Work and Society:

Places, Spaces and Identities

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**CHAPTER 7**

**WORK, RESILIENCE AND DISABILITY:**

**‘CRIPPING’ THE NORMS**

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This chapter sets out to explore the interconnections between resilience, work and disability. We suggest that what disabled people tell us about work and resilience requires us to think again about the work, disability and resilience in ways that challenge the often unspoken, but disabling, assumptions. This reflection is particularly important at a time when disabled people are excluded from the work place while simultaneously facing cuts to out of work benefits. Our approach draws on an idea from the disabled people’s movement that encourages us to ‘crip the norms’ (Goggin & Newall, 2004) in relation to resilience, work and disability.

*Why Resilience?*

This paper was from work carried out as part of a wider project carried out by the authors called: *Resilience in the lives of disabled people across the life course.* (For more information about the project visit: http://disability-resilience.posterous.com/). The project, commissioned and funded by the UK disability charity, Scope, had the following aims:

* to explore what resilience means to disabled people at different stages across the life course;
* to explore how resilience, or a lack of it, has affected disabled people’s ability to negotiate challenges and make the most of opportunities in their lives;
* to understand what works in building resilience amongst different groups of disabled people;
* to develop a toolkit for use by Scope’s policy and services functions that outlines what Scope means by resilience, what does or doesn’t work in supporting people to become resilient, and what we can do to build resilience in disabled people throughout the life course.

The research was carried out in four phases: a literature review; a life story phase in which we interviewed 43 disabled people (aged 5-83) and parents/carers of disabled children; a series of focus groups with disabled people of working age, parents/carers of disabled children and disabled young people and, finally, a Community of Practice phase (Lave & Wenger, 1991) which brought together disabled people and researchers to develop a toolkit for use with disabled people and in Scope’s services (For details about the project and methods visit: http://disability-resilience.posterous.com/).

Given the current climate of economic restraint and a shrinking state which is inevitably impacting on the services and support disabled people can access (Runswick-Cole & Goodley, 2012), a study which focuses on understanding better what resilience is and how it develops in the lives of disabled people is timely. Throughout the study, disabled people’s access to and engagement with work emerged as a key issue impacting on their sense of resilience.

*Thinking About Resilience*

In public discourse, resilience is perhaps most often described as the ‘ability to bounce back’ (Young et al., 2008). There is an implicit assumption that a person must have experienced adversity, or overcome a significant barrier, in order to be described as resilient. This lay understanding of resilience is rooted in psychological approaches to resilience which have characterised resilience as ‘a class of phenomena characterised by *good outcomes in spite of serious threats to adaptation of development.’* (Masten, 2001, p.228) or as ‘the positive pole of individual difference in people’s response to stress and adversity’ (Rutter 1987 cited in Young et al., 2008, p.41). Resilience is spoken of in relation to risk so that individuals who have not been exposed to risk but are judged to be ‘living well’ are not necessarily considered to be resilient whereas those that have been exposed to risk are (Masten, 2001).

*Resilience and ‘the Norm’*

Resilience is often discussed in the context of developmental child psychology where resilient children are judged to have met ‘normal’ developmental milestones despite ‘adversity’. As Masten (2001, p.235) says resilience is conceptualised as commonplace phenomenon arising from ‘the every day magic of ordinary, *normative* human resources in the minds, brains and bodies of children, in their families and relationships and in their communities’ (Emphasis added). However, as we argue elsewhere (Runswick-Cole & Goodley, 2013), concepts of resilience underpinned by ‘norms’ are clearly problematic when working with disabled people who are often viewed by medical professionals and by wider society in terms of their impairments and, by default, considered not to develop normally, nor to share personal characteristics with others without impairments. The presence of an impairment has, in and of itself, therefore excluded some disabled people from the category of ‘resilient’.

Furthermore, by focusing on resilience as the product of an individual person’s *normal* development and adaptation in the face of adversity, if a person fails to develop ‘normally’ or to adapt, there is an implicit assumption that the person is deficient in some way or is, perhaps, weak willed or lacking in ‘inner strength’. People who fail to bounce back are seen to be wanting and often the responsibility for, or cause of this lack is seen as belonging to the individual themselves. The consequence of this is that individuals are then blamed for failing to possess the necessary personal characteristics needed to overcome adversity.

*The Social Production of Resilience*

Understandings of resilience as a personal characteristic of the individual have been challenged in a number of ways (Ungar, 2004, 2007). First, the direct causal relationship between the experience of risk and the emergence of resilience and been challenged. Traditional approaches to resilience research seem to suggest that there is a predictable relationship between risk and resilience so that when normal development is said to have occurred, despite the presence of adversity or risk, then the person is judged to be resilient. Interestingly, in the lives of disabled people, just as the presence of an impairment has been used to exclude disabled people from the category of resilient, as we saw above, the presence of an impairment can also mean that disabled people who meet cultural norms (or exceed them) are automatically seen to have overcome ‘adversity’ and to be resilient. This judgement is made despite the fact that not all people living with impairments regard their impairment as an experience of adversity. Indeed, many people with impairments wish to affirm their identity as a disabled person stressing the positive aspects of living with impairment (Swain & French, 2000). Clearly, what constitutes ‘adversity’ is contested. Furthermore, as Boyden (2001) points out, the relationship between adversity and resilience is unpredictable. As such, the relationship between risk and resilience is chaotic, complex, relative, and context dependent (Boyden, 2001).

Crucially, for us here, Ungar (2007) has highlighted the global and cultural contexts in which resilience emerges. He points out that outcomes that might be seen as ‘risk factors’ in one context, such as leaving school early or becoming pregnant at a young age, are culturally embedded, reflecting the values of Global North countries (Ungar, 2007). Indeed, in a different context, the same outcomes might be seen as evidence of resilience, rather than risk-laden events. By paying attention to the cultural contexts in which resilience is said to emerge, Ungar (2007) reveals the ways in which resilience is socially created.

*The Social Production of Disability*

As we have described elsewhere (Runswick-Cole & Goodley, 2012), we are attracted to Ungar’s (2004, 2007) arguments that resilience is socially produced because we are already convinced by accounts that reveal the social production of disability (Oliver, 1990). In 1981, Mike Oliver first used the phrase ‘the social model of disability’. Oliver (2004, p.18-19) was trying to give people ‘a way of applying the idea that it was society not people with impairments that should be the target for professional intervention and practice’. In contrast to medical and individual models of disability, the social model of disability aims to move the focus away from the limitations of impaired bodies and to look instead at the difficulties caused for disabled people by disabling environments, barriers, attitudes and cultures. The aim, then, is to expose and remove barriers to disabled people’s participation in all areas of life including: education, work environments, the benefits system, health and social services, housing, transport and the devaluing of disabled people in the media (including newspapers, films, television and the internet) (Barnes, 2008).

By focusing on the social production of both resilience and disability, we can see that creating environments which support resilience can never simply be a matter of building individual capacity or family support, it must also be a case of challenging social, attitudinal and structural barriers which threaten resilience in the lives of disabled people (Young et al., 2008). Indeed, as Ungar tells us, there are ‘unique pathways to survival’ (2005, p.91) and that ‘[p]athways to resilience are a many splendoured thing’ (2007, p.19). So, we need to be wary of approaches to resilience building that assume that only a rational, developing, striving individual who has done well against the odds can be judged to be resilient.

*Networks of Resilience*

We suggest that by taking a social constructionist approach to resilience and to disability it is possible to think about resilience in ways that are more enabling in disabled peoples’ lives. Drawing influence from Ungar (2004, 2007), we have conceptualised resilience as a network made up of the following resources:

1. Material resources: Availability of financial, educational, medical, and employment opportunities or assistance, as well as access to food, clothing, and shelter to meet basic needs.

Exemplary question: How does access to employment opportunities and associated resources influence resilience?

1. Relationships: Relationships with significant others, peers, adults and children within one's family and community.

Exemplary question: how do relationships at work impact on a person’s sense of resilience

1. Identity: Personal and collective sense of self and purpose, self-appraisal of strengths and weaknesses, aspirations, beliefs and values, including spiritual and religious identification.

Exemplary question: How does a positive sense of self emerge through work?

1. Bodies: the influence of one’s body – including impairment - in relationships with others;

Exemplary question: How does the body influence access to work and relationships at work

1. Power and control: Experiences of caring for one's self and others; the ability to affect change in one's social and physical environment in order to access health, educational and community resources.

Exemplary question: To what extent do disabled people have power and control over their working lives?

1. Community participation: taking part in one’s community through a host of activities and engagements;

Exemplary question: how does work (or the lack of work) impact on meaningful community participation?

1. Social justice: Experiences related to finding a meaningful role in community and a sense of social equality.

Exemplary question: how do disabled people experience social equality at work

1. Community cohesion: Balancing one's personal interests with a sense of responsibility to the greater good; feeling a part of something larger than one's self socially and spiritually.

Exemplary question: How does work impact on a sense of community cohesion in the lives of disabled people?

These resources are represented visually in the figure below:

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Figure 1 Network of resources (Runswick-Cole & Goodley, 2012)

These categories are not discrete entities, but are overlapping and interconnected.

*The Economic and Cultural Context*

This research was carried out in a time of economic recession in England. Clearly, the impact of economic cutbacks has fallen disproportionately on disabled people (Roulstone, 2011). This is in part because of the number of disabled people who are not in employment. The Office for Disability Issues found that only 48% of disabled people are in employment compared with 78% of non-disabled people (ODI, 2011). The Children’s Society (2011) found that four in ten disabled children live in poverty. Only 16% of mothers of disabled children have employment, compared to 61% of other mothers (Contact-a-Family, 2009).

The state benefit system is also under going radical change. The Coalition government has made a commitment to cut Disability Living Allowance (a tax free benefit to help disabled people with extra costs) by 20% despite the lack of any evidence to suggest that there is this level of over claiming of the allowance (Grant, 2011). The government will replace the Disability Living Allowance with a Personal Independence Payment in 2014, the impact of which is, as yet, unclear. In addition, the government has begun to migrate Incapacity Benefit claimants (Incapacity Benefit is an out of work payment for people who cannot work because of illness or disability) onto Employment Support Allowance or other moving to work benefits (Disability Alliance, 2011).

The new gateway to work benefits is the Work Capability Assessment (WCA) (Grant, 2011) a medical assessment based on a points system that determines who is ‘ready for work’ or not. The WCA represents an increasing focus on the *medical* aspects of disability, in contrast to *social* approaches. As a result, the WCA fails to attend to the social and practical factors that affect disabled people’s lives. The outcome of the assessment is that disabled people are judged ‘ready to work’ or part of the ‘support group’ of people who are considered unable to work and will, therefore, be supported with benefits. It is expected that people with ‘moderate learning disabilities’, who may previously have been in receipt of Incapacity Benefit, will be placed in the ‘ready to work’ category and those with complex needs in the ‘support group’ and will receive benefits and not be required to seek work. The danger is that a medical assessment alone will be unable to take into account wider barriers to disabled people’s access to work including affordable and accessible childcare, appropriate housing and confidence levels. As a result, a medical assessment will mean that some disabled people, who face considerable barriers to work, will be judged ‘work ready’, while other disabled people will, because of the identification of their complex needs, be judged ‘unable to work’ no matter what their circumstances. Successful appeals against the WCA stand at 40% (BMA, 2012), this suggests that the assessment is not working well for disabled people.

The government is committed to ‘Work Choice’ (formerly the Specialist Disability Employment Programme) (DWP, 2010) a small project limited to disabled people. Participants will be offered a set curriculum including: life skills, curriculum vitae development and interview training, but the number of disabled people who will access this programme will be small, an estimated 16,000 people over five years

(http://www.goodaccessguide.co.uk/news/info.php?refnum=464).

Currently, the government also remains committed to the Access to Work scheme which funds equipment, or a support worker, for disabled people in the work place. This scheme is being extended to supplement new supported internships for people with ‘learning disabilities’ which are also intended to move more disabled people into work (DWP, n.d.). However, the government has decided to close 27 factories employing disabled workers as part of Remploy. The government has promised to re-distribute the £320 million budget savings to improve employment services, and, although the move has been broadly welcomed by disabled people’s organisations, the outcomes for the 1,700 redundant Remploy employees are expected to be poor (Butler, 2012).

Media coverage of Employment Support Allowance, Disability Living Allowance and the Motability Scheme (a scheme which provides transport for disabled people) have created an extremely negative public perception of the link between disability, welfare and work such that disabled people seen as a drain on, rather than part of their communities (Roulstone, 2011). Disabled people are depicted as benefit scroungers and stories of fraudulent disability claims make the front pages of newspapers (Daily Mail, 2011). Indeed, Inclusion London (2011) found that the media coverage describing disabled people in sympathetic and deserving terms had fallen, whereas there was an increase in the number of articles focusing on disability benefit fraud.

In the following sections, we reflect on the interconnections between disability, work and resilience in the lives of disabled people, drawing on their accounts of their lives. The analysis of the accounts is guided by the network of resilience we identified above with the aim of exploring the interconnections between work, disability and resilience.

*Material Resources*

At a time of high unemployment, austerity measures, economic downturn and a government agenda to move people off benefits and into work, access to *material resources* is a key issue for disabled people of working age. The materialfoundations from which it is possible to bounce back are seriously under threat in the lives of disabled people. Increased competition for jobs and cultural anxiety about ‘benefit scroungers’ make the reality of work ever more difficult for disabled people. Indeed, for some disabled people, barriers to work seemed insurmountable:

People don’t help you [find a job] as well …. You try to do voluntary work to try and get yourself better to try and help, but no one seems to want to give you a job. If they could help you with finding a job that you could cope with and you could manage and they had some understanding of your illness then it would be helpful but there is nothing like that. We will take your money off you and no one will help you.

(Focus Group 1, Participant 3)

Parents/carers reported the attitudinal barriers that prevented them from working:

If you’ve got an employer who knows that [someone has] got a disabled child, how flexible are they going to be? They need to be quite flexible and some employers aren’t.

(Focus Group 2, Participant 6)

Caring responsibilities were also identified as significant barriers to work:

Even I wouldn’t employ me, five doctors I see a month who is going to employ me?

(Focus Group 2, Participant 6)

The inaccessibility of paid work clearly impacts negatively on disabled people’s resilience in terms of material resources, however, work represented far more than simply a material resource in people’s lives, as we see below.

*Identity & Community*

For many disabled adults, work has a huge impact not only on financial resources, but also on sense of *identity* as someone who is valued and makes a contribution to the *community*. Matilda spoke of work as being a key part of her *identity*:

I think for me as well one of the things that is important to me is to be needed and at work. Those times when I feel like my work is making a difference; it’s almost as if I viewed resilience like a fuel that you put in your body; and it helps keep you going when times aren’t so great. I can think back and say ‘I might be having a rubbish day at work today, but remember how you felt when someone told you: ‘Matilda this is really helpful its really helped me with my work today’.

(Interviewee 1)

A parent told us:

[without work] you lose your identity, work is more than just bringing money in. You just want a life like everybody else.

(Focus Group 2, Participant 7)

Disabled people told us that work contributed to their sense of identity of someone who participated in and contributed to their communities.

*Social Justice: Disability, Work and the Law*

Crucially, disabled people reminded us of the ways in which legislation impacts on work opportunities:

I’d be a Community Service Volunteer but about six weeks after my friends had gone to university, they told me that they couldn’t take me because of my disability. This was pre-Disability Discrimination Act, of course.

(Interviewee 2)

Interviewee 2’s story is a timely reminder of the importance of protecting disabled people’s right to work in law and the impact of legislation on the lives of disabled people. Despite legislation, disabled people of working age often face battles within the work place to ensure that ‘reasonable adjustments’(The Equalities Act, 2010) are put in place and maintained:

A number of the things that she has raised are issues that I thought had already been dealt with through reasonable adjustment like time keeping for example. My recorded start time is 8:15, my hours are 8:15 to 4:15, but I have a reasonable adjustment so that I can arrive up to 8:30 as long as I then work till 4:30. My manager was questioning whether I actually stick around until 4:30 because her own working arrangements mean that she’s not there between 4:00 and 4:30 to physically witness it and I got rather naffed off about it so apparently there’s going to be another meeting so, I’m joining a union!

(Interviewee 2)

When Interviewee 2 finds herself at risk in her work place, she is forced to engage with issues of *social justice*. The impact of collective politicisation on disabled people has long been recognised (Oliver, 1990). Yet, this move towards political engagement in 2012 is a direct reflection of increased politicisation in a time of recession. Sadly, these politicised engagements were not always available as a support to disabled people in the study. Interviewee 3 had no support from the union in her workplace:

When I tried to point out it was a disability related absence and there had to be reasonable adjustments she said ‘oh well the adjustments are only reasonable if we think they are and as soon as we think they are unreasonable then we can dismiss you’. I gave her the leaflet explaining what the symptoms were and she didn’t even look at it she put it straight into a folder.

(Interviewee 3)

Chris told us that he felt he had earned the right to work flexibly in his work place, because people knew that he delivered and did his job well, but that the flexibility his current job offered also meant that he would be hesitant about taking a risk and applying for a different job. In this sense the work communities that disabled people feel they are able to participate in are limited by the commitment and flexibility of others.

*Bodies (In-The-Workplace)*

As we have seen, disabled people in work experience high degrees of uncertainty. However, some of this uncertainty arises when disabled peoples’ experiences of work are shaped by the interaction between their bodily impairments and their colleagues reactions to what is seen as bodily difference. Discussion of the body and the role it plays in relation to disability is hotly contested in disability studies. So, we need to take a moment to make three general observations:

1. the body is not solely a concern for disabled people (e.g. pain or the limits of the body impact upon everyone);
2. the way we feel, experience, sense and live in our bodies is always influenced by wider social and community relationships;
3. all of us, if we are not already impaired, can be described as being ‘TAB’: temporarily abled bodied (Marks, 1999) so, in this sense, all bodies are precarious entities.

(Runswick-Cole & Goodley, 2012)

Disabled people, in the study, feared that some time in the future their impairment, or the failure of others to accommodate their bodies or impairment, would mean that they might no longer be able to work:

I know I’ve been ill in the past, so I’ve got to have that contingency [savings] there. We are moving into a new building shortly and I’ve got real worries about access issues. Technically because of my spina bifida, I’m doubly incontinent but I manage it to the point where I rarely have accidents but I need to be able to get to the toilet very quickly. Fortunately both my managers are female so I’ve been able to be quite open about it. I’ve been in this job eight years and they’ve been aware of this. But now I face being in an office where I have to get through about five heavy fire doors and travel about thirty metres to the nearest toilet, which is going to be outside the door to a lecture theatre that holds about two hundred and fifty students, and it’s the only toilet accessible from our office. The writing’s on the wall. I know that that toilet is going to be abused, I know that that toilet is going to be full when I need to use it.

(Interviewee 2, disabled person)

*Relationships*

We have argued that resilience emerges, not within the bodies and minds of isolated individuals, but in relationships between people and in access to resources. In the work place, disabled peoples’ *bodies*were constructed by and experienced through *relationship****s*** with colleagues. This clearly had a big impact on how people experienced work that impacted on their sense of resilience:

It was very difficult getting back to work as well because people’s understandings and perceptions are very tricky to deal with. It took people a year to realise that there was a genuine problem…. I think people find that hard to understand when they see that you suffer from muscle aches or whatever they think:’ oh, just have a hot bath and you will be alright’, but it doesn’t work like that. I think because on the good days I can do loads, then they can’t understand there might be another day when I can’t get anything done.

(Interviewee 3)

These *relationships* were particularly troubled by the absence of a ‘visibly different’ *body*. This caused difficulties for disabled people who were not seen to conform to stereotypical norms of what their colleagues felt a disabled person should look like (See also Bellini & Dalgin, 2009):

There is just this overall perception that people with depression are supposed to be some cowering wreck in the corner crying and that I am not. Or they have this kind of stigma attached to a mental health condition and they don’t see me as a lunatic, coming out of an asylum or something. They have this vision of what should be a person with clinical depression should be and I don’t fit it. So when I tell them they say ‘really?!’

(Interviewee 4)

*‘Cripping’ the Norms*

The stories above reveal the complex interconnections between work and other resources such as relationships, identity, social justice, communities and bodies in terms of building (or indeed draining) resilience. We have tried to show how these accounts unsettle traditional understandings of resilience and disability. However, so far, the notion of work in these accounts has remained undisturbed. So here we consider how disabled people have ‘cripped’ (McRuer, 2006), or unsettled, normative notions of work and to do that we begin with a story collected as part of the project:

Neil has the label of Profound and Multiple Learning Disabilities. His parents were told that they should leave him in an institution because he would ‘destroy their marriage’. His mother, who was six months pregnant at the time, was offered a termination so that she did not bring another child ‘like that’ into the world. Neil is 28, he lives in his own home with support from carers and he has a job. For one hour each day, he takes the post from a local business to the post office. He has just learnt to carry the parcels by himself.

(Researcher’s notes)

We would argue that Neil is a resilient young man. Neil has bounced back, not by succeeding in spite of the presence of impairment, but by overcoming the devastatingly negative expectations of the professionals who diagnosed him. Neil is not a striving, able individual, meeting developmental norms despite his impairment, rather his resilience is built in relationships with others, particularly his parents, and they have together created a network of resources which enable Neil to work. Neil works one hour a day and this hour has enabled him to feel part of the local community, to build relationships with colleagues, to have a sense of himself as a worker, to have some power and control in his life. We would argue that for Neil work is also a political act, in which he invokes social justice for himself and his family and other disabled people.

In our attempts to ‘crip the norms’ of work we draw on another story:

I’ve found it very hard to recruit people. I’ve used a [website] but … I’ve also tended to employ people who haven’t worked in social care for that long and are not set in their ways, so I can train them a bit myself.

(Interviewee 5)

Sarah is an employee *and* an employer. At a time of economic downturn, when disabled people are being characterised as benefit scroungers, the focus has been on what disabled people *take* *from* the economy, sadly little attention has been paid to the contribution that disabled people *make* *to* the economy. In 1992, Albrecht identified the stakeholder groups in the political economy of disability and rehabilitation. These, of course, included disabled people but Albrecht also identified health care professionals, hospitals, therapy businesses, home care agencies, assisted living facilities, pharmaceutical companies, technological businesses, banks, lawyers and accountants specialising in disability as well as government and lobby groups. If we add disabled children, this list would also include a raft of ‘special education’ professionals (Mallett & Runswick-Cole, 2012). The profits of the disability business are huge but, of course, it is not disabled people who benefit from them – directly or indirectly, it seems. Despite the contribution disabled people make, they are still most likely to be portrayed as a drain on the economy in the press.

*Conclusions*

In this chapter, we have set out to explore the interconnections between disability, work and resilience in the context of economic downturn. In doing so we have sought to trouble traditional approaches to disability, work and resilience. First, by paying attention to the social production of resilience and disability, and then by trying to ‘crip’ the norms in relation to the world of work. We end with a note of caution, work is not a panacea in relation to the building resilience in the lives of disabled people; paid work outside the home may not be possible or desirable for all and, yet, as Neil’s story reveals, it is possible to re-think the relationships between disability, resilience and work in ways that promote the interconnections.

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