# Assimilation or Inclusion?

COLIN BARNES
GEOFF MERCER

ince the 1970s, a disabled people's movement has become established as a political force worldwide. It has confronted the orthodox view that disability should be defined in terms of individual impairment that requires medical treatment. In contrast, disability theory and practice argue that this movement arises from society's failure to remove the wide-ranging social, economic, and environmental barriers that underpin the social exclusion of disabled people and the denial of their basic citizenship rights—what has been termed a social model of disability (Finkelstein 1980; Oliver 1983, 1990). This has been complemented by concerted campaigns against the negative stereotypes contained in media and cultural representations. The politicization of disabled people has also highlighted the significance of an alternative disability culture, which celebrates a positive disabled identity and consciousness.

This chapter has four main objectives:

- 1. to review the analysis of culture and its relationship to society, the economy, and politics;
- 2. to outline the representation of disability in mainstream culture;
- 3. to explore the generation of disability cultures;
- 4. to examine the development of the disability arts movement and its implications for disability culture.

These issues will be illustrated with examples from both U.K. and U.S. cultures.

ANALYZING CULTURE

Sociological studies of culture have adopted a broad interpretation to include symbolic aspects of human society, such as beliefs, rituals, customs, and values, as well as work patterns, leisure activities, and material goods. "Culture consists of the values the members of a given group

hold, the norms they follow, and the material goods they create" (Giddens 1989:31). While values are "abstract ideals," norms encompass the rules or guidelines for what is acceptable in social life. This highlights a diffuse view of culture as a shared "way of life." The emphasis is on culture as a "signifying system" through which practices, meanings, and values are "communicated, reproduced, experienced and explored" (Williams 1981:13).

To become a member of a society, one must learn or be socialized into its cultural assumptions and rules, including what (or who) is considered "normal" and typical and categorized as "different." H. G. Wells, in a short story published in 1904, tells of a man called Nunez who falls off a mountain into an isolated valley populated entirely by people with congenital blindness. He presumes that "in the Country of the Blind, the One-eyed Man is King" (Wells 1979:129). In practice, the efforts of Nunez to help the people are rejected by the community, which is sustained by its own distinctive cultural norms and values.

In the conditions of complex industrial societies, cultures rest on something less than complete uniformity among its members. Moreover, such cultures are not static but typically exhibit a degree of flux:

A culture has two aspects: the known meanings and directions, which its members are trained to; the new observations and meanings, which are offered and tested. These are the ordinary processes of human societies and human minds, and we see through them the nature of a culture: that it is always both traditional and creative. (Williams 1989:4)

The exact form of the relationship between culture and society, particularly its material base, has attracted considerable theoretical debate, stretching back to the writings of classical social theorists, such as Marx, Weber, and Durkheim. In the "orthodox" Marxist variant, the ownership and control of the means of production provide the explanatory key. In some accounts, this leads to a crude determinism in which culture, ideas, and other aspects of what is called the superstructure reflect conditions in the material base. This highlights the political significance of culture as a "dominant ideology" that justifies or obscures social inequalities and perpetuates the oppression of one social group by another. More recent analyses have taken inspiration from a diverse range of social theories, particularly critical theory and neo-Marxism, feminism, poststructuralism, and postmodernism.

The Frankfurt school is generally credited with initiating studies of the media and culture in the 1930s located within critical theory. Its focus was multidisciplinary and spanned a political economy of the media (and the "culture industries"), an analysis of texts, and studies of the social and ideological effects of the media (mass culture) on audiences (Kellner 1989). While the primary focus was on the role of mass culture in promoting working-class passivity and stabilizing industrial capitalism, other studies explored the ways in which some "high" culture offered possibilities for stimulating social and political criticism. It was not until the late 1960s that such issues were picked up and reformulated with a revival of interest in the work of the Italian Marxist, Antonio Gramsci (1971, 1985). His analysis of capitalist domination stressed not only the significance of coercion but also the achievement of "hegemony"—by "willing consent"—through the dominant group's direction of the production and consumption of cultural activities.

Gramsci's influence is very evident in the British cultural studies approach associated with Stuart Hall and his colleagues in the Centre for Contemporary Cultural Studies (CCCS) at the University of Birmingham (Hall 1980; Hall and Jefferson 1976). A further important contributor has been Raymond Williams (1958, 1980, 1981), who developed the notion of cultural materialism. Their work has helped spark a vibrant cultural studies literature. It dismisses the notion of an all-enveloping culture and explores instead the "relative autonomy" between the dominant or "hegemonic" culture and the economy, society, and polity.

The CCCS analysis also stressed the importance of hierarchical and antagonistic social divisions located in gender, race, and generations. These subordinate groups generate "subcultures" or "counterhegemonies" that lead to a form of cultural conflict with the dominant social group. Early studies concentrated on the more spectacular youth subcultures of the post-1960s

period (i.e., teddy boys, mods, rockers, skinheads, and punks). In "resisting" adult culture, disillusioned, working-class youth find opportunities in the increasing consumerism of the late-twentieth-century Western capitalist societies to create their own meanings through peer group relations, style, and leisure activities (Hall 1992; Hall and Jefferson 1976).

Most recently, the analysis of late-twentieth-century society, with its emphasis on cultural difference and pluralism, has been at the heart of a burgeoning influence of postmodernism within the cultural studies literature (Inglis 1993). The emphasis on class conflict and struggle has been displaced by a much broader discourse on social and cultural difference, including race, sexuality, and age as well as disability (Hall 1997; Woodward 1997). This heralds a transition in cultural politics—what Stuart Hall in analyzing black culture refers to as a shift "from a struggle over the relations of representation to a politics of representation itself" (Hall 1988:27-28). This suggests that in the continuing campaign against the marginalization and subordination of disabled people, there is an emerging conflict over identity and competing interpretations of what it means to be a "disabled person" within the imagined "disability community." The political struggle assumes new forms that are manifested in the arena of cultural representation.

In the writings of the French "poststructuralist" Michel Foucault, the history of ideas about medicine, madness, and sexuality are analyzed as sociocultural products of particular epochs. His notion of "discursive practice" focuses on the ways in which individual subjects are constituted by discourse (by the ways we talk about them), which itself is structured by a "power/knowledge" complex. That is, the authority to define or describe people or events occupies a significant role in social regulation. This suggests an examination of the "invention" of disability in nineteenth-century medical discourse and of the relationship between "able-bodied normality" and the disabled "other," as increasingly defined by professional knowledge and practice (Hughes and Paterson 1997).

As a sign of the changing times, one of the first books in Britain to challenge the "able-bodied" orthodoxy by disabled people was Paul Hunt's (1966) edited collection, Stigma: The Experience of Disability. In his own essay, Hunt argues that disabled people "are set apart from the ordinary" in ways that represent them as a direct "challenge" to commonly held societal values. They are "unfortunate, useless, different, oppressed and sick" (Hunt 1966:146). This characterizes disability in industrial capitalist societies as a "personal tragedy" in which

people's shocked reaction to the "obvious deviant" stimulates their own deepest fears and difficulties, their failure to accept themselves as they really are and the other person simply as "other." (Hunt 1966:152)

This sets the scene for a struggle by disabled people to supplant oppressive representations with others that reflect their own experiences and values. It heralds the generation of a disability culture, which expresses and sustains a positive disabled identity. From this perspective, disability culture acts as a means of politicizing and cohering disabled people. In contrast, the recent influence of poststructuralist and postmodernist theory has been to highlight the importance of "difference" and multiple identities. This suggests a focus on disability subcultures and provokes debates about the possibilities for unified political action within the disabled population.

## CULTURAL REPRESENTATIONS OF DISABILITY

Historically, the characterization of disabled people in mainstream culture has stressed their significant "abnormalities." These are variously used as sources of "entertainment" or to induce and confirm the fears and abhorrence in the nondisabled population. In ancient Greece and Rome,

it would almost seem as if no fashionable household was complete without a generous sprinkling of dwarfs, mutes, cretins, eunuchs and hunchbacks, whose principle duty appears to have been to undergo degrading and painful humiliation in order to provide amusement at dinner parties and other festive occasions. (Garland 1995:46)

Evidence of society's fascination with perceived bodily abnormalities persisted throughout the Middle Ages. Many royal courts in Europe retained people of short stature as "court jesters" or kept a complement of "fools," including people with cognitive impairments and learning difficulties, as well as others who feigned "idiocy" to provide amusement. It was also common practice for people with perceived "deformities" and intellectual impairments to be put on display at village fairs on market days, festivals, and holidays, "and peasant parents are known to have toured the countryside displaying for money recently born infants with birth defects" (Gerber 1996:43). The public exhibition of the inmates of "madhouses," such as Bedlam, continued this practice.

By the nineteenth century, such displays had developed into "freak shows," which offered a "formally organized exhibition of people with alleged physical, mental or behavioural difference at circuses, fairs carnivals or other amusement venues" (Bogdan 1996:25). These flourished in Europe and North America in the nineteenth century and in the early part of the twentieth century. They were complemented by the so-called "Ugly Laws" in the United States, which placed social restrictions on those whose physical appearance might offend or frighten "normal" people (Bogdan 1996; Gerber 1996). The freak shows were undoubtedly the site for the exploitation and degradation of people with impairments, although some disabled performers enjoyed public celebrity status and sometimes earned corresponding financial rewards (Bogdan 1996).

While public acceptance of the freak show markedly declined in the early twentieth century, other cultural forms took over. These continued to reflect and confirm negative stereotypes and provide ample rationalization for treating disabled people as "defective" (Battye 1966; Campling 1981; Shearer 1981) or in a "liminal" state. "Neither fish nor fowl; they exist in partial isolation from society as undefined, ambiguous people" (Murphy 1987:112). Indeed, at the end of the century, as Susan Sontag graphically illustrates, the cultural meanings associated with "dread diseases," such as cancer and HIV/AIDS, are so powerful that "it is hardly possible to take up one's residence in the kingdom of the ill unprejudiced by the lurid metaphors with which it has been landscaped" (Sontag 1991:3).

Yet while illness and impairment are often the catalyst for stigma and dread, there is a converse reaction to romanticize their impact on the production of "high culture." For example, in the nineteenth century, tuberculosis or "consumption" became closely associated with individual creativity and artistic sensitivity, as with a number of well-known novelists and poets, including Robert Louis Stevenson, Katherine Mansfield, and John Keats. From this standpoint, some sickness or impairment is credited with adding to the appeal or the insight of the artist (Sontag 1991). This linkage continues through to contemporary musical performers, including Ray Charles, Stevie Wonder, and Hank Williams.

Yet overall, it is the negative cultural stereotyping of people with impairment that rules as the "norm." A series of American studies of representations of disabled people document this pattern across different forms of media culture (Biklen and Bogdan 1977; Clogson 1990; Haller 1995; Klobas 1988; Kurtz 1981; Zola 1985). One of the most cited collections, *Images of the Disabled, Disabling Images* (Gartner and Joe 1987), provides a comprehensive critique. In his contribution, Laurence Kriegel (1987) concludes, after reviewing sources as diverse as *Lady Chatterley's Lover* and *Moby Dick*, that

the world of the crippled and disabled is strange and dark, and it is held up to judgment by those who live in fear of it. The cripple is the creature who has been deprived of his ability

519

to create a self.... He must accept definition from outside the boundaries of his own existence. (P. 33)

This argument is echoed in John Schuchman's (1988) survey of images of deafness or "pathological myths" in Hollywood films. Other writers document how this disabling imagery extends to popular cartoon series (Longmore 1987).

Content analyses of the British media programs provide a similar picture. For example, Guy Cumberbatch and Ralph Negrine (1992) monitored television output for six weeks during 1988. Their central findings, reinforced by more recent studies (Ross 1997), are that television programs consistently adhere to a "personal tragedy" approach. The most prevalent story lines linked disabled people with medical treatment or cure, together with programs focusing on their "special achievements." More widely, the representations of disabled people were highly stereotypical, depicting them not as ordinary members of society and part of the "drama of life" but using them to evoke emotions of pity, fear, or admiration. Newspaper reporting of disability has attracted parallel criticism (Smith and Jordan 1991). A limited number of themes dominate newspaper coverage, with health, fund-raising, charity, and personal and individual interest stories most widespread. This unites tabloids and broadsheets, even if the former are particularly prone to dramatize and sensationalize.

A summary audit of the media's preference for "crippling images" includes a fondness for "wonder cure" stories, the role of charity appeals, the invisibility of disabled people on television, the stereotyped portrayal of disabled characters, and the underemployment of disabled people in TV and radio (Karpf 1988). The most frequently documented cultural stereotypes represent the disabled person as pitiable and pathetic, as an object of violence, as sinister and evil, as atmosphere or curio, as "super-cripple," as an object of ridicule, as their own worst and only enemy, as a burden, as sexually abnormal, as incapable of participating fully in community life, and as "normal" (Barnes 1992). While the latter stands apart as the sole positive viewpoint, it remains the least widely expressed, and its representation of "normality" largely ignores the social exclusion of disabled people. The overall effect is clear:

The general culture invalidates me both by ignoring me and by its particular representations of disability. Disabled people are missing from mainstream culture. When we do appear, it is in specialized forms—from charity telethons to plays about an individual struck down by tragedy—which impose the non-disabled world's definitions on us and our experience. (Morris 1991:85)

However, this initial focus on disability alone has given way to more complex analyses in which the representation of disabled people is mediated by other social factors, such as gender, ethnicity, class, and age. The most detailed studies have focused on the "gendering" of disability in literary texts:

In many instances, the disabled woman is little more than a metaphor through which the writer hopes to address some broader theme. . . . Disability seems to undermine the very roots of her womanhood. Not surprisingly, therefore, the disabled women in these works frequently feel inferior to others and regard themselves with loathing. (Kent 1987:60, 63)

Studies have also explored the interaction between definitions of masculinity and disability. Thus, in films such as *Born on the Fourth of July* and *Waterdance*, individuals are portrayed as desperately trying to cope with the onset of impairment. The polarization of masculine potency and disabled impotency accentuates the presumption that if it is hurtful to feel unloved, it is much more damaging to be incapable of making love. In contrast, women are typically represented as vulnerable, passive, and dependent, so that the artistic interest in portraying disabled women is more focused on their role as tragic or saintly figures who may perhaps be "saved" by

an "able-bodied" man. This reluctance to depict disabled women as sexual beings or in traditional female roles as wives and mothers is explored by two Australian writers, Helen Meekosha and Leanne Dowse (1997). They point to the contradiction between the general support by the disabled people's movement for images of disabled people in "normal" roles and the desire of feminists to challenge gender stereotypes.

The increasing breadth of the cultural studies literature is demonstrated in its engagement with specific artworks, texts, and performances. Lennard Davis (1995) traces the development of the "lexicon of disability," along with the social construction of "normalcy." "The implications of the hegemony of normalcy are profound and extend into the very heart of cultural production (Davis 1995:49). Indeed, he suggests that "one can find in almost any novel...a kind of surveying of the terrain of the body, an attention to difference...physical, mental and national" (p. 41). Another significant contributor to the analysis of disability representation in American culture is Rosemarie Garland Thomson (1997). Her sources include the traditional freak show, sentimental novels such as *Uncle Tom's Cabin*, and contemporary African American fiction. She also draws heavily on diverse theoretical traditions, including contemporary literary, feminist, and social theory, particularly its postmodern versions, to examine how "corporeal deviance" is a "product of cultural rules" about "able-bodiedness."

Constructed as the embodiment of corporeal insufficiency and deviance, the physically disabled body becomes a repository for social anxieties about such troubling concerns as vulnerability, control and identity. (Thomson 1997:6)

Unlike so much of the cultural studies literature, Thomson also explores the appearance of an "active" counterrepresentation. For example, in the novels of Toni Morrison, "physically disabled or anomalous black women triumph," and the novels "repudiate stigmatization itself" (Thomson 1997).

Martin Norden (1994) also advances the understanding of disability representation in his comprehensive history of cinema. He shows how, going back to Thomas Edison's 1898 short film, Fake Beggar, stereotypical and distorted representations of disability were standard fare. As a visual medium, cinema used pictures to reveal character, and emotional and physical "cripples" were routinely equated. The cinema also inherited the entrepreneurial traditions of the freak show, or as Cecil B. De Mille remarked, "Affliction is much more saleable" (quoted in Norden 1994:71).

Norden (1994) traces the development of a range of stereotypes—Elderly Dupe, Saintly Sage, Obsessive Avenger, Sweet Innocent, Comic Misadventurer, Tragic Victim, Noble Warrior—which are used to oppress disabled people. However, he does detect positive changes of this imagery as it evolved from the early exploitative phase (1890s-1930s) through the explorative phase (1930s-1970s) to the incidental phase (1970s to present). Nevertheless, even in contemporary films, the negative stereotypes still appear.

Similar themes are stressed by Paul Darke in his examination of the representation of disability in films such as *The Elephant Man* (Darke 1994) and *When Billy Broke His Head and Other Tales of Wonder* (Darke 1995). He categorizes the latter as a *rite de passage* movie in which Billy Golfus, himself newly impaired after a motorcycle accident, explores the meaning of disability in America with its strong emphasis on individualistic (and capitalistic) values. Darke (1998) also explores the concept of "normality drama," which refers to a genre that uses abnormal or impaired characters to represent a perceived threat to the dominant view of normality. As such, it encompasses the cultural rationalization of the social disablement of the person with a perceived impairment.

One of the most widely cited attempts to locate an aesthetic and theoretical analysis of bodily representation with a broader concern toward social and political context is advanced by David Hevey (1992) in his study of charity advertising, *The Creatures That Time Forgot*. Hevey examines how British charities "market" particular impairments in ways that parallel the "branding" of commercial products in their search for public support. A hallmark of the early charity approach is the stark image of a person with impairment, usually in black and white, which centers

on their physical "flaw." Its purpose is to evoke fear and sympathy in the viewer. Charity advertising is described as "the visual flagship for the myth of the tragedy of impairment" (Hevey 1992:51) and a highly significant component in the cultural construction of disability.

It represents the highest public validation of the isolation of disabled people. It presents a solution to the "problem" of disablement by a disguised blaming of the victim. It fails to find a solution because it is itself the problem. (Hevey 1992:51)

The role of charity imagery in the lives of disabled people has been further linked to the role of pornography in women's oppression. In both cases, the focus is on the body, particularly on parts of the body (the breasts/the impairment). Moreover, the conditions in which the image is produced and interpreted are outside the control of the subject and involve wider meanings and power relationships (Shakespeare 1994). The aim is to stimulate an emotional reaction from the viewer that turns the subject into an object of desire or fear. This has particularly threatening consequences for many disabled women.

There are also dangers here of the advertising industry moving from selling the beautiful and sculptured non-disabled body to selling the beautiful and sculptured disabled body. For women with degenerative or acquired disabilities, or illnesses not amenable to physical body sculpting, these images can further demoralize and undermine their sense of self-worth. (Meekosha and Dowse 1997:97-98)

Nevertheless, there have been recent moves by some charities away from the use of traditional images of disability to generate public donations. This approach has been categorized as "look at the ability, not the disability." Recent campaigns in Britain by SCOPE (formally known as the Spastics Society) have focused on prejudice and discrimination as constitutive of disability, although they have not dispensed entirely with a personal tragedy approach. The Leonard Cheshire Foundation followed suit as it shifted its emphasis from residential homes to other support services by developing a national advertising campaign that focused on the word *enabled*. The charity for people with learning difficulties, Mencap, has also sought a new and more "radical" image. Its tearful "Little Stephen" logo gave way to a more positive representation that embraced citizenship and social rights, although its advertising images are still dominated by the "desire to market attractive pictures" (Corbett and Ralph 1994:11).

More generally, through the last quarter of the twentieth century, there has been a discernible rise in more "positive" cultural and media images of disabled people. Through the 1980s in America, disabled characters began to appear in advertisements for Levi jeans, McDonalds, and Kodak films (Longmore 1987). There are also more "disabled" characters (although not all are played by actors with impairment) and disability story lines in British and American soap operas and dramas. A notable shift in British TV programming was signaled by the showing in 1994 of Skallagrigg, a mythical hero in stories told by disabled inmates of institutions. Such examples demonstrate how the media have begun to take "legitimate and conscious account of the film maker's or artist's encounter with and progress through the experience of disability" (Pointon 1997:237).

On a theoretical level, there remain contrasting emphases, with postmodernist, cultural studies approaches to disability representation relatively more evident in the American literature, compared with the more sociological studies of disabling imagery provided by British writers. The latter have been particularly influenced by the social model distinction between impairment as a property of the body and disability as a social relationship. Moreover, the American literature stresses linguistic and textual analysis and the link between corporeal diversity, unequal status and power, and cultural meanings, while its British counterparts have mostly concentrated on media representation to provide an ideological pretext for social exclusion.

# Media Effects

As the media have grown in importance throughout the twentieth century as mechanisms for communicating ideas and information, their significance as a terrain of cultural politics has also increased. There has been a widespread presumption, in both the American and British literature on disability, that cultural and media imagery has a potent if not direct effect on its audience. This remains an empirical question, but it sits uneasily with recent characterizations of late-twentieth-century society and culture, which stresses the significance of social and cultural diversity rather than homogeneity. This raises doubts about the impact of the media in disseminating specific views, including disabling messages.

Hitherto, a straightforward "hypodermic syringe" model has prevailed in which the "naturalness" of disability is promoted or reinforced through the range of cultural forms. Against this, a "uses and gratifications" approach claimed that people are not simply inert or passive but actively interpret media materials in accordance with their own needs and interests (McQuail 1972). Others have used Gramsci's notion of hegemony to explore how the media "manufacture consent" to the dominant order while acknowledging that the media may be "read" in contrary ways so that audiences may negotiate or reject the intended messages (Hall 1980, 1997).

The possibility of an active audience is yet to be fully explored in the context of the media and disability. Certainly, media audiences will have already been socialized in a variety of ways and have developed firm views about particular subjects. There is a widespread presumption that negative cultural and media stereotypes of disability and disabled people reinforce and extend disability stereotypes held by the general public. This is evident in studies of mental illness (Philo 1996) and of HIV/AIDS (Kitzinger 1993), which demonstrate the media's pivotal role in the dissemination of information, images, and opinions. However, what is less certain is the extent to which the disabled population at large, as opposed to disability activists, interprets media representation.

Models tend to be static and do not necessarily reflect contradictory representations and change over time. They help us "fit" media stories into boxes, but do not necessarily aid in a more complex analysis of the processes involved in disability construction. Thus overall, the variety of elements of media analysis necessary to understand disability cannot be reduced to a simple categorization of content, but require a complex sensitivity to multiple dimensions of the process. (Meekosha and Dowse 1997:95)

## DISABILITY CULTURE

Disability culture presumes a sense of common identity and interests that unite disabled people and separate them from their nondisabled counterparts. The exact bases for group cohesion and consciousness will vary, as will the level and form of any engagement in social and political action. The potential for disability consciousness is enhanced when there is agreement on the source of their collective social exclusion. This division between "insiders" and "outsiders" is developed and maintained by specific cultural styles, customs, and social interaction, such as in segregated, residential schooling, or from a distinctive language (as with Deaf culture). There is a further presumption that a disability culture rejects the notion of impairment-difference as a symbol of shame or self-pity and stresses instead solidarity and a positive identification. However, the transition from a medicalized, impairment-based self to a disabled identity and consciousness is not necessarily one-directional or one-dimensional.

A key issue is whether the disabled community is based on those with the range of impairments or restricted to a specific or limited impairment range. This might be the basis for differentiating a general disability culture from disability subcultures that are located around specific groups of disabled people. However, one immediate snag is that adherents to Deaf subculture

would reject such a designation on the grounds that they are not a subgroup within the disabled population but a separate linguistic community. In contrast, organizations of people with learning difficulties have argued that they are effectively ignored or excluded by other disabled people.

From a postmodern perspective, the emphasis is on multiple and fluid identities. The notion of cultural politics has been layered with different subjectivities. The dominant (nondisabled) discourse regards difference as a technical or essential category, whereas postmodernists view it as a social construction. Equally, solidarity is not regarded as undermined by "difference"; in contrast, it accepts and thrives on diversity. For postmodernists, disability politics must move away from a concentration on single-issue politics, in which disability alone is the concern. In practice, this deflects attention away from the multiple and simultaneous sources of oppression based, for example, on age, class, race, gender, and sexuality. While the notion of internal differences within the disabled population is now broadly accepted, it remains a contentious issue in terms of political strategy. Whereas postmodernists stress diversity and fragmentation and the diminished relevance of broad political projects, more "traditional" disability theorists argue that this leads to political inaction. Can disabled people have it both ways, stressing their diversity while seeking unified political action?

Traditionally, the responses of the dominant culture to the prospect of a disability culture have questioned its legitimacy, being variously hostile, dismissive, and patronizing. Hence, disability culture has been built out of political struggle and with few resources. It is also important to note that within the disabled population, most people will have acquired their impairment later in life, and this means that their embrace of disability culture is inhibited by their immersion hitherto in a nondisabled environment.

Historically, embryonic disability communities have emerged most often from those segregated on the basis of their perceived impairment. With the growth of industrialization and urbanism, the resort to specialized institutions for the most severely impaired or "threatening" individuals has expanded significantly across North America and Britain. Their early religious character has increasingly been overtaken by a more secularized and professional medical regime (Parker 1988). For the disabled inmates, the shared experiences in areas such as schooling and rehabilitation agencies have raised the potential for development of a shared, albeit "defensive," consciousness. There are several sociological studies of this phenomenon. The most well known is Erving Goffman's (1961) picture of in-patient psychiatric life in Asylums. This work stresses the regulation of social deviance, but it also documents the possibility for individual and group subversion and the development of an alternative, shared culture of resistance. The seeds of a more critical and proactive disability culture are contained in the writings of Paul Hunt, who himself was a long-term inmate of residential institutions.

Maybe we have to remind people of a side of life they would sooner forget. We do this primarily by what we are. But we can intensify it and make it more productive if we are fully conscious of the tragedy of our situation, yet show by our lives that we believe this is not the final tragedy. (Hunt 1966:156)

From the 1960s, with gathering forms of social protest spurred initially by the black civil rights movement in America, residential institutions provided a fertile seedbed for disabled activism. The emergence of the independent living movement in America gained a further significant stimulus with the return of disabled veterans from the Vietnam War. In Britain, disabled people's campaigns can be traced to action by a group of disabled residents at the *Le Court* Cheshire Home in Hampshire. These early years were taken up with identifying common interests and a policy focus for political grievances. As the disabled activist Elspeth Morrison explains,

In the early days, if you take the personal as political argument, then meetings were deeply political in that it was very much personal experience which was getting people up and talking; about what it was like to have their particular impairment, what things dis-

abled them, how the world saw them and what it felt to be like that. (Quoted in Campbell and Oliver 1996:108-9)

The crucial divide in developing a disability consciousness has been to move away from the view that disability is an individual problem that requires equivalent individual (mainly medical) solutions—hence the significance of reading or hearing about other disabled people's experiences in books and journals and watching specialist disability TV programs. Since the 1970s, there has been a steady growth of disabled people's writings on their experiences, including the appearance of an "alternative" disability press, such as *Disability Rag* and *Mouth* in the United States. A significant proportion of disabled people have become sensitized to the shared experience of disability, although diagnoses of its sources and appropriate action are less agreed on.

Increased political activism also confronts the images of passivity and dependence that are so widely disseminated in the media. This has led to new representations of disabled people as active participants in protest action against inaccessible buildings and transport, charity events such as telethons, welfare benefit cuts, and a broad range of campaigns for civil rights. In the United Kingdom, for example, the media started to provide images of disabled people chaining themselves to buses and trains, blocking roads, and crawling along the streets (Pointon 1999). This, in turn, threw the spotlight on competing views among disabled people and contrasts between established organizations for disabled people and those organizations of disabled people that are controlled by disabled people themselves. A whole new realm of disability politics impressed itself on the media.

How the news media have responded is revealing. There was an overwhelming consensus that ensured the portrayal of disabled people as embroiled within a personal tragedy, a burden, surrounded by devoted caregivers, and, in the "best" cases, demonstrating the quality of courageous battlers. Initially, newspapers and TV were bemused and uncertain how to present these contrary images. References to the "last civil rights battle" were mixed with concerns that disability protest threatened to alienate their supporters or that acceding to the protesters' demands for an accessible environment was simply too expensive to contemplate. Although the political climate was changing toward disabled people, there was ample evidence that traditional prejudices had not been eliminated. Thus, editorial space was granted by the respected British broadsheet, *Sunday Telegraph*, to a condemnation of "the furious Quasimodos" who had engaged in a "red paint" demonstration in Downing Street. According to the writer, "They seemed not merely visually revolting, but completely horrible, embittered people" (Wilson 1997).

Years of campaigning eventually led to the 1996 Disability Discrimination Act, but it failed to go far enough for significant sections of the disabled people's movement. As Ann Pointon (1999) notes, "The press was playing to a largely sympathetic but relatively uninformed readership" (p. 232). Stories about the inclusion of people with HIV/AIDS with the "disabled" category and fears of the cost and impact of destroying historic sites to make them accessible dominated, rather than continuing concerns among disabled people that the act was little more than symbolic. Specialist disability radio and TV programs gave this subject fuller attention but failed to reach a mass audience, particularly among nondisabled people. There were also splits in the alliance of disability organizations. In sum, the wider disabled audience has started to openly reevaluate its own circumstances and experiences, leading to increased political activity, without overturning dominant media images.

#### **IDENTITY POLITICS**

Over the past decade, social theorists on both sides of the Atlantic have become engrossed with theories of the body and the ways in which it has become a key site for struggles around identity. Attention to self-improving and healthy "body projects" is regarded as a central theme in contemporary consumerist culture. This has given added significance to and exacerbated the exist-

ing representation of many disabled people in terms of their "flawed" bodies and as "dustbins for disavowal." Nondisabled people's anxieties about loss of control and incapacity are projected onto disabled people through artistic and media imagery (Hevey 1992; Shakespeare 1994; Thomson 1997; Wendell 1996).

What we fear, we often stigmatize and shun and sometimes seek to destroy. Popular entertainments depicting disabled characters allude to these fears and prejudices or address them obliquely or fragmentarily, seeking to reassure us about ourselves. (Longmore 1987:66)

In contrast, identity politics is based on membership of an oppressed or marginalized group and extolling its virtues. According to survey evidence, Fine and Asch (1988) report that 74 percent of disabled Americans report a sense of common identity. This sense of "commonality" is not necessarily based on adherence to a social model of disability, nor does it necessarily lead to political activism. The transition to a disabled identity is often slow and uncertain, rather than a dramatic conversion "on the road to Damascus." Moreover, the character and the extent of this identification are not fixed but open to reformulation. This uncertainty is compounded because disability interacts within other major sources of identity or difference. Hence, what it means to be a young, disabled white woman, as opposed to an older, disabled black man, for example, defies easy categorization.

The generation of a separate cultural identity has divided disabled people. While some groups, such as deaf people, have long regarded themselves as having a distinctive culture, the most disabled people have been less enthusiastic. As Vic Finkelstein has noted,

Firstly, there is a great deal of uncertainty amongst disabled people whether we do want "our own culture." After all, we all have had the experiences of resisting being treated as different, as inferior to the rest of society. So why now, when there is much greater awareness of our desire to be fully integrated into society do we suddenly want to go off at a tangent and start trying to promote our differences, our separate identity? Secondly, at this time, even if we do want to promote our own identity, our own culture, there has been precious little opportunity for us to develop a cultural life. Certainly few of us would regard the endless hours that disabled people used to spend basket weaving under the direction of occupational therapists in day centres as an artistic contribution that disabled people made to the cultural life of humankind. (Finkelstein, quoted in Campbell and Oliver 1996:111)

Yet as Simi Linton (1998) notes, from her American vantage point of the end of the century, disabled people have "solidified" as a group, although this still encompasses considerable individual variation.

The cultural narrative of this community incorporates a fair share of adversity and struggle, but it is also, and significantly, an account of the world negotiated from the vantage point of the atypical. Although the dominant culture describes that atypical experience as deficit and loss, the disabled community's narrative recounts it in more complex ways. The cultural stuff of the community is the creative response to atypical experience, the adaptive maneuvers through a world configured for non-disabled people. The material that binds is the art of finding one another, of identifying and naming disability in a world reluctant to discuss it, and of unearthing historically and culturally significant material that relates to our experience. (Linton 1998:5)

The process has been likened to the experience of black people or gays and lesbians, insofar as attitudes and emotions hitherto confined to the "private" sphere have been translated into a public affirmation.

"Coming out" has become a favoured phrase among disabled people to signify moving toward an open identification as a disabled person. The personal is political, as shame and fear are personal burdens that are challenged by being made public. (Linton 1998:22)

This emphasis on identities, which have been "hidden from history" or submerged by "master" identities such as social class, "whiteness", or heterosexuality, is very much a feature of recent social protest movements (Weeks 1994). What had been a source of exclusion and marginalization is translated into a source of pride (as in "glad to be gay"). Yet this application to people with impairment is typically regarded as more contentious, with the notion of "glad to be impaired" far less accepted as a unifying theme for disabled people, and the calls for people with impairment to "come out of the closet" are meaningless for so many disabled people.

Hence, the emphasis on "multiple identities" focuses on what differentiates one disabled person from another disabled person. This is illustrated by the ways in which "disabled dykes" are excluded in "every sphere of lesbian cultural production" (Tremain 1996:16) because they expose

the white heterosexualism that dominates the disability rights movement, a movement which seldom aligns itself with queer struggles for justice in the institutional, symbolic-discursive, and social realms. (Tremain 1996:21)

The ambition of "consciousness raising" was to build on what was regarded as the common experience of social oppression among disabled people. This would lead to the growth of a general disability culture. However, this prospect has been increasingly criticized on the grounds that it reflects a white, middle-class, male perspective on the social world (Barnes, Mercer, and Shakespeare 1999). With the acknowledgment of social divisions within the disabled population, the presumed homogeneity of disability culture was replaced by cohesive subgroups identified (e.g., on the basis of gender, race, and age) or by impairment. Most recently, social theorizing has been preoccupied with the fluidity of social identity and its continuing re-creation and representation, through practice and discourse, across "multiple identities." This stressed the shifting boundaries of a disabled identity and the dissolution of the category of "disabled person."

An often overlooked issue in this deconstructionist approach, as Iris Young (1990) argues, is that it ignores power differences and conflicts of interest, both within and between these communities, while "contingent identities" are themselves reified in social policy and social protest.

## **DEAF CULTURE**

The process of exclusion has been fundamental to the development of Deaf culture. There are references to hearing impairment stretching back at least to ancient Greece and the Old Testament in Western history. In the case of contemporary Deaf culture, it has its roots in the eighteenth century and the discovery of "deafness" and the development of schools for deaf children. Indeed, this was a period when countries across Europe began to develop education and training for specific groups of people with impairment, with a dozen schools for children with severe hearing impairment established by the end of the eighteenth century (Davis 1995).

Until that time, deaf people had little shared experience. They were typically isolated from other deaf people and lacked a shared, complex means of communication. The only exceptions were those who lived in families or areas where there were other deaf people. Given their effective exclusion from an oral culture, regular social interaction with other deaf people encouraged the growth of sign language as a means of communication. Restricted finger signs were supplanted by sign language (as is illustrated in its use by an established Deaf community in Paris in the second half of the eighteenth century) (Lane 1984). In North America, this potential is vividly illustrated in Nora Groce's (1985) study, Everyone Here Speaks Sign Language: Heredi-

527

tary Deafness in Martha's Vineyard. An inherited trait was brought to this island off Cape Cod, Massachusetts, in the early seventeenth century, which led to deafness in a relatively high proportion of the island's population. The ratio is estimated at 1 per 150 nondeaf people. Of particular significance is the general use of sign language by the islanders that led to the integration of the deaf minority into the "normal" life of the community. Groce quotes the comments of a Boston Sunday Herald reporter in 1895:

The kindly and well-informed people whom I saw, strange to say, seem to be proud of the affliction—to regard it as a kind of plume in the hat of the stock. Elsewhere the afflicted are screened as much as possible from public notoriety. But these people gave me a lot of photographs, extending back four generations. (Groce 1985:51)

As Linton states (1998:66), "The reporter presaged the deaf pride movement by almost one hundred years," in his amazed comments that "the mutes are not uncomfortable in their deprivation" (quoted in Groce 1985:52-53). In short, the "knowledge of Deaf people is not simply a camaraderie with others who have a physical condition, but is . . . historically created and actively transmitted across generations" (Padden and Humphries 1988:2).

However, in understanding the cultural experience of deafness, it is necessary to distinguish between the following:

- people with a hearing impairment who may be described as deaf or hard of hearing, people who have often acquired or developed hearing loss and are not native users of British Sign Language (BSL) or American Sign Language (ASL),
- people with congenital hearing impairment who have been immersed in a BSL or ASL environment (whether at home with deaf parents or by attending a deaf school) and who then define themselves as deaf.

It is the latter group who provides the members of a Deaf culture that is located in a distinctive, shared language. (Here, the use of the capital "D" denotes membership and recognition of Deaf culture.) In addition, the community may also comprise certain hearing people, such as the children of deaf adults (CODA) who have grown up with sign language and other aspects of Deaf culture (Davis 1995).

Many deaf people explicitly refer to themselves as a linguistic and cultural minority, making the analogy with minority ethnic groups who are similarly likely to be excluded because they lack fluency in the dominant language. This goes with a resistance to being identified as disabled people or people with impairment (Lane 1995). This has been accompanied by considerable resistance to cochlea implants, which have the capacity to restore some hearing function, and to genetic screening to identify for termination a fetus with a likely hearing impairment.

In their struggles to avoid assimilation within an "oralist" culture and retain their separate cultural identity, deaf people have opposed wider campaigns by disabled people's organizations for inclusive schools. Instead, the Deaf community supports special deaf schools as the bastions of Deaf culture generally and, more specifically, for its emphasis on teaching and learning through the media of BSL and ASL. As British deaf activist Paddy Ladd affirms,

Basically deaf people whose first language is BSL should be seen as a linguistic minority . . . our schools go back to the 1790s and our clubs to the 1820s. Our language is much older. Deaf people marry each other 90% of the time, 10% have deaf children. Our customs and traditions have been passed down the ages and these, together with our values and beliefs, constitute our culture. . . . The whole definition of culture is so much wider than the one the disability movement is espousing. (Ladd, quoted in Campbell and Oliver 1996: 120)

Here, separate schooling for deaf children is regarded as central to maintaining deaf identity and consciousness:

All this has been achieved despite the disgusting work of oralists, our schools are where we are socialised into the culture. Integration threatens to destroy these centres of achievement, quite apart from the damage caused by thrusting lone deaf kids into mainstream schools with no access to what teachers are saying, no easy access to the rest of the school's activities, no deaf adults, the total lack of a peer group etc., etc. (Ladd, quoted in Campbell and Oliver 1996:121)

While there are those with a hearing impairment who do not identify in the same way with Deaf culture but see themselves as part of the broader disabled population and disability culture (Corker 1998), they are in a minority. As a result, there has been an uneasy "standoff" between deaf people and organizations of disabled people that has inhibited a political alliance with other groups of disabled people.

## BEYOND "WESTERN" VIEWS OF DISABILITY

While the growth of the disabled people's movement has progressed significantly on a world-wide basis, the Euro-American literature on disability has been slow to acknowledge and review non-Western approaches to disability, including the form and character of disability culture(s). While there has been increased recognition that impairment and disability have different meanings, this is too often a preliminary to describing cultural differences at a superficial level. It encourages a particular form of academic voyeurism in which there is an opportunity to contrast approaches to disability, focusing on the "more exotic" differences, and variously condemn or celebrate one side of the "cultural divide" (Stone 1999).

Comparative studies are a valuable support in arguments for the social construction and contrasting meanings attached to disability, particularly when they attempt to provide an explanation that incorporates material as well as cultural factors (Ingstad and Whyte 1995). Such studies reveal the contingent character of disability over time and between cultures. Religion—over time and across societies—has been a particularly potent force in separating people regarded as "abnormal" (Miles 1995). There is a belief in Western societies that Eastern religions such as Hinduism, Buddhism, and Shintoism represent impairment as a divine judgment and retribution for past sins. This Eurocentric tendency to categorize notions of disability in other parts of the world, where most people (disabled and nondisabled) are thought of as "primitive" or variants on a "personal tragedy," is an approach that has not been seriously addressed by disability writers.

The predominant tone of discussions on disability in non-Western societies is that their approaches and cultures represent traditional life-worlds. These are viewed as inferior or anachronistic, rather than contrary and enduring, with their own strengths, contradictions, and relevance for the present day. The problems in bridging this divide are illustrated in debates within the World Health Organization over the international adoption of a Western, biomedical classification and terminology. There have also been attempts by Disabled Peoples' International to agree on a social model of disability, with its specific terminology. This has been hampered by considerable difficulties in translating the key terms.

## **DISABILITY ARTS**

The emergence of a disability arts movement marks a significant stage in the transition to a positive portrayal of disabled people that builds on the social model of disability. Its focus is on cul-

tural and media representation, and it represents the further self-identification of disabled people while drawing on and contributing to wider political campaigns.

Disability arts would not have been possible without disability politics coming along first. It's what makes a disability artist different from an artist with a disability. (Sutherland 1997:159)

The disability arts movement encompasses several reinforcing dimensions. First, it argues for disabled people to have access to the mainstream of artistic consumption and production. Second, it includes impaired-focused art that explores the experience of living with impairment. Third, and most crucially, disability arts offers a critical response to the experience of social exclusion and marginalization. It involves the development of shared cultural meanings and the collective expression of the experience of disability and struggle. It entails using culture and media to expose the discrimination and prejudice disabled people face and to generate a positive group consciousness and identity (Barnes et al. 1999). This schema importantly retains the crucial distinction between "disabled people doing art" and "disability arts." It is important that disabled people have the right to paint, create, and write about anything, in any way; it does not have to be overtly "political."

Disability arts is potentially educative, transformative, expressive, and participative. It is a conception of cultural action that owes much to playwrights such as German dramatist Berthold Brecht and educationalists such as Brazilian Paolo Freire. They emphasized the potential of disability arts as a progressive, emancipatory force at both individual and social levels. Brecht wrote plays and songs that focus on oppression and injustice, while Freire viewed education as a means of unleashing people's political consciousness. Such accounts have their parallels in feminist analyses, which celebrate a "politics of signification" in which subversive representations or performances illuminate and confront discriminatory barriers and attitudes.

In contrast, traditional approaches to disabled people and the arts have been based on paternalism. It is where disabled people are viewed as incapable of productive work, filled with negative thoughts or unable to communicate their thoughts and feelings with others through normal conversation, that art is offered as a means of therapy or as part of the process of "rehabilitation." This is particularly a feature of the activities promoted within special schools, day centers, and segregated institutions. Such initiatives have tended to individualize and depoliticize creativity, but they have also been exploited for commercial purposes, such as charity Christmas cards. While there is obviously a place for art therapy, disabled people have increasingly developed a more active orientation, which goes beyond conveying a sense of their psychological state of adjustment to their impairment. Too often, art therapy is based on the assumption that disabled people have "nothing to communicate" (Sutherland 1997:159). Disability arts argues exactly the opposite (Vasey 1992). Since its emergence, disability arts has made a distinctive contribution to the growing politicization of disabled people:

Arts practice should also be viewed as much as a tool for change as attending meetings about orange badge provision. . . . Only by ensuring an integrated role for disability arts and culture in the struggle can we develop the vision to challenge narrow thinking, elitism and dependency on others for our emancipation. To encourage the growth of a disability culture is no less than to begin the radical task of transforming ourselves from passive and dependent beings into active and creative agents for social change. (Finkelstein and Morrison 1992:20, 22)

Far from being a sideshow to the "real" political action, disability arts and culture have an important role to play in advancing the interests of disabled people. From the mid-1980s, there has been a substantial increase in work by disabled poets, musicians, artists, and entertainers that articulates the experience and value of a "disabled" lifestyle. These developments repre-

sent a gathering self-confidence among disabled people. Given their widespread exclusion from or disempowerment by mainstream arts training, it has been necessary to start from scratch. It is for this reason that the disabled people's movement has supported and nurtured its own artists (Cribb 1993; Morrison and Finkelstein 1993). Indeed, the involvement of significant numbers in the disability arts is one indicator of the maturity of the disabled people's movement.

Early initiatives in Britain include the first production of a television program in 1975 specifically for (and increasingly produced by) disabled people titled Link and the production of a range of newsletters and magazines by disabled people and groups. In From the Cold, is another magazine produced between 1981 and 1987 by Britain's Liberation Network of Disabled People. Coalition, the magazine of the Greater Manchester Coalition of Disabled People (GMCDP), first appeared in 1986 and is still going strong. In addition, DAIL (Disability Arts in London) magazine first appeared in 1987 and has a national circulation of 3,000 with an estimated 8,000 readers. These magazines include articles, features, reviews, and commentary on disability issues, culture, and arts. Further illustrations of this gathering trend include the establishment of the London Disability Arts Forum in 1986, the Disability Arts Conference in Manchester in 1987, and an upsurge of disability arts in conferences, exhibitions, workshops, cabaret, and performance throughout Britain (Keith 1994; Pointon and Davies 1997). Indeed, by the late 1980s, and in line with the general shift toward programming for minorities, other "specialist" disability programs appeared on British television, including Same Difference, See Hear, and One in Four. In 1993, the British Broadcasting Corporation (BBC) set up the Disability Programmes Unit staffed in the main by disabled people, many of whom had learned the skills of media presentation with Link. This promoted a critical awareness of the rights of disabled people and their growing militancy, which in turn stimulated others to adopt a "disabled"

Parallel trends in North America led to a flourishing disability press, including *The Disability Rag*, the unofficial newspaper of the American independent living movement that began publication in 1980 (Brown 1997; Davis 1995). Frank Bowe (1978) offers one early view of the beginnings of a disability consciousness in America in the 1960s and 1970s. Autobiographical accounts flourished, and if most concentrated on the routine "living with my impairment" approach and individualistic adjustments (Brown 1997; Kleinfield 1977; Orlansky and Heward 1981), there were notable exceptions, such as Irving Zola's (1982) account of his personal and intellectual journey in rethinking disability and identity. This literature was complemented by a gathering production of novels, comedy, songs, poetry, drama, paintings, and sculpture that increasingly conveyed an emerging sense of group identity and interests (Brown 1997; Davis 1995; Hirsch 1995; Saxton and Howe 1989; Tremain 1996). The conclusion of American commentators is that disability culture flowered through the 1980s as a complement to disability rights protests. It helped to cement a group consciousness so that by the early 1990s, a "disability culture movement" was firmly established (Brown 1997; Hirsch 1995; Longmore 1995; Shapiro 1993).

Recognition of the importance of involving disabled people in mainstream culture has also taken off. In the United States, the Americans with Disabilities Act (ADA), for example, forced suppliers of television sets to build in a decoder chip so deaf people could receive a "closed-caption" (a type of subtitling) system for viewers with hearing impairment. In the United Kingdom, National Lottery funding was awarded to the Royal School for the Deaf to help build Europe's sign language video library, the first phase of a £1 million National Sign Language Video Centre.

Yet despite all these developments, notions such as "disability culture," "disability pride," and the "celebration of difference" remain problematic for many disabled people. This is particularly the case for those whose impairment is debilitating and painful or often results in premature death. While other oppressed groups may proclaim that "black is beautiful" or pronounce themselves "glad to be gay," it is harder for many disabled people to offer similar accolades to their impairment. While agreeing about the significant sociopolitical origins of many of the disabling barriers facing disabled people, many feel uneasy with assertions such as, "We can celebrate, and take pride in, our physical and intellectual differences" (Morris 1991:189).

Disabled people are more likely to develop an attitude of ambivalence toward impairment, insisting that people with perceived impairment should be allowed to lead valued lives while also refusing to glorify impairment.

The potential of disability arts is that it provides a vital component in the construction of an accessible route to empowerment. As Morrison and Finkelstein (1993) argue, disability arts, as well as the disabled people's movement, provides space for critical reflection on the variety of experiences among disabled people. However, the impact of disability culture and art will itself be exclusionary if it loses touch with its disabled constituencies. There is also the constant concern that it will be assimilated into mainstream culture with the result that its political significance is neutralized. Yet the potential contribution of disability arts to challenging the social exclusion of disabled people remains crucial.

We are a long way... from emancipation, but to help us to get there I think committed disabled activists have the job of producing work of real clarity which truly describes our situation, so there can be no misunderstanding by anyone of the fact that we are oppressed and that there must be no recreation of that oppression in millennia to come. (Vasey 1992:13)

#### CONCLUSION

Historically, nondisabled people have produced representations of disability. This has resulted in a pervasive disabling imagery that has reinforced social and cultural divisions between disabled and nondisabled people. With the recent politicization of disabled people, a stimulus has been given to the formation of a disability culture. The aim has been to counter the individualization and medicalization of disability, the essentialist and determinist definitions of disability, the moral-laden character of "normalcy" and negative stereotyping of disabled people as well as disability as a metaphor for social exclusion, and the lack of subjectivity and agency among disabled people.

By highlighting difference and multiple identities, the spotlight immediately focuses on its political implications. Whereas some see renewed solidarity born out of recognizing multiple identities and differences, others fear that this, coupled with loss of a clearly defined goal, undercuts both a disability culture and a serious political project. An emphasis on fluid identities undermines political cohesion. It is a disability culture that helps generate and sustain those meanings, identities, and the consciousness that take a political movement forward.

The "new cultural politics of difference" seeks to resist the dominant representations of disability and establish a new disability identity (or identities). This is cast as a struggle over cultural hegemony, which entails shifting the balance of power relations. The search for new political strategies by disabled people has led to the development of a vibrant disability arts movement that is contesting a Gramscian-style cultural "war of position" in which dominant perspectives are being openly challenged (Hall 1992). The dilemma for those engaged with a broad disability culture is that it is constructing from new, where disabled people are themselves drawn in several directions by their own internal "differences." A further concern is that the exclusive focus on cultural representation is that it is disconnected from the wider processes of social exclusion and material disadvantage.

The potential of disability culture is revealed in its reinforcement of an "essential" similarity that makes political intervention possible; the dilemma is that disabled people, like other oppressed groups, have to constantly negotiate several kinds of difference, such as gender, race, class, and age, in their lives. Canadian writer Susan Wendell (1996) contends that "it would be hard to claim that disabled people as a whole have an alternative culture or even the seeds of one" (p. 273). As we have tried to show, many disabled people would strongly dispute her conclusion. They would also recognize that the impact of disability consciousness and culture has not been evenly felt across the disabled population. It offers new possibilities but also presents

new contradictions. Nevertheless, the generation of a vibrant disability culture is central to confronting the social exclusion of disabled people.

### REFERENCES

Barnes, C. 1992. Disabling Imagery and the Media: An Exploration of Media Representations of Disabled People. Belper: British Council of Organisations of Disabled People.

Barnes, C., G. Mercer, and T. Shakespeare. 1999. Exploring Disability: A Sociological Introduction. Oxford, UK: Polity.

Battye, L. 1966. "The Chatterley Syndrome." Pp. 3-17 in Stigma, edited by P. Hunt. London: Chapman.

Biklen, D. and R. Bogdan. 1977. "Media Portrayals of Disabled People: A Study of Stereotypes." Interracial Books for Children Bulletin 8:6-7.

Bogdan, R. 1996. "The Social Construction of Freaks." Pp. 23-38 in Freakery: Culture Spectacles of the Extraordinary Body, edited by R. G. Thomson. New York: New York University Press.

Bowe, F. 1978. Handicapping America. New York: Harper & Row.

Brown, S. E. 1997. "'Oh, Don't You Envy Us Our Privileged Lives?' A Review of the Disability Culture Movement." Disability and Rehabilitation 19 (8): 339-49.

Campbell, J. and M. Oliver. 1996. Disability Politics: Understanding Our Past, Changing Our Future. London: Routledge Kegan Paul.

Campling, J., ed. 1981. Images of Ourselves: Women with Disabilities Talking. London: Routledge Kegan Paul.

Clogson, J. 1990. Disability Coverage in Sixteen Newspapers. Louisville: Avocado.

Corbett, J. and S. Ralph. 1994. "Empowering Adults: The Changing Imagery of Charity Advertising." Australian Disability Review 1:5-14.

Corker, M. 1998. Deaf and Disabled, or Deafness Disabled. Milton Keynes, UK: Open University Press.

Cribb, S. 1993. "Are Disabled Artists Cotton-Wooled?" Disability Arts Magazine 3 (2): 10-11.

Cumberbatch, G. and R. Negrine. 1992. Images of Disability on Television. London: Routledge Kegan Paul.

Darke, P. 1994. "The Elephant Man (David Lynch, EMI Films, 1980): An Analysis from a Disabled Perspective." Disability and Society 9 (3): 327-42.

——. 1995. "Autobiographies of Discovery." Disability Arts Magazine 5 (2): 11-13.

——. 1998. "Understanding Cinematic Representations of Disability." Pp. 181-97 in The Disability Reader, edited by T. Shakespeare. London: Cassell.

Davis, L. J. 1995. Enforcing Normalcy: Disability, Deafness, and the Body. London: Verso.

Fine, M. and A. Asch. 1988. Women with Disabilities: Essays in Psychology, Culture, and Politics. Philadelphia: Temple University Press.

Finkelstein, V. 1980. Attitudes and Disabled People. New York: World Rehabilitation Fund.

Finkelstein, V. and K. Morrison. 1992. "Culture as Struggle: Access to Power." In *Disability Arts in London*, edited by S. Lees. London: Shape.

Garland, R. 1995. The Eye of the Beholder: Deformity and Disability in the Graeco-Roman World. London: Duckworth.

Gartner, A. and T. Joe, eds. 1987. Images of the Disabled, Disabling Images. New York: Praeger.

Gerber, D. 1996. "The Careers of People Exhibited in Freak Shows: The Problem of Volition and Valorisation." Pp. 38-53 in Freakery: Culture Spectacles of the Extraordinary Body, edited by R. G. Thomson. New York: New York University Press.

Giddens, A. 1989. Sociology. Cambridge, UK: Polity.

Goffman, E. 1961. Asylums. Harmondsworth, UK: Penguin.

Gramsci, A. 1971. Selections from the Prison Notebooks of Antonio Gramsci. Edited and translated by Q. Hoare and G. Nowell Smith. London: Lawrence and Wishart.

——. 1985. Selections from the Cultural Writings. Edited and translated by D. Forgacs and G. Nowell-Smith. London: Lawrence and Wishart.

Groce, N. E. 1985. Everyone Here Speaks Sign Language: Hereditary Deafness in Martha's Vineyard. Cambridge, MA: Harvard University Press.

Hall, S. 1980. "Encoding/Decoding." Pp. 128-30 in Culture, Media, Language: Working Papers in Cultural Studies, 1972-79, edited by D. Hobson and S. Hall. London: Hutchinson. ——. 1988. "New Ethnicities." Pp. 27-31 in *Black Film*, *British Cinema*, edited by K. Mercer. London: Institute of Contemporary Arts.

533

- . 1992. "What is This 'Black' in Black Popular Culture?" Pp. 21-33 in *Black Popular Culture*, edited by G. Dent. Seattle, WA: Bay.
- -----, ed. 1997. Representation: Cultural Representations and Signifying Practices. London: Sage.

Hall, S. and T. Jefferson, eds. 1976. Resistance through Rituals. London: Hutchinson.

Haller, B. 1995. "Rethinking Models of Media Representations of Disability." Disability Studies Quarterly 15 (2): 26-30.

Hevey, D. 1992. The Creatures That Time Forgot: Photography and Disability Imagery. London: Routledge Kegan Paul.

Hirsch, K. 1995. "Culture and Disability: The Role of Oral History." Oral History Review 22 (1): 1-27.

Hughes, B. and K. Paterson. 1997. "The Social Model of Disability and the Disappearing Body: Towards a Sociology of Impairment." Disability and Society 12 (3): 325-40.

Hunt, P., ed. 1966. Stigma: The Experience of Disability. London: Chapman.

Inglis, F. 1993. Cultural Studies. Oxford, UK: Blackwell.

Ingstad, B. and S. R. Whyte, eds. 1995. Disability and Culture. Berkeley: University of California Press.

Karpf, A. 1988. Doctoring the Media. London: Routledge Kegan Paul.

Keith, L. 1994. Mustn't Grumble. London: The Women's Press.

Kellner, D. 1989. Critical Theory, Marxism and Modernity. Cambridge, UK: Polity.

Kent, D. 1987. "Disabled Women: Portraits in Fiction and Drama." Pp. 47-63 in *Images of the Disabled*, Disabling Images, edited by A. Gartner and T. Joe. New York: Praeger.

Kitzinger, J. 1993. "Media Messages and What People Know about Acquired Immune Deficiency Syndrome." Pp. 271-304 in Getting the Message, edited by Glasgow University Media Group. London: Routledge Kegan Paul.

Kleinfield, S. 1977. The Hidden Minority: A Profile of Handicapped Americans. Boston: Little, Brown.

Klobas, L. E. 1988. Disability Drama in Television and Film. Jefferson, NC: McFarland.

Kriegel, L. 1987. "The Cripple in Literature." Pp. 31-46 in *Images of the Disabled, Disabling Images*, edited by A. Gartner and T. Joe. New York: Praeger.

Kurtz, R. 1981. "The Sociological Approach to Mental Retardation." Pp. 14-23 in *Handicap in a Social World*, edited by A. Brechin, P. Liddiard, and J. Swain. London: Hodder and Stoughton.

Lane, H. 1984. When the Mind Hears: A History of the Deaf. New York: Random House.

——. 1995. "Constructions of Deafness." Disability and Society 10 (2): 171-89.

Linton, S. 1998. Claiming Disability: Knowledge and Identity. New York: New York University Press.

Longmore, P. 1987. "Screening Stereotypes: Images of Disabled People in Television and Motion Pictures." Pp. 65-78 in *Images of the Disabled, Disabling Images*, edited by A. Gartner and T. Joe. New York: Praeger.

——. 1995. "The Second Phase: From Disability Rights to Disability Culture." Disability Rag and Resource 16:4-11.

McQuail, D., ed. 1972. Sociology of Mass Communications: Selected Readings. Harmondsworth, UK: Penguin.

Meekosha, H. and L. Dowse. 1997. "Distorting Images, Invisible Images: Gender, Disability and the Media." Media International Australia 84 (May): 91-101.

Miles, M. 1995. "Disability in an Eastern Religious Context: Historical Perspectives." Disability and Society 10 (1): 49-70.

Morris, J. 1991. Pride against Prejudice. London: The Women's Press.

Morrison, K. and V. Finkelstein. 1993. "Broken Arts and Cultural Repair: The Role of Culture in the Empowerment of Disabled People." Pp. 122-27 in *Disabling Barriers—Enabling Environments*, edited by J. Swain, V. Finkelstein, S. French, and M. Oliver. London: Sage.

Murphy, R. 1987. The Body Silent. London: Phoenix House.

Norden, M. 1994. The Cinema of Isolation: A History of Disability in the Movies. New Brunswick, NJ: Rutgers University Press.

Oliver, M. 1983. Social Work with Disabled People. Basingstoke, UK: Macmillan.

— . 1990. The Politics of Disablement. Basingstoke, UK: Macmillan.

Orlansky, M. and W. Heward. 1981. Voices: Interviews with Handicapped People. Columbus, OH: Merrill.

Padden, C. and T. Humphries. 1988. Deaf in America: Voices from a Culture. Cambridge, MA: Harvard University Press.

Parker, R. A. 1988. "An Historical Background." Pp. 1-38 in *Residential Care: The Research Reviewed*, edited by National Institute for Social Work/I. Sinclair. London: Her Majesty's Stationery Office.

- Philo, G., ed. 1996. Media and Mental Distress. Harlow, UK: Addison-Wesley.
- Pointon, A. 1997. "Rights of Access." Pp. 234-40 in Framed: Interrogating Disability in the Media, edited by A. Pointon and C. Davies. London: British Film Institute.
- . 1999. "Out of the Closet: New Images of Disability in the Civil Rights Campaign." Pp. 222-37 in Social Policy, the Media and Misrepresentation, edited by B. Franklin. London: Routledge Kegan Paul.
- Pointon, A. and C. Davies, eds. 1997. Framed: Interrogating Disability in the Media. London: British Film Institute.
- Ross, K. 1997. Disability and Broadcasting: A View from the Margins. Cheltenham, UK: Cheltenham and Gloucester College of Higher Education.
- Saxton, M. and F. Howe. 1989. With Wings: An Anthology of Literature of Women with Disabilities. London: Virago.
- Schuchman, J. 1988. Hollywood Speaks: Deafness and the Film Entertainment Industry. Urbana: University of Illinois Press.
- Shakespeare, T. 1994. "Cultural Representations of Disabled People: Dustbins for Disavowal." Disability and Society 9 (3): 283-301.
- Shapiro, J. P. 1993. No Pity: People with Disabilities Forging a New Civil Rights Movement. New York: Times Books.
- Shearer, A. 1981. Disability, Whose Handicap? Oxford, UK: Blackwell.
- Smith, S. and A. Jordan. 1991. What the Papers Say and Don't Say about Disability. London: Spastics Society.
- Sontag, S. 1991. Illness as Metaphor: AIDS and Its Metaphors. London: Penguin.
- Stone, E., ed. 1999. Disability and Development. Leeds, UK: The Disability Press.
- Sutherland, D. 1997. "Disability Arts and Disability Politics." P. 159 in Framed: Interrogating Disability in the Media, edited by A. Pointon and C. Davies. London: British Film Institute.
- Thomson, R. G. 1997. Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature. New York: Columbia University Press.
- Tremain, S. 1996. Pushing the Limits: Disabled Dykes Produce Culture. Toronto: The Women's Press.
- Vasey, S. 1992. "Disability Arts and Culture: An Introduction to Key Issues and Questions." In *Disability Arts Culture Papers*, edited by S. Lees. London: Shape.
- Weeks, J. 1994. The Lesser Evil and the Greater Good: The Theory and Politics of Social Diversity. London: Rivers Oram.
- Wells, H. G. 1979. The Complete Short Stories of H. G. Wells. London: Ernest Benn.
- Wendell, S. 1996. The Rejected Body: Feminist and Philosophical Reflections on Disability. London: Routledge Kegan Paul.
- Williams, R. 1958. Culture and Society 1780-1950. London: Chatto and Windus.
- ----. 1980. Problems in Materialism and Culture, London: New Left.
- ----. 1981. Culture. Glasgow, UK: Fontana.
- -----. 1989. Resources of Hope. London: Verso.
- Wilson, A. N. 1997, "How Not to Win Friends," Sunday Telegraph, December 28.
- Woodward, K., ed. 1997. Identity and Difference. London: Sage.
- Young, I. M. 1990. Justice and the Politics of Difference. Princeton, NJ: Princeton University Press.
- Zola, I. K. 1982. Missing Pieces: A Chronicle of Living with a Disability. Philadelphia: Temple University Press.
- ——. 1985. "Depictions of Disability—Metaphor, Message, and Medium in the Media: A Research and Political Agenda." *The Social Science Journal* 22 (4): 5-17.