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Breakdown Is Built into It: A Politics of Resilience in a Disabling World

Katie M Ellis

Resilience is an interdisciplinary concept that has been interrogated and investigated in a number of fields of research and practice including psychology, climate change, trauma studies, education and disaster planning. This paper considers its position within critical disability studies, popular understandings of disability and the emergence of a disability culture. Patrick Martin-Breen and J. Marty Anderies offer a colloquial definition of resilience as:

Bouncing back after stress, enduring greater stress, and being less disturbed by a given amount of stress. ... To be resilient is to withstand a large disturbance without, in the end, changing, disintegrating, or becoming permanently damaged; to return to normal quickly; and to distort less in the face of such stresses. (1182)

Conversely, Glenn E. Richardson argues that resiliency is a 'metatheory' that can best be described as 'growth or adaptation through disruption rather than to just recover or bounce back' (1184). He argues that resiliency theory has progressed through several stages, from the recognition of characteristics of resilient individuals to an appreciation of the support structures required beyond the level of the individual.

In her memoir *Resilience*, Ann Deveson describes resilience as a concept that people think they understand until they are called upon to define it. Deveson offers many definitions and examples of resilience throughout her book, beginning with stories about disability, people with disability and their experiences of changing levels of social inclusion and exclusion (632). She paints an evocative picture of a young mother whose five year old son has cerebral palsy giving evidence before a Royal Commission into Human Relationships during a period of significant social change involving the deinstitutionalisation of people with disabilities:

A few years earlier, this child with cerebral palsy would have been placed in an institution. His mother might not even have seen him. Now she had care of her child but the pendulum had swung in the opposite direction. (632)

During the 1980s a number of large institutions caring for people with developmental impairments and psychiatric illnesses were closed in favour of community care (Clear 652). Although giving an appearance of endorsing equality of disabled people in the community, the 'hidden agenda' of this initiative was to cut public expenditure on social services (Ellis 163). As a result, an undue burden fell to women who became primary carers with little support such as the woman Deveson remembers. She questions where this young mother mustered such 'magnificent resilience' when she had such little support:

When he was born, she had been discharged from the hospital with her baby, a feeding formula and a tiny pink plate for the child's cleft palate. The only advice she received was to come back later to have the plate refitted. Her general practitioner prescribed her sedatives for depression, and she and her husband found their own way to the Royal Blind society by asking a blind man they saw outside a supermarket. She had only learned accidentally from one of the nurses that her baby was blind. 'He's mentally retarded too,' the nurse had added, almost as an afterthought. (632)

Thus Deveson's consideration of resilience includes both an individual's response to what could be described as tragedy and the importance of social support and the drive to demand it. Despite her child's impairment and the lack of community resources made available to her family to cope, this young woman was leading public discussion about the plight of people with disabilities and their families in the hopes the government would intervene to help improve the situation (Deveson 632).

Indeed, when it comes to the experience of disability, resilience is implied and generally understood to mean an attribute of the individual. However, as resilience theory has progressed, resilience can no longer be considered as existing exclusively within the domain of an individual's personal qualities. Environmental support structures are vital in fostering resilience (Wilkes). Despite resiliency theory moving on from the level of the individual, popular discourses of resiliency as an individual's attribute continue to dominate disability. As such, some critical disability commentators have redefined resilience as a response to a disabling social world.

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My aim in this paper is to explore this discourse by engaging with ideas about disability and resilience that emerge in popular culture. Despite the changing social position of people with disabilities in the community, notions of resilience are often invoked to describe the experience of people with disability and attributes of successful (often considered 'inspiring') people with disability. I begin by offering a definition of resilience as it is bound up in notions of inspiration and usually applied to people with disabilities. The second part of the paper explores disability as a cultural signifier to comment on the ways in which disability offers cultural meanings that may work to reassure nondisabled people of their privileged position. Finally, the paper considers interpretations of disability as a personal tragedy before exploring the emergence of a disability culture that recognises the social and cultural oppression experienced by people with disabilities and reworks definitions of resilience as a response to that oppression.

Defining Resilience: Good Outcomes in Spite of Serious Threats

Disability is often invoked in stories about resilience. Gillian King, Elizabeth Brown, and Linda Smith argue that a clear link exists between resilience and feeling that life is meaningful. They argue that the experiences of people with disabilities can offer a template for how to develop resilience and cope with life changes (King, Brown and Smith 633).

According to the *Oxford English Dictionary Online*, resilience is 'the action or an act of rebounding or springing back' (653). King et al add that several concepts are associated with resilience such as hardiness, a sense of coherence and learned optimism (633). Deveson, resilience 'has come to mean an ability to confront adversity and still find hope and meaning in life'. She comments that it conjures up notions of heroism, endurance and determination (632). Each of these characteristics we might describe as inspirational. It is telling that both Deveson and King et al use people with disabilities as signifiers of resilience in practice.

However, Katherine Runswick-Cole and Dan Goodley argue that this definition of resilience has not necessarily been useful to people with disabilities and instead recommend a definition of resilience that Deveson only alludes to. For Runswick-Cole and Goodley resilience can be located in social processes. They argue that a thorough investigation of resilience in the lives of people with disabilities considers the broader social and cultural restrictions placed on top of impairments rather than simply individualising resilience as a character trait of people who can 'overcome the odds':

An exploration of resilience in the lives of disabled people must, then, focus on what resources are available and who is accessing those resources. Crucially, in seeking to build resilience in the lives of disabled people, this 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 increase adversity in the lives of disabled people. (634)

This is an alternative approach to disability that sees 'the problem' located in social structures and inaccessible environments. This so-called social model of disability is based on principles of empowerment and argues that able-bodied mainstream society disables people who have impairments through an inaccessible built environment and the perpetuation of stereotypes and prejudicial attitudes.

Disability Dustbins and Inspirational Cripples

Arthur Frank, sociologist and author of *The Wounded Storyteller*, explains that 'the human body, for all its resilience, is fragile; breakdown is built into it. Bodily predictability, if not the exception, should be regarded as exceptional; contingency ought to be accepted as normative' (634). Frank argues that we do not want to admit that our bodies are unpredictable and could 'break down' at any moment. Those bodies that do break down therefore become

representatives of many of the things [the able-bodied, normal world] most fear-tragedy, loss, dark and the unknown. Involuntarily we walk- or more often sit- in the valley of the shadow of death. Contact with us throws up in people's faces the fact of sickness and death in the world ... A deformed and paralysed body attacks everyone's sense of well-being and invincibility. (Hunt 186)

People with disabilities therefore become loaded cultural signifiers, as Tom Shakespeare argues in *Cultural Representations of Disabled People: Dustbins for Disavowal*: 'it is non-disabled people's embodiment which is the issue: disabled people remind non-disabled people of their own vulnerability' (139). As a result, people with disabilities are culturally othered. Several disability theorists have argued that this makes the non-disabled feel better about themselves and their tenuous privileged position (Barnes; Ellis; Kumari Campbell; Oliver, Goggin and Newell; Shakespeare).

Disability, as a concept, is both everywhere and nowhere. Generally considered a medical experience or personal tragedy, the discipline of critical disability studies has emerged to question why disability is considered an inherently negative experience and if there is more to disability than a body that has something wrong with it. Fiona Kumari Campbell suggests

ableism – ‘the network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species typical and therefore essential and fully human’ – is repeatedly performed in our culture.

This cultural project is difficult to sustain because by their very nature all bodies are out of control. People with disability are an acute reminder of the temporariness of an able bodied ontology (650). In order to maintain this division and network of beliefs, the idea that disability is a personal tragedy rather than a set of social relations designed to exclude some bodies but not others is culturally reproduced through stereotypes such as the idea that people with disabilities who achieve both ordinary and extraordinary things are sources of inspiration. Resilience as a personal quality is implicated in this stereotype.

In a powerful *Ramp Up* blog that was republished on the ABC's *Drum* and the influential popular culture/mummy blogging site website *Mamamia*, Stella Young takes issues with the media's framing of disability as inspirational:

We all learn how to use the bodies we're born with, or learn to use them in an adjusted state, whether those bodies are considered disabled or not. So that image of the kid drawing a picture with the pencil held in her mouth instead of her hand? That's just the best way for her, in her body, to do it. For her, it's normal. I can't help but wonder whether the source of this strange assumption that living our lives takes some particular kind of courage is the news media, an incredibly powerful tool in shaping the way we think about disability. Most journalists seem utterly incapable of writing or talking about a person with a disability without using phrases like "overcoming disability", "brave", "suffers from", "defying the odds", "wheelchair bound" or, my personal favourite, "inspirational". If we even begin to question the way we're labelled, we slide immediately to the other end of the scale and become "bitter" and "ungrateful". We fail to be what people expect. (610)

These phrases, that Young claims the media rely on to isolate people with disabilities, are synonyms for the qualities Deveson attributes to resilient individuals (632). As Beth Haller notes, although disabled activists and academics attempt to progress important political work, the news media continue to frame people with disability as courageous and inspirational simply for living their lives (216). By comparison, disability theorist Irving Zola describes rejecting his leg braces (symbolic of his professional status) electing instead to use a wheelchair:

If we lived in a less healthiest, capitalist, and hierarchal society, which spent less time finding ways to exclude and disenfranchise people and more time finding ways to include and enhance the potentialities of everyone, then there wouldn't have been so much for me to overcome. (654)

Harilyn Russo agrees, and in her memoir *Don't Call Me Inspirational* highlights the socially created barriers put in her way and the ways these are ignored in favour of individualising social disablement as something inspirational people 'overcome':

I'll tell you why I am inspirational: I put up with the barriers, the barricades, the bullshit you put between us to avoid confronting something—probably yourself—and still pay the rent on time and savor dark chocolate. Now that takes real courage. (651)

Throughout her book, Russo seeks to 'overcome disability prejudice' rather than 'overcome disability'. Russo establishes herself and her experiences as normal and every day while articulating the tedium she finds in being pigeon holed as inspirational. These authors are constructing a new way of thinking about disability. Michael Oliver first described this as the 'social model of disability' in 1981. He sought to overturn the pathologisation of disability by giving 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' (Runswick-Cole and Goodley 634).

Resilience: A Key Concept

Fiona Kumari Campbell questions whether resilience is a useful concept in the context of disability and reflects on its use to obscure "the 'real' problem, namely disability oppression" (649). She interrogates traditional definitions of resilience as they draw on notions of good outcomes in spite of risk factors or experiences of severe trauma and calls for an understanding of the interactive and dynamic features of resilience as opposed to 'individualised psychological attributes'. Thus, individualised notions of resilience as they are implicated in the cultural stories of inspirational people with disabilities are embedded within the ableist relations that Kumari Campbell seeks to expose.

In *Empowerment, Self-Advocacy and Resilience*, Dan Goodley argues that resilience is a key concept that has repeatedly emerged throughout his research into disability and self-

advocacy. He draws on the reflections of people with disabilities to offer a re-definition of resilience as a response to a disabling society that includes five interrelated aspects (648). First is resilience as contextual, which recognises resilience as the result of the contexts in which it emerges, including through relationships with others and the experience of disabling and enabling environments. Secondly, resilience complicates preconceived notions about people with disabilities such as the view that they are passive. Goodley's third feature of resilience is optimism. He notes resistance toward oppression as a key characteristic of optimistic resilience. Goodley again considers the importance of interpersonal relationships and group identity when he argues that the fourth feature of resilience relies on people with disabilities forming relationships with each other and group identities to question their oppression. Finally, Goodley argues 'resilience is indicative of disablement' and suggests that people with disability must be resilient in everyday life because we live in a disabling society.

Kumari Campbell posits that individualised notions of resilience are a 'cop out' designed to 'distract and defuse the reality of people labouring under very difficult circumstances of which the solution is better access to quality services'. She is hopeful, like Goodley, that resilience can be redefined as a political project, and encourages people with disabilities to develop a critical consciousness and find a new sense of community through art, humour and peer support. Therefore, according to Kumari Campbell and Goodley, resilience can be redefined as a response to social disablement rather than bodily impairment.

Disability Culture: Acts of Resilience in a Disabling Society

Russo and Zola's work is part of a disability culture that has emerged in response to narrow ways of understanding disability. Steven Brown emphasises the importance of experience and personal identity in his definition of disability culture:

People with disabilities have forged a group identity. We share a common history of oppression and a common bond of resilience. We generate art, music, literature, and other expressions of our lives and our culture, infused from our experience of disability. Most importantly, we are proud of ourselves as people with disabilities. We claim our disabilities with pride as part of our identity. (520)

Brown's definition of disability culture therefore draws on all five of Goodley's features of resilience. Disability culture is contextual, complicating, optimistic, interpersonal and indicative of disablement. The forging of a group identity reveals the resilience of disability culture as contextual and interpersonal. The creation of art, music, literature and other cultural artefacts reveals resilience as optimistic. The notion that people with disabilities are proud of their identity complicates traditional understandings of disability as a personal tragedy. Brown's emphasis on the common history of the oppression of people with disabilities, as it initiated the whole disability culture movement, is 'indicative of disablement'. The bonds of resilience that create the disability cultural movement are a result of the social oppression of people with disabilities (Gill; Martin; Brown; Goodley).

Conclusion

Whereas people with disabilities going about their every day lives have often been considered inspirational and as possessing resilient qualities, a new disability culture is emerging that repositions the resilience of people with disabilities as a political response to social oppression. Drawing on Runswick-Cole and Goodley's argument that individualising qualities of resilience in inspirational people with disabilities has not benefitted people with disabilities, this paper sought to reveal the importance of resilience as a response to social oppression. People with disabilities in their formation of a disability cultural movement are reworking and redefining resilience as a response to oppression. Throughout this paper I have drawn on the reflections of a number of people with disabilities to illustrate the emergence of a disability culture as it has begun the work of redefining resilience as a political project that "'outs' the problems that disabled people face and names and prioritises the concerns" (Kumari Campbell 649). As Goodley argues, people with disabilities have developed a politics of resilience 'in the face of a disabling world'.

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