

WHOSE TRAGEDY? TOWARDS A PERSONAL NON-TRAGEDY VIEW OF DISABILITY

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Introduction

Our aim in this chapter is to address and challenge what Oliver calls the ‘grand theory’ of disability, that is, again in his words, ‘the personal tragedy theory of disability’ (1990: 1). In doing so we are building on our previous work (Swain and French, 2000; French and Swain, 2002) and on the developing politics of personal identity which reinterprets the experience of disability in positive rather than negative terms (Morris, 1991).

In the personal tragedy theory, disability, or rather impairment which is equated with disability, is thought to strike individuals causing suffering and blighting lives. This view is so dominant, so

prevalent and so infused throughout media representations, language, cultural beliefs, research, policy and professional practice that we can only hope to cover a few illustrative examples. In relation to language, for instance, 'suffering/sufferer' is perhaps the most widely used terminology in tragedy discourses to characterise the experience of disability. In the media, personal tragedy underlies representations of disability in numerous ways for different dramatic purposes, such as being bitter and twisted (e.g. the character Potter in *It's a Wonderful Life*) or pathetic (e.g. Tiny Tim in *A Christmas Carole*). Perhaps the most intrusive, violating and invalidating experiences, for disabled people, emanate from the policies, practices and intervention which are justified and rationalised by the personal tragedy view of disability and impairment. The tragedy is to be avoided, eradicated or 'normalised' by all possible means. Such are the negative presumptions held about impairment and disability, that the abortion of impaired foetuses is barely challenged (Parens and Asch 2000) and compulsory sterilisation of people with learning difficulties was widely practised in many parts of the world, at least until the 1970s (Park and Radford 1999). The erroneous idea that

disabled people cannot be happy, or enjoy an adequate quality of life, lies at the heart of this response. The disabled person's problems are perceived to result from impairment rather than the failure of society to meet that person's needs in terms of appropriate human help, accessibility and inclusion. There is an assumption that disabled people want to be 'normal' although this is rarely voiced by disabled people themselves who know that disability is a major part of their identity (Mason 2000). Disabled people are subjected to many disabling expectations, for example to be 'independent', 'normal', to 'adjust' and 'accept' their situation. It is these expectations that can cause unhappiness: rarely the impairment itself (French 1994).

There are a number of different possible explanations of this personal tragedy theory of disability. It is sometimes thought to reflect a deep irrational fear of non-disabled people's own mortality (Shakespeare, 1994). A second form of explanation refers to dominant social values and ideologies, particularly through the association of disability with dependence and abnormality (Oliver, 1993). There is a third type of explanation, however, which

suggests that the personal tragedy perspective has a rational, cognitive basis constructed through experiences in disablist social contexts. Unlike within other social divisions, such as between men and women or between members of different races, non-disabled people daily experience the possibility of becoming impaired and thus disabled (the causal link being integral to the tragedy model). It can be argued that so-called 'irrational fears' have a rational basis in a disablist society. To become visually impaired, for instance, may be a personal tragedy for a sighted person whose life is based around being sighted, who lacks knowledge of the experiences of people with visual impairments, whose identity is founded on being sighted, and who has been subjected to a daily diet of the personal tragedy model of visual impairment. Thus, the personal tragedy view of impairment and disability is ingrained in the social identity of non-disabled people. Non-disabled identity, as other identities, has meaning in relation to and constructs the identity of others. To be non-disabled is to be 'not one of those'. The problem for disabled people is that the tragedy model of disability and impairment is not just significant for non-disabled people in understanding themselves and their own

lives. It is extrapolated to assumptions about disabled people and their lives.

From this point of view, too, the adherence to a personal tragedy model by disabled people themselves also has a rational basis.

For a non-disabled person whose life is constructed on the basis of being non-disabled, the onset of impairment and disability can be experienced as a tragedy, perhaps amplified if it is associated with the trauma of illness or accident. Even in affirming the social model, Oliver and Sapey state:

Some disabled people do experience the onset of impairment as a personal tragedy which, while not invalidating the argument that they are being excluded from a range of activities by a disabling environment, does mean it would be inappropriate to deny that impairment can be experienced in this way. (1999: 26)

Furthermore, a personal tragedy view can have a rational basis for people with congenital impairments, living through the daily barrage from non-disabled people, experts, parents and the media invalidating themselves and their experiences. Indeed, within the

disabling context we have outlined here, the expression of a non-tragedy view by disabled people flies in the face of dominant values and ideologies. It is likely to be denied as unrealistic or a lack of 'acceptance', distorted as an expression of bravery or compensation, or simply ignored. The tragedy model is in itself disabling. It denies disabled people's experiences of a disabling society, their enjoyment of life, and their identity and self-awareness as disabled people.

In the next section of this chapter, we demonstrate, by reviewing the literature and drawing upon research, that being disabled need not be a tragedy for disabled people, but may, on the contrary, enhance life or provide a life-style of equal satisfaction and worth.

Who needs cure and normality?

A personal non-tragedy view of impairment and disability, similar to a tragedy view, can take many forms and be expressed in a variety of ways. Perhaps at the most basic level, impairment is simply a 'fact of life'. A participant in Watson's research typifies this:

Tommy argued that 'I don't wake up and look at my wheelchair and think "shit, I've got to spend another day in

that", I just get up and get on with it'. (2002: 519)

Furthermore, from the documented viewpoint of disabled people, far from being tragic, being disabled can have benefits. Disabled people sometimes find that they can escape class oppression, abuse or neglect by virtue of being disabled. Peter Holmes who attended an 'open air' school in the 1950s states:

My first impression at the age of seven or eight years was its vastness. Previously all I had ever seen was factories, terraced houses and bomb sites. To a child like myself it was magnificent. The countryside and woods were overwhelming and very beautiful and the air so sweet.....We would walk through the woods and visit farms seeing animals and flowers and trees that most of us had only ever seen in books. (Wilmott and Saul 1998:257)

A further way in which disability and impairment may be perceived as beneficial to some disabled people is that society's expectations and requirements are more difficult to satisfy and may, therefore, be avoided. A disabled man quoted by Shakespeare et.al. said, "I am never going to conform to society's

requirements and I am thrilled because I am blissfully released from all that crap. That's the liberation of disfigurement." (1996: 81) If, for example, a person has sufficient resources, the ability to give up paid employment and pursue personal interests and hobbies, following an accident, may enhance that person's life. Similarly, young people (especially women) are frequently under pressure to form heterosexual relationships, to marry and have children. These expectations are not applied so readily to disabled people who may, indeed, be viewed as asexual. Although this has the potential to cause a great deal of anxiety and pain, some disabled people can see its advantages. Vasey states:

We are not usually snapped up in the flower of youth for our domestic and child rearing skills, or for our decorative value, so we do not have to spend years disentangling ourselves from wearisome relationships as is the case with many non-disabled women. (1992: 74)

Though it is more difficult for disabled people to form sexual relationships, because of disabling barriers, when they do any limitations imposed by impairment may paradoxically, lead to

advantages. Shakespeare et.al., who interviewed disabled people about their sexuality and sexual relationships states:

Because disabled people were not able to make love in a straight forward manner, or in a conventional position, they were impelled to experiment and enjoyed a more interesting sexual life as a result. (1996: 106)

For some people who become disabled their lives change completely though not necessarily for the worse. A woman quoted by Morris states:

As a result of becoming paralysed life has changed completely. Before my accident it seemed as if I was set to spend the rest of my life as a religious sister, but I was not solemnly professed so was not accepted back into the order. Instead I am now very happily married with a home of my own. (1989: 120)

The experience of disability may also give disabled people a heightened understanding of the oppressions other people endure. French (1991) found that most of the forty-five visually disabled physiotherapists she interviewed could find advantages to being

disabled in their work. An important advantage was their perceived ability to understand and empathise with their patients and clients. Others believed that their visual disability gave rise to a more balanced and equal relationship with their patients, that patients were less embarrassed (for example about undressing) and that they very much welcomed the extra physical contact the visually disabled physiotherapist was obliged to make. One person said:

Even as students when we had the Colles fracture class all round in a circle, they used to love us treating them because we had to go round and touch them. They preferred us to the sighted physios. I'm convinced that a lot of people think we are better. (1991: 4)

Other disabled people believe that disability has given them a different and beneficial outlook on life. Tom, who is disabled through the drug thalidomide states:

Life is very good.....being born with no arms has opened up so many different things that I would never have done. My motto is 'in life try everything'. I wouldn't have that

philosophy if I'd been born with arms. (Archive Hour BBC Radio 1 June, 2002).

As for non-disabled people, the quality of life of disabled people depends on whether they can achieve a life-style of their choice. This in turn depends on their personal resources, the resources within society and their own unique situation. Nevertheless, the writings of disabled people demonstrate that being born with an impairment or becoming disabled in later life can give a perspective on life which is both interesting and affirmative and can be used positively. This is not generally recognised by non-disabled people as Ian Basnett a doctor who became disabled, explains:

I was horrified by what I imagined to be the experience of disabled people, which I encountered in my practice. Now 15 years after becoming disabled, I find myself completely at home with the concept, of effectively being me!.....Now I know that my assessment of the potential quality of life of severely disabled people was clearly flawed. (Basnett 2001:453)

From Tragedy to Identity

In recognising a positive view of disability, it is essential that this is set in the context of the social model of disability and the oppression and discrimination faced by disabled people. Our argument is that, even in a disabling society, disabled people have directly challenged the personal tragedy theory of disability.

Phillipe summarises a non-tragedy view succinctly:

I just can't imagine becoming hearing, I'd need a psychiatrist, I'd need a speech therapist, I'd need some new friends, I'd lose all my old friends, I'd lose my job. I wouldn't be here lecturing. It really hits hearing people that a deaf person doesn't want to become hearing. I am what I am! (Phillipe in Shakespeare et. al., 1996, 184)

These perceptions of impairment are by no means confined to the disabled people of today. Writing in the early 19th century Husson states:

I have just reached by twenty second year, and I still don't remember ever forming a single regret concerning the loss of my eyes, a loss that seems to me to be of little

importance.....people who see tell me 'You don't have the slightest understanding of treasures you have never known.'

I would like to believe in the justice of this reasoning which, however, does nothing to persuade me that I am unhappy.

(2001: 16)

Nor are they confined to people with physical and sensory impairments. Susan Wendell and Liane Holliday Willey state:

....I cannot wish that I had never contracted ME, because it has made me a different person, a person I am glad to be, would not want to have missed being, and could not relinquish even if I were 'cured'. (Wendell 1996: 83)

I do not wish for a cure to Asperger's Syndrome. What I wish for is a cure for the common ill that pervades too many lives, the ill that makes people compare themselves to a normal that is measured in terms of perfect and absolute standards, most of which are impossible for anyone to reach. (Holliday Willey

1999:96)

Nobody can predict the amount of tragedy or happiness a person will experience in life and yet people feel confident to make such predictions about disabled people. The inherent assumption is that disabled people want to be other than as they are, even though this would mean a rejection of identity. The notion of identity broadens the personal to the political, moves from the 'I' to the 'we'. Disabled people, encouraged by the Disabled People's Movement, are creating positive images of themselves and are demanding the right to be the way they are - to be equal but different. Tollifson, Michlene Mason and Colin Cameron, three disabled people, explain this position:

After a lifetime of isolating myself from other disabled people, it was an awakening to be surrounded by them. For the first time in my life, I left like a real adult member of the human community. Finally identifying myself as a disabled person was an enormous healing. It was about recognising, allowing and acknowledging something I had been trying to deny and finding that disability does not equal ugliness,

incompetence and misery. (Tollifson, 1997:107)

A few years later, at my special school, I remember one of the care staff loudly telling me that I should never give up hope because one day doctors would find a cure for my affliction, and I loudly told her that I did not want to be 'cured'. I remember this incident because of the utter disbelief this statement caused amongst all the non-disabled people present, and the delight this statement caused amongst my disabled friends. The school decided that I had 'The Wrong Attitude' and that I should indeed go to Lourdes so that Jesus, the Virgin Mary and St. Bernadette could sort me out. (Michlene in Mason 2000:8)

We are who we are as people with impairments, and might actually feel comfortable with our lives if it wasn't for all those interfering busybodies who feel that it is their responsibility to feel sorry for us, or to find cures for us, or to manage our lives for us, or to harry us in order to make us something we are not, i.e. 'normal'.

(Colin in Tyneside Disability Arts, 1999:35)

Whose tragedy? For many disabled people the tragedy view of disability is in itself disabling. It denies their experiences of a disabling society, their enjoyment of life, and even their identity and self-awareness as disabled people. The affirmation of positive identity is collective as well as individual. The growth of organisations of disabled people has been an expression not only of the strength of united struggle against oppression and discrimination, but also of group identity. Disabled identity, as non-disabled identity, has meaning in relation to and constructs the identity of others. To be disabled is to be 'not one of those'. The affirmation of positive identity challenges the tyranny of the personal tragedy theory of disability and impairment.

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