in turn left her isolated from communicating with the rest of her world. To escape workfare governance, she needed to disconnect herself from her primary form of communication – the telephone: "so I was at the point she had me so terrified, haranguing and bullying me, I took the phone off the hook, and all but hid under the bed".

Rachel's experiences and practices of resistance, along with Beatrice's experiences of unworthiness, also demonstrate the contradictory nature of workfare governance, which combines the New Right agenda of market activity with neo-conservative authoritarian logic of obligation. Neo-conservatives such as Mead (1986) have long argued that these necessarily

coercive strategies promote active engagement with the labour market and society, but in fact, these practices of shaming disabled workfare conscripts into compliance, as experienced by Rachel and Beatrice, did not encourage or enable them to seek employment; rather, it ensured that they used *active practices of exclusion* to protect themselves from further injury by a violent and punitive system. These findings reinforce Sayer's (2005, p. 153) argument on shame wherein he states that it leaves people 'feeling inadequate and hid[ing] from the gaze of others'. Rather than wanting to participate and collaborate with workfare services, Rachel adopted a range of practices to remove herself as far as possible from the workfare spaces even at risk of losing access to their entitlements. Hiding at home appeared as a central mechanism for Australian disabled people on welfare to hide one's shame from the world of being a disabled welfare recipient, and also to hide from further possible shaming from neoliberal activation strategies.

In the UK, however, the home no longer represented the possibility of hiding from the public shaming that neoliberal workfare advances. The research participants from the UK were clearly able to articulate how neoliberal workfare brought shame to their home via the brown envelope. Its distinct brownness and typeset clearly demarcate it from other official correspondence. Thus, the envelope was readily identifiable as coming from social security to both the postman – the deliverer, and the disabled people at home – the receiver (Reeve 2012). It is understood by disabled people as a key mechanism of neoliberal governance of inter-scalar relations, that brings the authority of administrative bureaucracy down to the intimacy of the home. The contents contained within the brown envelope summoned disabled welfare recipients to disability re-assessments, a process that either verified or refuted their disability identity which in turn, had material ramifications via the disability support payment system. Sarah, a young women with Multiple Sclerosis living with her parents on a disability welfare payment stated that the confluence of media reporting, political speak, and general gossip within one's friendship group about neoliberal welfare retraction brought shame to disabled people's homes on two fronts. First,

the brown envelope publicly identifies your status as someone on welfare who is potentially 'scrounging'. It also represented the fear of potentially losing one's disability status and hence, access to the disability social security system. Thus, for disabled people in the UK, hiding at home was not safe from the external world that drew upon shame to force disabled people to participate in neoliberal workfare. The inter-scalar labour of neoliberal shame asserts its authority over everyday life, where disabled individualised shame brings stigmatisation to one's most intimate spaces, to keep disabled people in their place. In fact, this inter-scalar labour of shame created its own risks and fear, which threw its recipients into whirlwinds of despair as they were required to manage their internalized shame, hiding from their communities, their families and even themselves:

Sarah: Yeah, I have a general brown envelope fear.

….
I know that brown envelopes are from the DWP [Department of Work and Pensions]. I've actually got one upstairs that's been there for three days and I haven't yet opened it. I will open it, just it takes me a couple of days to pluck up the courage. So yeah, I knew it was from, brown envelopes are generally from the DWP so.

Thus, the invasion of safety within the home with the distinct brown envelope brought new fears and risks for all of the participants that were interviewed in the UK. Moreover, Sarah's hiding of the envelope in her home until she built up her courage to review the letter unfortunately, puts her at greater risk of losing access to benefits, as disabled people were expected to respond to these notifications within 10 working days of receipt. If not, disability support payments were discontinued.

These experiences of shaming reiterate Young's (1990) understanding of violence. In these instances, these are felt as random attacks on the person and reveal the importance disclosing the association of shame with violence in workfare governance. Michael, a young married Australian man with a physical disability, describes the constant fear, shame and violence that many disabled people live with on a daily basis, particularly in having to try to

comply with a highly coercive and unpredictable system that has total control over one's material resources. As Michael's experience suggests, while neoliberal states are highly efficient in delivering, via mail, the set of instructions that aim to refute one's claim to disability entitlements, when state workfare agencies withdraw these entitlements mistakenly, disabled people experience the added shame of not being informed of the error via mail:

Like when they make the mistake when they cut me off disability. They made the mistake and they sent me no apology. You could imagine how I felt when I got a letter saying... sorry you've been cut from disability.. you know your income is gone.. shh... and that took a whole month to send out a letter. They cut disability, didn't notify me until a month later. So I was without payment for a whole month... It was really quite a shock as we complied with all of their rules and things and they never told us why they did it.

Thus, for both disabled people in Australia and the UK, feeling ashamed of oneself and one's body was coupled with the personal indignity of the material implications of randomly losing access to, and thus control of, one's income. The structural intent of such everyday experiences is to deepen the regulatory logic of the market society so that it becomes internalised and hence, naturalised. The shame of individualised market failure normalises the everyday forms of neoliberal structural violence, appearing abstract and intangible (Tyler, 2013). Shame, as it labours on behalf of neoliberalism, maintains people in their place.

Shame, however, was highly mobile. In fact, it travelled from the home to the place of disability verification. This was particularly acute within the UK, where respondents highlighted the ways in which one's disability was verified by one's ability to navigate travel between spaces and places, as they travelled from their homes to the disability testing centres to verify or refute your status. Katherine, a women who acquired a disability less than two years prior to interview, illustrates how the disabled subjectivities are regulated across varying spaces, and how this navigation is tested with a high degree of suspicion:

You go in there completely honest and open and yet the first question is 'how did you get here?' As if, if you've got there by yourself then you have absolutely no right to be here and I just kind of looked at her. 'A friend gave me a lift.' 'Well where did she drop you off?' It's like the Spanish inquisition over something as --. And then the stairs and the lift obviously and how did you negotiate entrance, did you use the stairs or did you use the lift? How long did it take you to get from --? And I just was stunned."

Thus, Katherine's description of the assessment process identifies how disability becomes spatially regulated. To get her assessment for a disability support payment Katherine needed to navigate an upstairs isolated room, hidden from the main entrance of the room. As Katherine describes, this spatial location of the disability assessment office becomes pivotal to the process of jointly assessing disability and shaming disabled people for claiming a disabled subjectively. As Katherine outlines, the neoliberal disability assessment actively questions her spatial orientation, where the navigation of space and, the movement from place to place is embedded within the assessment to mark out the 'really disabled' and the 'welfare scroungers'. In the UK, this was repeated in nearly all of the interviews, where disabled people were strongly aware how they were watched as they navigated inaccessible assessment sites.

In Australia, suspicion was not built into all of the dynamics of the assessment process, and generally, disabled people initially felt more confident in their initial navigation of workfare spaces. However, suspicion was embedded throughout the system, and was even extended to individuals who were 'marked' in the system as disabled, but may have been seeking additional entitlements that were associated with their lawful disability status. Paul, a man with a mental illness, supports a number of peers in a voluntary role in dealing with the Australian neoliberal workfare agency - Centrelink. Paul describes how shaming, mistrust, and randomised attacks on the person's integrity results in individuals withdrawing from the system:

The stress it caused her was just unbelievable, because they were making out that she is a liar, like, you know. "This person is telling lies.

She is trying to cheat the system." You know, like, she is trying to get mobility. It was only a few dollars.

Such practices and their random application, even when unprovoked, reaffirms Young's (1990) definition of systemic violence. Disabled people who took part in this study disclosed that their experiences of a neoliberal workfare state resulted in both a collective and personal injury. Their feelings of shame, and their ongoing experience of fear, demonstrate the continued role of violence in state institutional practice. With the state's transformation to a neoliberal workfare state, its governing institutions have developed a number of shaming strategies to meet this end.

The participants' experiences of neoliberal workfare governance demonstrate the importance of shame as a state tool to produce rigid conformity to a highly punitive system. Further, research participants' experiences in both Australia and the UK of the workfare system signify the level of personal shame and humiliation that violate disabled people's dignity, through the randomisation and unpredictability of their access to material resources – previously a recognized entitlement of disability citizenship. Personal feelings of failure are a direct result of state coercive practices of shaming, which are reaffirmed by the constant material insecurity and negotiation of minimal resources to maintain a basic standard of living. Thus, the structural reproduction of shame, in turn, reinforces individual feelings of personal failure. As Bourdieu (1996) has noted, those who experience failure through no fault of their own are still likely to feel shame, which Sayer (2005, p. 154) argues is a 'structurally generated effect'.

Disabled people must both comply with and reproduce the medicalised classifying regime of their bodies, and in fact participate in a game of shaming oneself in order to gain access to the required resources to support their effective participation in workfare governance. This balancing act of negotiating the lived bodily space of severe material deprivation, rigid state

regulatory compliance and the moralisation of their bodies can fall at any time. For some, such as Emma, a young single mother living in Melbourne, Australia, who has had a number of encounters with state child welfare agencies, the intensity of shame she has been made to feel about herself, her material deprivation and her mothering have led to Scheff and Retzinger's (1991) shame-rage spiral. Emma describes below a recent 'run-in' that she has had with state workfare authorities and the police:

It's bad when you've got a family. I remember one week I was supposed to get paid but I didn't get paid. I got so mad at them. I said 'if you don't pay me I'm going to rob your place'. They got scared, then thought I was going to rob them so they said 'Ok we will pay you next week'. I'm like 'I need the money now because I have to pay my son's childcare. They said 'we are so sorry we can't give you your money today as your money doesn't go in until next week. I said, 'this week is my pay day and I want my money now' and I made a smart remark that I'm going to rob the [...] Bank and the police came and thought that I was really going to rob the bank and arrested me that day.

Emma's case demonstrates the extreme levels of state violence that underpin neoliberal authoritarian workfare governance. The state, as Emma's description above reveals, will use extensive measures to bring shame on disabled people to ensure compliance with its neoliberal authoritarian workfare governance. Rather than seek to redress the harmful injustices that Emma has experienced, the state uses its full force to ensure compliance with a system that has forced Emma to this position. Of course, Emma may have had other choices, but the material destitution of her real life, her commitment to caring for her young son and the constant shame she has endured under workfare governing institutions rendered almost all other options futile. As Sayer (2005) argues, the shame that is caused by severe structural deprivation and stigmatisation often results in individual acts of violence. Unfortunately for Emma, the consequences of highly individualised acts of violence, result in state aggression and further violence, and the state is more than willing to use disabled women on workfare, such as Emma, as public examples to produce and reproduce violent, authoritarian neoliberal workfare regimes.

Concluding thoughts

In this chapter we have explored the way in which the implementation of workfare-based welfare reform in Australia and the UK has utilised shame as a form of neoliberal governance. The chapter illustrates the ways non-market actors signify significant fiscal risk for the future health of the nation. The penetration in the public imagination of statistical doom and gloom associated with disabled people on welfare aims to deepen and normalise regulatory regimes that advance the neoliberal market society. Disabled people, a particularly targeted group, are being subjected to activation technologies that are frequently re-classifying them (often without any accompanying change in their condition) as insufficiently or inadequately disabled to remain as *exceptions* to the demands of a neoliberal citizenship that is premised upon able-bodied, masculine notions of contribution and individual responsibility. The experiences of our respondents reaffirm that, despite the development of the disability rights movement with its emphasis on a collective identity based on pride with claims couched in the language of rights, 'fundamentally disability is defined by public policy. In other words, disability is whatever policy says it is' (Hahn 1985, p. 94). In this chapter we have provided an alternative reading of the statistical disability panic employed to drive neoliberal welfare reform. Through the narratives of the disabled people in our study we have illustrated the central role shame plays in classifying and (self) regulating the behaviour and emotions of welfare recipients.

While shame has long held a position of close proximity to disability, with the onset of neoliberalism and its latter intensification vis a vis, austerity, the experience of shame for disabled people takes on a qualitative new form. Shame and its attachment to disability has now reached new political heights; no longer are disabled people discursively positioned as the deserving poor. The crafting of neoliberal political discourse to legitimise disability retraction pervades historical discourses of charity and pity. Moralising discourses of

charity and pity were historically situated to keep disabled people in place, contained within the walls of the institution, removed from the streetscape. Neoliberal political discourses of shame aim to mobilise disabled bodies as active members of the precarious low wage labour market, compelling them to compete with few labour protections and regulations. Contradictorily, as many of the participants reveal, ongoing public shaming often resulted in a counter response – to hide from the world and the violence that it entails with neoliberal intensification – to escape from the qualitatively new risks created for disabled people at the scale of the everyday.

Processes of neoliberal reclassification undermine the wellbeing of disabled people subjecting them to damaging forms of psycho-emotional disablism. Disabled people are forced into highly precarious positions as they negotiate the labouring affect effects of neoliberal shame. Insecure and low wage employment or, the random and unexplained withdrawal of benefit income become the everyday, mundane effects of neoliberal inter-scalar violence. Moreover, the manner in which the reforms of disability-based entitlement to welfare benefits has been framed demonstrates the ways in which stigmatization is employed as a form of governance to legitimise the dominant mantra of 'there is no alternative' to either welfare reform of the shaming of disabled people. The misrecognition of the structural disadvantage experienced by disabled people enables popular discourse to vilify disabled people, either as a result of their reclassification as 'faux' disabled people (Roulstone & Morgan 2014) or their continued failure to achieve the neoliberal imperative of self-sufficiency.

Thus through this stigmatizing, shaming and shameful reclassification disabled people are 'mobilized to do the ideological dirty work of neoliberalism' (Tyler 2013, p. 211) accepting the blame and resultant shame that accompanies this. This refocusing of an invalidating gaze through the lens of shame exacerbates the exclusion of disabled people. More overt forms of socio-spatial segregation such as the residential institution or day centre, have given way to more nuanced and complex forms of exclusion and regulation. The

isolation of disabled people in their own homes serves to individualise the political nature of emotions which are to be endured away from opportunities for collective opportunities to resist and subvert the affects of shame. The affect effect, is to keep disabled people, in place.

Acknowledgements

Note

1. All the names used in this chapter are pseudonyms.

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Introduction

Rural spaces have long been viewed as idyllic with therapeutic landscapes and strong cohesive communities and the rural idyll remains a powerful myth in the British imagination. Popular culture is scattered with examples of 'escaping to the country' whether to escape the prying eyes of urban society or to enjoy the benefits of rural environments and lifestyles. As in many other spheres disabled people have been largely absent from these imaginings and from rural scholarship. The writing [of]the rural (Cloke et al 1994) that has taken place in recent decades exposed myths and stereotypes about rural lives that have masked diversity and concealed social problems. In response to this there has been a focus on neglected rural identities and on the myriad of factors that influence, shape and disrupt them. However, despite considerable interest in 'hidden others' (Cloke and Little 1997) disabled people remained for the most part out of sight in academic writing about the rural.

This chapter explores the contradictory space of the rural for disabled women enduring the harsh realities of neoliberal welfare reform by drawing on interviews undertaken in Spring 2012 with disabled women living in rural towns and villages in Northern England. Building on an Australian study (Pini and Soldatic 2012) we wanted to hear about their experiences of involvement in rural communities and activities, of work and leisure, of disability support, and the effects of changing

disability policy upon them. For all of the women their rural location played an important role in shaping their identity as disabled women, predominantly living with chronic long-term conditions. The contradictory nature of the rural, at times exasperating in its inaccessibility and potential for isolation was also the source of welcome seclusion as well as community. Belonging in rural places was complex where the very features most valued by the women, such as quietness and access to open natural spaces, were also the source of considerable labour as the women sought to mediate the effects of distance, solitude and limited access to other disabled women. What in particular stood stood out from all the interviews were the ways in which increasingly hostile narratives about disability and welfare were permeating the rural spaces the women occupied and the emotions this provoked for them and their families.

Emplacing Disability: Writing in the rural

The renewed social geography and sociological interest in rural lives since the early 1990s has opened 'new windows into the social and spatial processes of boundary formulation in rural areas whereby some groups and individuals are separated out from society as being different, often deviant' (Cloke and Little 1997:3). As the title of Cloke and Little's edited collection *Contested countryside cultures: otherness, marginality and rurality* demonstrates, a paramount concern of this rich body of work is on identifying and exploring the contested nature of identities in rural settings. This has resulted in more multi-layered, complex, understanding of the characteristics of the rural. As Cloke and Thrift (1994: 1) proposed the notion of the rural 'as a fixed location has faded' replaced by a concern with the ways in which rural spaces and places are socially constructed and mediated. Central to this approach are 'people's everyday interpretations of rural places and ideas of the rural' (Jones 1995:35 cited Little 2002:11) that challenged the emphasis upon 'Mr Average' in earlier rurality literature (Cloke and Little 1997) or as Cresswell

characterised it 'in the search for the "essence" – "difference" ha[d] no place"' (2015:40). There is now a burgeoning literature (cf Cloke and Little 1997; Little 2002; Bryant and Pini 2011) that considers in depth the experiences of gender and rurality and its intersections with other forms of diversity. However, as the introduction to this book sets out, disability remains marginal from these writings, particularly in comparison to other areas of intersectionality (Briant and Pini 2011:101).

Similarly Disability Studies is largely silent on rurality and the experiences of rural disabled people and of disablism in rural settings. For example, the otherwise wide ranging *Routledge Handbook of Disability Studies* (Watson et al 2012) contains only passing reference to rural economies in developing countries (Roulstone 2012; Shakespeare 2012). However, there has been considerable interest emerging in disability studies about the ways in which disabled people experience and are influenced by space and place which provides a lens through which to examine the experiences of rural disabled women. The central focus of this literature has been the constrained nature of disabled people's experiences of spaces (cf. Butler and Bowlby 1997; Imrie 1996) initially focusing upon the built environment but latterly broadening to consider a wider range of spaces and places and in particular the ways in which legislation and public policy 're/map, re/frame and re/shape divergent spatial relations and realities for disabled people' (Roulstone et al 2014:2).

Kitchin (1998) argued that disabled people are frequently 'out of place', that is, they live, and move, within spaces that are structured in ways that create 'landscapes of exclusion' for disabled people. This can be the direct result of physical barriers that prevent or limit their access to particular spaces but is also the result of 'ideological messages…that are inscribed in spaces…[that tell disabled people] 'you are out of place', 'you are different' (Kitchin 1998:351) rendering

spaces unwelcoming and uncomfortable. Thus as Chouinard et al note 'mainstream spaces are often disabling, in emotional as well as material ways' (2010:4). This can be the consequence of implicit assumptions that disabled people would or should not be using these spaces that become embodied in the fabric of spaces. Examples here include the lack of accessible provision or alternative forms of provision that are stigmatising or second class in their nature, such as having to use a service entrance to enter the building (Reeve 2014). This experience is captured in the concept of *psycho-emotional disablism* coined by Thomas (1999) to describe the way in which disabled people's 'psycho-emotional well-being' is undermined by exposure to disabling barriers and attitudes creating internalised oppression and eroding self-confidence.

As the structure of public spaces is gradually changing, it is increasingly the case that it is psycho-emotional forms of disablism that are restricting and limiting the participation of disabled people. The presence of anti-discrimination legislation and greater awareness of disabled people, particularly as customers, has broadly improved the physical access of public places usually with accompanying 'visible signs of disabled people's growing place within the wider tracts of non-disabled space' (Hansen and Philo 2007:409). However, a negative consequence of these developments has been an assumption that because specific accessibility regulations have been met a space is now accessible to disabled people (Hansen and Philo 2007; Titschkosky 2011). This fails to acknowledge that such regulations tend to be minimal requirements that are subject to the *reasonable adjustment* proviso of British disability equality legislation. Thus what is deemed reasonable provision for disabled people often fails to adequately make a space fully accessible and inclusive (Roulstone and Prideaux 2009). In addition it is often the case that the access needs of disabled people can be contradictory and the focus remains on people with physical and sensory impairments rather than people with

learning difficulties or experiencing madness, distress or neurodiversity. Therefore, disablism has become more insidious as public spaces appear to become more accessible for disabled people while the experience of moving through them becomes increasingly hostile and problematic as the next section explores (Reeve, 2014; Roulstone and Morgan 2014).

Standing fast? Rural disabled women

The unleashing of 'disability anxiety' generated by neo-liberal discourses as a response to the global financial crises has created a toxic environment for disabled people (Soldatic and Morgan 2015). The cost (or burden) of disability particularly in relation to welfare spending has been cast as unaffordable and its reduction a necessary element of the UK Government's programme of austerity. A central element of this programme has been the whipping up of a moral panic over disabled people's 'dependency' on welfare provision (Roulstone 2000) and a steady chipping away of their status as 'deserving' recipients of state support (Garthwaite 2011). Processes of reclassification are being used to shrink the disability welfare category (Roulstone 2015) and are accompanied by considerable political and media attention on 'faux' disabled people who are described using derogatory language like 'cheat, scrounger or fraud' (Briant et al 2013:874). People living with 'hidden' impairments or more contested conditions are particularly vulnerable to being constructed as undeserving and their receipt of benefit explained in ways that were 'personalised and pathologised' (Roulstone and Morgan 2014:72). As Elder-Woodward contends anticipating and being subject to [re]assessment processes 'is truly undermining the feelings of security and well-being amongst its recipients; let alone the material practicalities of their well-being' (2014:312).

Always a more complex, contradictory and disabling space than traditional literature and popular imagining suggests the rural as a place of refuge was under threat for the disabled women we talked to. As the excerpt from *Passing Landscape* by Hilde Domain conveys, rural disabled women value the rootedness their rural lives provide while at the same time acknowledging its limitations in providing access to collective disabled identities that provide succour from the harsh individualising and penalising narratives of welfare reform. The chapter uses Jenny's[4] story to explore the contradictions and the complexity of the rural for disabled women.

Jenny, a young woman with a long-term chronic illness, has ambivalent feelings about the rural setting where she grew up and where she returned, and continues to return, when her health deteriorates. The countryside provides access to the quiet open space she craves and to her parents who provide a safety net of emotional and practical support. The small rural hamlet they live in provides sanctuary from the stress and pressures of life in the local town where she spends time with her boyfriend. Town supplies access to a wider social circle and importantly for Jenny to a disability arts group, where she finds a welcoming community and network of support. There is also the opportunity to be 'invisible' and 'anonymous' which is impossible at home where she and her family are well known. However, Jenny is not free to navigate her own path between town and country. A range of factors contribute to create a growing sense of precarity and insecurity in her life. Looming largest were the impending changes to disability benefits and as she anticipates the arrival of the 'brown envelope' that will call her for reassessment the spectre of welfare reform is a constant presence for Jenny's.

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[4] Jenny is a pseudonym.

Hiding, Isolation and Solace: Jenny's story

Jenny is in her mid-thirties and at the time we met was living in a rural part of Northern England. At 18 she moved away to university, returning home briefly after graduation before moving out and living overseas. While Jenny was living abroad she had a breakdown. After this she decided she wanted to change careers and so, primarily for financial reasons, decided to return home to live with her parents while she set up her own business. Looking back Jenny recognised that she was '*heading for another breakdown*' and that '*taking care of [her] health*' was a factor in the decision to return home to the rural area she had grown up in and where she is able to 'be herself'. It is home, the place where she 'feel[s] a sense of attachment and rootedness' (Creswell 2015:39) both to her family but also to the countryside they live in.

At the time of the interview (Spring 2012) Jenny was in receipt of welfare benefits including income support, Employment Support Allowance (ESA) and Disability Living Allowance (extra costs benefit) (DLA). She had been living back with her parents for a number of years and described herself as '*functioning much better*' than when she had returned home. Jenny uses her DLA to run her car and pay for things like '*self-care and social life*' that contribute to her wellbeing and '*which is good for [her] health*'. She is very clear about the contribution this makes to her life:

It sound kind of trivial, but it's not, for me it isn't trivial, things like being able to get my hair done and buy …vitamin supplements. And what else? And being able to pay for adult college courses as well. And being able to meet my friends for coffee is a really good one.

One of the most important things for Jenny about receiving her benefits was that it enabled her to be financially independent and not reliant on her parents to fund things like her car as she has been before she was awarded her benefits. Like many other rural dwellers her car is a vital resource for Jenny as it enables her to visit friends and family, and to access services and other forms of support from the isolated '*dirt track*' where they live. She described the way in which being reliant on her parents for money '*exacerbated a feeling of depression]* and '*made me feel bad …a bit inadequate*'. Being able to use DLA instead means she feels '*like I've got a bit more …dignity is the word, you know I feel like I've got a bit of dignity*'.

For Jenny the countryside provides respite from the stimulation and close quarters of busy urban settings, which she can find challenging particularly when unwell. She describes the location of her home as ' … *brilliant, it's just great. The quiet, well it's great and it's not great, but my instant feeling, is yeah, it's the right place to be. Because it's quiet and it's beautiful and it's just peaceful, you know*'.

The countryside is a place of withdrawal and seclusion during periods of illness when her parents provide the practical and emotional support she needs. Being in the countryside allows Jenny the space she craves at certain times. She talked about the way in which rural spaces allow an opportunity for isolation and solitude, in the positive sense of choosing to be by herself and away from other people when she wanted to. A local horticulture project Jenny was involved with offered this flexibility because '*you could say 'I'm feeling a bit confined, can I go and work at the other end of the turnip field' or whatever*'. This is a stark contrast to working part-time in a shop or volunteering in a charity shop in town both of which were flexible in many ways but had the potential to be over stimulating which would exacerbate Jenny's symptoms.

As for many of the women we talked to Jenny's rural home also offers a hiding place from the 'neoliberal acts of shaming' inflicted on disabled people during their engagement with welfare benefit (re)assessment processes (Soldatic and Morgan 2015:14). Jenny is well aware of the ways in which disabled people are increasingly constructed in political and policy discourse as 'faux' or insufficiently disabled to deserve welfare provision (Roulstone and Morgan 2014). For Jenny and the other rural disabled women we interviewed '*the pressures …from the media and government policy*' are permeating what had previously been spaces of respite and sanctuary. Home as a site where disabled women can hide from this public shaming has been undermined as the private, intimate spaces of home and familial relationships are penetrated by the 'brown envelope' that signifies their assessment of eligibility for disability benefits (Reeve and Soldatic 2012; Garthwaite 2014; Soldatic and Morgan 2015).

All of the women were acutely aware that the intense surveillance they felt under during welfare assessment processes was replicated in their everyday lives and interactions. As Hadley suggests disabled people are 'unwittingly or unwillingly compelled to play certain roles to shore up the mechanics of a public space from where they themselves are often ostracised or excluded' (2014:2).

Jenny is very conscious of the impact of being ill, or more accurately being seen to be ill and of people's responses to her, on her parents. As she put it '*you want your parents to be alright, you want people to think well of your parents, that reflects off you*'. So for Jenny the rural was not necessarily an accepting space where she belongs unconditionally, despite it being where she grew up and the long-term location of her family home. Her sense of belonging was contingent on behaving in certain ways or for *passing* as 'normal' when she was outside her or her wider family's homes. Jenny reflected that she '*been fortunate …not to have behaved in an anti-social way or behaved in a strange way*' when she was living at home. She

was acutely aware that some of her behaviour in the past would have been construed as '*weird*' or '*strange*' by her neighbours and had that behaviour happened at home '*it might be different*'. Jenny's feeling of belonging in this rural space, of it being home, was thus conditional on a series of standards she had imposed on herself which have a psycho-emotional impact on her sense of wellbeing (Reeve 2012) as she seeks to perform her identity as an 'acceptable' and 'deserving' 'normal' women. Jenny is very aware she often has the option of 'passing', that is performing in a way that means others presume she non-disabled. She describes her 'success' in doing so by highlighting the way in which when at the local supermarket she '*often gets asked 'are you having a shopping day today' You know, is it your day off?*' which she contrasts with the experience of her friend Brian who says ''*they never bloody ask me', … 'it must be obvious that I'm sick*''.

The relative isolation of Jenny's surroundings allows a spotlight to fall upon her. As Parr et al note from their research on the experiences of people with mental health problems living in the Scottish Highlands personal and familial histories 'can be collectively known, remembered and narrated by other rural community members' (2004: 403). In one way this provides Jenny with a form of social capital, she and her family are established as members of their rural community but at the same time there is no space for anonymity in the sparsely populated hamlet she grew up in. As Jenny points out '*the thing is I don't see people very much [at home] so when I do see people I'm more aware of how I present myself*. Thus the isolation of the rural is multi-faceted. It can be sustaining and nurturing at times for Jenny while at other times being alone leaves her feeling detached and remote from many of the things that contribute to her well-being.

As her relationship with her partner Paul developed Jenny has been spending increasing amounts of time in the nearby large town where he lives and where she is able to '*get out and about*' doing things like adult education classes and a disability arts group. Spending time in town offers greater potential for connections, particularly with friends and people who share similar experiences of disability, of not being in work and of receiving benefits that Jenny has been unable to make in the rural area she lives in with her parents. Amenities and services are inevitably at a distance and Jenny spends limited time with people outside her immediate family when she is at home.

Jenny wanted to be flexible in where she spends her time to allow her to respond to how she was feeling. She would like to have '*the option of going home and being a bit looked after and being in a rural area, y'know being in the countryside. But ideally if I wanted to spend two weeks at a time here [town], I would.*' However, the regulations governing her benefits means Jenny is not free to navigate her movements between her rural home and the life she is building with her partner in town in the ways she would choose. Jenny is very conscious her eligibility for benefits is greater when she lives with her parents than if she formally moved in with her boyfriend when '*because he's my partner, I wouldn't be entitled*' to some of her benefits. Instead of spending time in the places that best enable her to manage her health and wellbeing Jenny works within the constraints of the welfare system:

How do I work it out? I spend, officially because of the benefits people, I spend about four days, three-four days here, three-four days over there. Before Christmas I was spending like two weeks at a time here [Paul's house] and then, the reason why is because there was stuff going on at the weekend and I was well enough to do stuff on the weekend. At the moment I'm going back to my parents

on the weekends and that's partly, well a lot of it, is because of my benefits basically.

She must, and must be seen to be, adhering to the requirements of welfare conditionality by seeking to progress and move out of welfare dependency. Here, given paid employment is not currently viable for Jenny, the option is to become prematurely financially dependent on her partner before they independently reach a stage of permanent commitment. Jenny was acutely aware of the pressures this financial dependency had placed on some of her disabled friends when they became reliant of their partners income. Like many other disabled people Jenny is under great pressure to make choices when the future is unknown. She wants to retain the flexibility of where to live (and by implication her benefit entitlements) as a mechanism to enable her well-being and in response to a relationship that was still evolving. In times of 'disability anxiety' where disabled people are cause and symptom of the financial crises it is shameful to be strategic in your engagement with welfare provision. To do so is to act fraudulently or 'cheat' and to call into question your status as a genuine and deserving recipient of welfare provision. Jenny is very mindful of the surveillance benefit recipients are under:

Well I lie awake at night going 'oh my god', the people who I get the money from, is that going to change, is someone spying on me now 'cause I'm here [boyfriend's house]. You know… but because I have mental health problems, its huge, and also because its such a paranoia-inducing system

The negative impact on her wellbeing is tangible in the way Jenny talks about how the uncertainty makes her feel, '*I was petrified is the word. I was just scared.. The scaredness is worrying that they're going to take away my benefits, that's where the fear comes from*'.

There are particular hazards for those, like Jenny, with fluctuating or hidden impairments, whether negotiating the benefits assessment process or day-to-day interactions with other people. Jenny now has a diagnosis of '*bipolar disorder'* but describes a period when she had a much more '*tentative diagnosis'* where letters from her GP to her psychiatrist would say '*Jenny believes she has bipolar disorder*' or '*I am putting Jenny on medication to treat bipolar as these are the symptoms she feels she has'*. She described feeling taken aback being described in these ways and relieved when the diagnosis became 'formal'. It allowed her to say '*it's not me, its an illness*' and significantly for her material and emotional well-being it 'gave [her] access to benefits and to a language that describes her in a way the people with whom she interacts understand.

Having a formal or officially sanctioned diagnosis is of critical importance to Jenny as it allows her to craft a way of presenting herself and justifying her situation. She recalls initially saying '*I don't work', y'know, which is like 'ooh she's an heiress' type of thing''* which was then qualified with '*I've got bi-polar disorder'*. Later Jenny refined this to talk about not working '*because I've got a chronic illnes*s' although she continues to '*caveat that with 'I spend my time at the adult college doing courses'*. It is clear Jenny is very conscious about presenting her condition and situation in a way others will understand but also in anticipation of assumptions about mental health diagnoses and of welfare recipients. Jenny illustrated the considerable psycho-emotional labour she has invested in getting her presentation 'right'

All this thinking… about how to present things, it sounds, again, these things I'm telling you, they sound like I've spent such a lot of effort thinking these things through for something that's actually quite trivial like an exchange but I've had to. I've had to really think these things through.

The exception from the requirement to work provided by welfare benefits is highly precarious. (Soldatic and Grover 2012; Grover and Soldatic 2014) Jenny was anticipating being reassessed for her employment and support allowance and as part of the implementation of the transition from DLA to the Personal Independence Payment (PIP). She is highly anxious about the outcome of these processes not least because '*everything I'm hearing is from the media, I've had no communication from the benefits people*'. Jenny's well-being is undermined as she continues to '*feel pressure from people that I should get back into work because I present quite well sometimes and when I'm ill people don't see me*'.

For women like Jenny the experience of living with fluctuating and unseen impairments is at odds with the binaries that dominate in welfare and media discourses. Individuals can be hard working and striving or shirkers and scroungers (Garthwaite 2011), disabled or non-disabled, sick or healthy, fit for work or unfit for work. There is no room for manoeuvre, for periods of progression and relapse instead women like Jenny have to find ways to negotiate these contradictions. Jenny found not being in paid work much more visible in the rural setting where she was very conscious that '*lot of people work or are retired and I'm not really in the same boat as them*'. Whereas she '*can go into town during the week and everybody's on benefits in town so its like 'wahey'*''. From Jenny's perspective it was much more 'normal' to be out and about in town during the day.

This experience was mirrored in Jenny's attempts to access peer support. In the rural area she had joined a local impairment specific support group. This provided access to information about the condition and self-help skills but it was '*full of retired people*' with whom she felt she '*didn't have very much in common with*'. In contrast the disability arts group Jenny attends when she is in town provides access to the type of disabled collectivities envisaged by Finkelstein (1987 cited Roulstone and Morgan 2009:337). Jenny gets to '*hang out with some people in my*

situation and it did loads for my confidence and self-esteem'. In the companionship of the arts group Jenny finds solace in their shared experience of living with chronic illness in a disabling society. They are 'all in the same boat' and can ' *just talk about common experience…that you can't talk about with other people and it makes you bond very closely with these people just because these are conversations that you don't get with anybody else?'*.

As with the individual interview the overriding concern of the group was their fear about the impact of welfare reform. It was clear the group members had accumulated a great deal of expertise about the welfare assessment processes and regulations, which they used to advise each other. *The Impact of Welfare Reform in Scotland* study highlighted the particular importance of peer support networks as a form of collective support in the face of welfare reform. (Graham et al 2015). Their findings emphasized that 'the primary benefit of these groups was to share experiences of, and see how others had experienced, welfare reform' (Graham et al 2015: 36). The project also identified a tension at the heart of these groups. Meeting together to provide mutual support can reduce the sense of being alone or isolated for many of the participants but there is also the potential to raise anxieties about what is to come. Jenny had expressed concerns about the impact of spending time with other people who were unwell *'I'm just worried about the people who are ill and they'll end up draining me more than I end up getting support from it'*. This was less of an issue in the arts group compared with the rural impairment specific support group she had attended at home. An important aspect of the arts group was flexibility around attendance, the approach was explained at *'it doesn't matter if you don't turn up and that's what keeps it going'*. They were not at risk of losing their place if they were unable to attend, a familiar experience of statutory funded projects.

There are significant challenges involved in bringing rural disabled people together to form peer support groups or networks. The arts group met in town in part because it had been instigated by a couple who lived there but also because of accessible transport links and the sense it gave the group of *'being part of the community and all, not just out on a limb'*. As Jenny reflected *'I wouldn't commute from there [rural area] if I didn't stay over at my boyfriend's'*.

In their national study of user-led disability organisations Barnes and Mercer (2006) highlighted the additional resource and other costs associated with covering large geographic areas including lack of accessible transport and travel time. While Maynard-Campbell et al in their survey of disability peer support found that a factor in the disintegration of a rurally based disability consortium was the impact of an often remote rural area 'where it is hard to get together and "spark off" each other' (2007:62). Given the levels of welfare retrenchment and swingeing cuts to local authority spending it is likely to become significantly more difficult to bring disabled people together for mutual support in rural areas.

Concluding thoughts: Austerity permeating rural spaces

In seeking to exercise choice in her movement between rural and urban settings Jenny was unusual in the group of rural disabled women we talked to. The majority of the women wanted to live and stay in rural areas although for some this was not possible for a range of financial and practical reasons. Like Jenny they all highlighted aspects of their rural settings as central to their sense of wellbeing and often to their health. They also recognised that the very factors they valued in rural areas, such as the remoteness and what might be described as the therapeutic nature of the countryside had the potential to isolate them and leave them particularly dependent on themselves or close family and without access to peer support.

Jenny works hard, often in hidden ways, to create the balance she has learned she needs to manage her condition and to make a contribution to her family and communities. Jenny's strategies for managing her illness are directly undermined by the precarious uncertain situation she is in. She is caught in a double bind. Policy rhetoric echoes the disabled people's movement's calls for choice, control and participation in mainstream society. But for Jenny mainstream spaces and places can be over-stimulating and infused with neo-liberal ableist assumptions about how disabled people should participate within them. Echoing a line in Hilde Domin's poem *Passing Landscape* Jenny needs to 'be able to go a away and yet be like a tree rooted in the earth'. The toxic hostile atmosphere generated by neoliberal welfare reform is to be endured. As a report produced by Demos at the same time as our interview with Jenny acknowledged, and we now know 'for disabled people, the worse is yet to come' (Wood 2013: pp). Jenny's rural roots provide her some protection allowing her to stand fast.

Acknowledgements

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