



Review of Disability Studies

AN INTERNATIONAL JOURNAL

Volume I Issue 4 2005

The Review of Disability Studies: An International Journal

Volume 1, No. 4, 2005

ISSN 1553-3697 (Print) 1552-9215 (Online)

www.rds.hawaii.edu

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University of Hawaii at Manoa, Honolulu, Hawaii, U.S.A.

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Printing and Design – CDS Media Center, Coordinator, Thomas H. Conway.

The Editors would like to thank the following individuals for their support of the Review of Disability Studies (RDS):

RDS Distinguished Fellows – Barbara Altman, U.S.A.; Colin Barnes, United Kingdom; Rolf Bergfors, Sweden; Frank Bowe, U.S.A.; Vic Finklestein, United Kingdom; Lex Frieden, U.S.A.; Gisella Hermes, Germany; Judith Heumann, U.S.A.; Kalle Konkola, Finland; Kathy Martinez, U.S.A.; Mark Medoff, U.S.A.; Paul Steven Miller, U.S.A.; Osamu Nagase, Japan; Susan O’Hara, U.S.A.; Trevor Parmenter, Australia; Joakim Peter, Chuuk, Federated States of Micronesia; Adolf Ratzka, Sweden; Katherine Seelman, U.S.A., Susan Sygall, U.S.A., and Anthony Thanasayan, Malaysia.

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Research Articles

Independent Living, Politics and Policy in the United Kingdom: A Social Model Account

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Abstract: This paper provides a social model of disability inspired analysis of the philosophy of independent living and its implications for policy developments for disabled people in the United Kingdom. It is argued that the policy changes needed for disabled people's meaningful emancipation pose a direct challenge to current thinking on disability policy in particular and capitalist development in general.

Key Words: capitalism, independent living, politics

Introduction

Firmly rooted in the ideological and cultural traditions of western society, the notion of independent living, as used by the international disabled people's movement, represents a radical challenge to conventional thinking on disability. It encompasses both an ideological and practical solution to the everyday economic and social deprivations encountered by the overwhelming majority of disabled people and their families across the world. Also independent living has the potential not only to enhance the quality of life of people directly affected by disability, but also that of other structurally disadvantaged groups such as women, minority ethnic groups, lesbians and gay men, and older people.

To explain these claims further this paper will first examine orthodox thinking on disability and an alternative view emanating from disabled people and their organisations. Attention will then turn to the idea of independent living

and its impact on policy development. The final part will address the ideological, cultural and practical implications of these developments.

Orthodox Views of Disability and the Challenge from Disabled People and Their Organisations

There is a wealth of anthropological evidence that throughout history people with accredited impairments, who would today be considered disabled, have existed in relatively large numbers in all societies across the world. It is also evident that social responses to impairment and disability are historically, culturally and situationally variable (Hanks & Hanks, 1948; Scheer & Groce, 1988; Ingstad & Whyte, 1995).

Notwithstanding variations within Western culture, there is a discernable cultural bias against people with any perceived biological abnormality or flaw that can be traced back to the ancient world of the Greeks and Romans (Garland, 1995). Although variable both in form and degree at different times and in different locations across Europe during the dark ages and the feudal period, perceptions of impairment and disability have been fairly consistent since the Enlightenment and the industrial revolution of the nineteenth century (Finkelstein, 1980; Oliver, 1990; Stiker, 1998; Gleeson, 1999).

This bias is due to the ideological, cultural and material changes that accompanied capitalist development. During the eighteenth century, Enlightenment thinkers produced a range of progressive ideas including a critique of established religions, an emphasis on the value of rational science, a commitment to social progress, and the generation of philosophies of secular, rational self-interest such as Liberal Utilitarianism. Later, these ideas were compounded by the evolutionary theories of Charles Darwin and their use by Social Darwinists and the Eugenics Movement.

In the nineteenth century, industrialisation, urbanisation and the spread of wage labour further enhanced the problems faced by anyone either unable or unwilling to compete for employment in the newly formed factory-based work systems (Ryan & Thomas, 1980; Oliver, 1990; Barnes, 1991; Gleeson, 1999). Such people were scrutinised and categorised in various ways by doctors and related professionals and segregated from the community into long stay hospitals and various institutions. These policies proliferated throughout much of the Western world during the first half of the twentieth century. The eugenic legacy was particularly influential in many developed countries including the USA and Sweden. The eugenic impulse came to its logical conclusion in the death camps of Nazi Germany in the 1930s and 40s, with the systematic murder of thousands of disabled people considered a burden to the state and, therefore, unworthy of life. A more so-called humanitarian response to the problem of the growing problem of disability did not emerge until the post 1945 period (Drake, 1999).

Before the eighteenth century, impairment and any subsequent disablement was usually explained with reference to religious teachings and/or traditional superstitions, myths and legends from earlier times. Notwithstanding that these miss-interpretations are still evident in some circles, today the prevalent view is that impairment causes disability and that disability is an individual medical problem or personal tragedy with overtly negative economic and social consequences for the individuals concerned, their families and society as a whole.

Moreover, since impairments are the cause of the problem logic dictates that they must be eradicated, minimised or cured. But where cures are ineffective, which is more often than not the case, people with impairments who are labelled disabled are viewed as not quite whole, not normal, and incapable of participating in and contributing to the everyday life of the community. They are, therefore, in need of care. In many

countries this has resulted in the generation of a thriving and costly disability industry comprised of state institutions, private businesses, charities and voluntary organisations staffed by vast armies of professional helpers including doctors, nurses, therapists and social workers. The end result is that disabled people's assumed inadequacy and dependence is assured and reinforced. These perceptions were not seriously challenged until the 1960s and the emergence of the disabled people's movement (Campbell & Oliver, 1995).

Underpinning the political demands of disabled people and their organisations is a socio/political re-interpretation of disability widely referred to as the social model of disability. Originally devised by disabled activists in Britain, this approach derives from disabled people's direct experiences of living with impairment in Western society (UPIAS, 1976). Since its development in the 1970s, the social model has been increasingly accepted and adapted by disability groups throughout the world, and now underpins, either implicitly or explicitly, their thinking (WHO, 2001). It is also evident in disability related policies and initiatives in countries as diverse as Britain, the European Union and China (Stone, 1999; European Commission, 2003; Prime Minister's Strategy Unit, 2005) and the World Health Organization's recently devised "International Classification of Functioning Disability and Health" (WHO, 1999).

The social model of disability is nothing more complicated than an emphasis on the economic, environmental and cultural barriers encountered by people viewed by others as having some form of impairment. These barriers include (a) inaccessible education, information and communication systems, and working environments, (b) inadequate disability benefits, (c) discriminatory health and social support services, (d) inaccessible transport, housing and public buildings and amenities, and (e) the devaluing of people labelled as disabled by negative imagery and representation in the media – films, television and

newspapers. From this perspective, people with designated impairments are disabled by society's failure to accommodate their individual and collective needs within the mainstream of economic and cultural life (Barnes, 1991).

Although the social model has been linked to various theoretical approaches (Priestley, 1998) it is not, nor never was, conceptualised as a social theory of disability. The social model has provided the conceptual foundation for the development of a fully comprehensive materialist account of the social creation of disability, rooted in the work of Karl Marx and Antonio Gramsci and evidenced in the work of Vic Finkelstein (1980), Mike Oliver (1990), and Brendan Gleeson (1999). However, and in view of recent misrepresentations by some writers (Shakespeare & Watson, 2001; Watson, 2002), there are three main points that need to be reiterated about the social model of disability:

- 1) In contrast to the conventional individual medical/deficit model of disability, the social model is a deliberate attempt to switch the focus away from the functional limitations of impaired individuals onto the problems caused by disabling environments, barriers and cultures.
- 2) The social model is a holistic approach that explains specific problems experienced by disabled people in terms of the totality of disabling environments and cultures.
- 3) A social model perspective does not deny the importance or value of appropriate individually based interventions in the lives of disabled people, whether they be medically, re/habilitative, educational or employment based, but draws attention to their limitations in terms of furthering their empowerment and inclusion in a society constructed by non-disabled people for non-disabled people.

In short, the social model of disability is a tool with which to gain an insight into the disabling tendencies of modern society in order to generate policies and practices to facilitate their eradication (Oliver, 2004). It is this train of thought that has influenced the concept of independent living as it is understood in the new millennium in the United Kingdom (UK) (Barnes, 2003).

Independent Living in the 21st Century

The phrase "independent living" first entered the English language in the 1970s, following its adoption by disability activists in the USA. What became known as the American Independent Living Movement (ILM) emerged partly from within the campus culture of American universities and partly from repeated efforts by American disability activists to influence US disability legislation. During the 1960s, some American universities had introduced various self-help programmes to enable students with "severe" physical impairments to attend mainstream courses. But these schemes were rarely available outside university campuses. This unacceptable situation prompted some disabled students to develop their own services under the banner of "Centres for Independent Living" (CILs).

Unlike other services *for* disabled people controlled by mainly non-disabled professionals, these new CILs were self-help organisations exclusively run and controlled by disabled people. Further, in contrast to other professionally dominated provisions that focused almost exclusively on medical treatments and therapies within institutional settings, effectively removing disabled people from everyday life, CILs provided a new and innovative range of services and support systems designed to enable people with impairments to adopt a lifestyle of their own choosing within rather than apart from the local community.

Subsequently, the phrase “independent living” has had a considerable impact on disability policy throughout the world. Disabled people and representative organisations are increasingly involved in the development of disability policy at both the national and international level. Also, there are now CILs or similar user controlled organisations providing services and support for disabled people and their families throughout Britain (Barnes, Mercer & Morgan, 2000) and many countries across the globe (Charlton, 1998; Alonso, 2003).

Part of the reason for this apparent and unprecedented success is the almost universal appeal of the concept of independent living within Western culture. The term is apolitical in the sense that it appeals directly to advocates of the politics of the right and of the left, and it is political in that the environmental and cultural changes needed to facilitate meaningful independent living for disabled people will benefit everyone regardless of impairment or status.

Early exponents of independent living allied themselves with the radical consumerism of the 1960s and 70s. Consequently, the independent living movement has a particular appeal to proponents of the ideological cornerstones of capitalist development such as economic and political freedom, consumer sovereignty, and self-reliance. This realization prompted some critics to suggest that the philosophy and policies of the ILM favoured only a relatively small section of the disabled population; notably, young, intellectually-able, middle-class white males (Williams, 1984).

This is, however, a misrepresentation of what the term independent living has come to represent. Indeed, though they are often characterised as providing services for people with physical impairments only, historically, CILs have struggled to provide services for all sections of the disabled community. Where they have not, this is usually due to limited resources, material and human, and/or entrenched opposition from

vested interests within traditional disability service providers.

Furthermore, in view of the dangers of misinterpretation, some disability activists, particularly in the UK where social model thinking is especially influential, have adopted the terms “integrated” or “inclusive” living rather than the original “independent” living to characterise the philosophy on which their activities are based. Such terms have a far greater appeal to the left of centre elements within Britain’s disabled people’s movement. They recognise that humans are by definition “social” beings, and that *all* humans, regardless of the degree and nature of impairment, are interdependent and, therefore, that a truly independent lifestyle is inconceivable (Barnes, 2003).

From this perspective, the ideologies and practices that justify the systematic oppression of people with impairments within capitalist society are similar to those that legitimise the oppression of other disadvantaged sections of the population such as women, minority ethnic groups, lesbians and gay men, and older people. Taken together, they represent an increasingly costly and complex barrier to the development of a truly meaningful inclusive and representative democracy.

Due largely to the intensifying politicisation of disability by disabled people and their organisations during the 1980s and 90s, both in the UK and elsewhere, the phrase “independent living” has been increasingly evident in policy documents produced by health and social service professionals in the context of “community care” services for disabled people. Usually focusing on professionally-led assessments of functional ability and inability, these initiatives bear little resemblance to the principles and practices of the international disabled people’s movement. It is therefore important in the context of political and policy analysis to establish clearly the fundamental principles of independent living according to the writings of disabled activ-

ists, their organisations and supporters around the world.

Despite terminological differences there is general agreement amongst disabled activists and their allies that the philosophy of independent living is founded on four basic assumptions. These include:

- 1) That all human life, regardless of the nature, complexity and/or severity of impairment is of equal worth;
- 2) That anyone, whatever the nature, complexity and/or severity of their impairment, has the capacity to make choices and should be enabled to make those choices;
- 3) That people who are disabled by societal responses to any form of accredited impairment – physical, sensory or cognitive – have the right to exercise control over their lives, and
- 4) That people with perceived impairments who are labeled “disabled” have the right to participate fully in all areas, economic, political and cultural, of mainstream community living on a par with non-disabled peers (Bracking, 1993; Morris, 1993; Charlton, 1998; Barnes, 2003).

Discussion: A Way Forward?

Clearly the concept of independent living is a broad one that encompasses the full range of human experience and rights, including the right to be born with access to appropriate medical treatments as and when they are needed. Moreover, although independent living is commonly associated with disabled people with physical or sensory conditions in the younger or middle age groups, it applies to all sections of the disabled population. This includes people with complex and high support needs, people with cognitive conditions who are labelled in various ways (“learning difficulties”, “behavioural difficulties”, “mental illness”, etc.). Equally impor-

tant, disabled activists have long since pointed out that disabled women, disabled lesbians and disabled gay men, disabled people from minority ethnic groups, disabled children and older disabled people are particularly disadvantaged due to sexism, heterosexism, racism, ageism and other forms of structural oppression and prejudice.

Furthermore, people with designated impairments, however defined, will always experience varying degrees of economic, political and social disadvantage in societies organised around the core capitalist values of individual self help, economic rationality, and the profit motive. In the current socio/political context, in order for disabled people to secure an independent lifestyle, they are required to make a considerable effort. Hence, we need to re-configure the meaning of work for disabled people with complex and comprehensive support needs (Oliver & Barnes, 1998; Abberley, 2002; Barnes, 2003).

To pursue the goal of a “society in which all disabled people are able to participate as equal citizens” (DRC, 2004), we must generate a cultural environment that places the needs of the many on a par with those of the few, and rejects the market led policies of the past. We must also celebrate rather than denigrate the meaning of social welfare, and the state’s role in its provision (Oliver & Barnes, 1998). This is not to suggest that we need more of the traditional top-down approach to state welfare; quite the reverse. There is mounting evidence, from a variety of sources, that conventional professionally-led services are counter productive both in terms of the effective use of resources, financial and human, and the elimination of dependence.

What is needed is a significant shift away from Government support for services controlled and run by professionals and non-disabled people, whether they be state-run or in the voluntary sector, and far greater investment in user-led initiatives at both the national and local levels.

Two notable examples in the U.K. include direct payments to disabled individuals, and the network of user controlled service providers and advocacy groups known variously as Centres for Independent, Integrated, or more recently, Inclusive Living: namely, CILs. The former allows the disabled individual to devise, pay for and, therefore, control their own support systems including the employment of personal assistance according to their own requirements. As in many countries across the world, Britain's CILs provide a range of services for disabled people, their families and related professionals. Examples include user-controlled information, advice and peer support systems, self-operated personal assistance schemes, personal assistant users' support groups, and advocacy and campaign groups. The general ethos of these organisations is to enable people with impairment/s, regardless of cause, to achieve an independent lifestyle of their own choosing and commensurate with that of non-disabled peers (Barnes, Mercer & Morgan, 2000).

Moreover, given that thousands of disabled people across the UK are denied the chance to achieve independent living due to the reluctance of many local authorities to implement a direct payment policy (Glasby & Littlechild, 2002; CSCI, 2004) (legalised under the 1996 "Community Care [Direct Payments] Act", following years of lobbying by disabled people's organisations [Hasler, Campbell & Zarb, 1999]), the distribution of direct payments should be centralised. This could be achieved by setting up a new national body accountable directly to the National Centre for Independent Living (NCIL), an organisation controlled and run by disabled people that emerged from within and is accountable to Britain's CIL movement.

Besides the distribution of direct payments, this new national body could have two further roles; first, to produce an appropriate and standardised assessment procedure for accessing direct payments and, second, to develop and support the nationwide network of locally-based

user-controlled agencies and groups providing services for local direct payment users. To fulfil these roles, NCIL would naturally draw on the wealth of experience that already exists amongst its member organisations, many of whom have been providing these and similar services for more than twenty years (Barnes, 2004).

To achieve a lifestyle comparable to non-disabled peers, disabled people need far more than simply user-controlled services. To attain Independent living disabled people need equal access to mainstream schools, jobs, transport, houses, public buildings, leisure etc. or all the things that non-disabled people take for granted (Bracking, 1993, 14). It is a goal that is far from being achieved despite the introduction of the U.K.'s 1995 Disability Discrimination Act and subsequent amendments. It will be necessary to strengthen and enforce the law and ensure that people with an awareness of disability and "independent living" issues are integrated fully into *all* Government Departments at *all* levels, nationally, regionally and locally. The aim is to initiate and develop effective policies with which to eradicate the various barriers to inclusion in *all* areas of economic and social activity and, in so doing, usher in a further stage in the on-going struggle for a truly equitable and inclusive society.

It is inevitable that this strategy will have significant implications for those charged with the responsibility for managing the economy, as effective barrier-removal will prove costly. But these short-term costs must be offset against the long-term gains of a barrier-free environment in which socially created dependence is considerably reduced if not eliminated altogether. Moreover, whilst such a policy may fly in the face of recent economic and political trends in Britain and elsewhere, it is important to remember that any notion of an inclusive and equitable capitalism is unrealistic and unachievable. And that over recent decades the gulf between the rich and poor has increased rather than decreased within and across nation states, environmental instabil-

ity remains unchecked, and political and social uncertainty has intensified at both the national and international levels. If these tendencies are not to intensify further it is high time that politicians and policy makers, both in Britain and throughout the world, acknowledge this fact and take appropriate steps to develop a meaningful and just alternative.

For disabled people this alternative must be a society in which all human beings regardless of impairment, age, gender, sexual orientation, social class, minority ethnic status can coexist as equal members of the community, secure in the knowledge that their needs will be accommodated in full and that their views will be recognised, respected and valued. It will be a very different society from the one in which we now live. It will be a society that is truly democratic, characterised by genuine and meaningful equal opportunities and outcomes with far greater equity in terms of income and wealth, with enhanced choice and freedom, and with a proper regard for environmental and social interdependence and continuity.

The creation of such a world will be a difficult arduous process and progress toward its construction will be inhibited by cynics who will argue that such a world is unachievable, and little more than a utopian dream. However, as Oscar Wilde so cogently pointed out over a century ago in *The Soul of Man Under Socialism* (first published in 1990):

“A map of the world that does not include Utopia is not even worth glancing at, for it leaves out the one country that Humanity is always landing. And when Humanity lands there, it looks out, and seeing a better country sets sail. Progress is the realisation of Utopias”
(Wilde, 1966, 1090).

Colin Barnes, Ph.D., is a Disabled writer, researcher and activist. He is professor of Disability Studies and founder and director of the Centre for Disability Studies at the University of Leeds, England. He also founded the Disability Archive UK and is cofounder with Geof Mercer of the Disability Press.

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(Other relevant literature can be downloaded free from the Disability Archive UK at: <http://www.leeds.ac.uk/disability-studies/archiveuk/index.html>)

(An earlier version of this paper was presented at the “Social Care Institute for Excellence” Conference on Independent Living: Copthorne Tara Hotel, London, 22nd November 2004).

Leprosy in South India: The Paradox of Disablement as Enablement*

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Abstract: Rooted in ethnographic fieldwork with people affected by leprosy in India, this article argues that certain impairments, in certain social contexts, are simultaneously disabling *and* enabling. This paradox poses difficult challenges, not only for those working with individuals affected with leprosy, but for disability activists and policy-makers.

Key Words: social anthropology, leprosy, South India

Introduction

A clawed hand, with missing or deformed digits, and a face distorted by a sunken nose speaks unambiguously, in most parts of the world, of leprosy. It is the presence of these corporeal signifiers of untreated leprosy that, in the Indian context at least, stigmatises the person affected with leprosy as “a leper” and sees him, or her, barred from many social spaces. Prevent bodily difference, runs much contemporary thinking within leprosy aid agencies, and the person with leprosy will be able to continue with life as usual, rehabilitated within the community, rather than rejected from it. What such a perspective misses, however, is that the same clawed hand and distorted face that provokes social ostracism might also serve as a vital resource for collecting alms and for accessing other benefits. It is this paradox, and its ramifications, that this article sets out to address. It will argue that, in certain contexts, commonly accepted meanings attributed to disability, including those defined by the social model (Oliver, 1990), do not fit with the lived experiences of disabled people. This has important implications both for disability theory and activism.

My argument traces its roots to intensive field research conducted with leprosy-disabled people in South India, a group I have been involved with, in the blurred guises of social worker, friend, donor and anthropologist, for two full decades. Part of my recent fieldwork, in 1999 and 2000, was concerned with illuminating the embodied experience of leprosy. Accepting that leprosy was a socio-historically constituted category as well as a medical condition caused by *Micobacterium leprae*, I had set out to explore what it was like to have leprosy and, in some cases, to be labelled as a “leper.” This label, I should point out, was by no means an inevitable consequence of being diagnosed as having leprosy. Many contemporary patients on new drug regimens bear none of the impairments classically associated with leprosy and so do not usually become categorised as lepers. However, my focus here is on leprosy disabilities, by which I mean the social consequences of leprosy, rather than on leprosy *per se*.

Methodologically, in addition to a conventional anthropological toolbox of participant observation, surveys, interviews and life history accounts, I also experimented with participatory children’s workshops, informant diaries and drama performance. Contemporaneous notes were taken in a daily field diary format, and the illustrative data drawn upon in this article comes from that source. The majority of the research took place in one particular leprosy community, and my movements across its geographical boundaries – accompanying villagers on begging trips or on visits to natal places, for example – reflected those of the people with whom I worked. I did, however, also visit several other leprosy colonies and hospitals for short-term stays (from a couple of days to a week), as well as the head offices of a number of leprosy aid agencies and the projects they supported.

One of the findings of my research was that the assumption of oppression or stigma I started out with formed far too narrow a framework within which to describe the daily lives of the

people I worked with. Disability – or *vikalan-gamu* in Telugu, the language of my informants – was by no means peripheral to their experience, but it was nevertheless only one of the multiple identities on which people drew. In addition, there were times when aspects of the “leper” identity were as enabling as they were disabling. These aspects of disability are often absent from conventional analyses carried out within both medical and social frameworks. My suspicion that an ambiguous experience of disability is not confined to individuals with leprosy in a leprosy colony in India, however, has been borne out by other research. Bogdan’s (1988, p.1996) historical analysis of the American Freak Show, for example, reveals striking resonances between the relationships of showmen and those who have leprosy to their respective bodily differences.

Before illustrating how disability might be simultaneously disabling *and* enabling it is necessary to problematize the notion of disability and other terms associated with it. I thus begin here with a brief exegesis of the British social model, in response to which my argument has been formulated. Subsequent sections, offering an ethnographic overview of the community with which I did my research and an exploration of how leprosy has been socially constructed within India, provide the more specific contexts on which that argument draws for illustration. I then go on to offer particular examples from my own fieldwork and from a wider literature of how disabilities might, in certain cases, be construed as enabling. All this provides the background for our discussion, in a final section, of the implications of such findings for Disability Studies.

Definitions

Debate over the meaning of disability is not simply a matter of semantics. Definitions provide the conceptual frameworks through which disability is theorised and its experience interpreted. In Disability Studies the terms “impairment” and “disability” have been used most

regularly in the ways the Union of the Physically Impaired Against Segregation (UPIAS), a British political organisation, defined them in 1976. These definitions are very familiar to disability scholars, but less so to social anthropologists. An “impairment”, according to UPIAS, refers to “the lack of part of or all of a limb, or having a defective limb or mechanism of the body” (UPIAS, 1976, pp. 3-4; cited in Barnes et al. 1990, p.28). “Disability”, by contrast, is defined as describing the social consequences of particular impairments. As Young neatly exemplifies: “Moving on wheels is a disadvantage only in a world full of stairs” (2002, p. xii)¹.

Such an approach has obvious and enduring appeal for disability activists. If disability is socially constructed, aspects of social structure can be identified as causing the barriers that prevent the full-inclusion of those whose bodies are different from a socially-defined ideal, rather than the biological realities of individual people’s bodily differences. Nevertheless, the imposition of a radical dichotomy between impairment as entirely biological and disability as entirely cultural is problematic in the same way that Cartesian dualism more generally has been shown to be². Quite apart from the bias toward physical disabilities in the UPIAS definition, it is also the case that “impairments” are culturally constructed in much the same way that “sex” is as culturally determined as “gender” (Moore 1994). The Tamasheq of northern Africa, for example, are said to consider the likes of excessive freckles, protruding navels and small buttocks as impairments (Halantine and Berge, 1990, pp.58-59, cited in Ingstad and Whyte, 1995, p.6), none of which are likely to feature on a comparable list in, say, North America. On the other hand, Oliver’s assertion that disablement is nothing to do with individual bodies (1996, p. 35), a statement which suggests that the social production of disability is entirely separate from the embodied experience of impairments, is also problematic. Such a definition demarcates disabled people exclusively as victimised objects

without agency, a characterisation that this article aims to dispel.

As a way of confronting these problems with social model definitions, then, in this article I tend towards Shuttleworth’s and Kasnitz’s more recent definition of impairment as “a negatively construed, cultural perception of a bodily, cognitive, or behavioural anomaly” (2004, forthcoming). Disability, within this framework, is seen as “a negative social response to a perceived impairment” (ibid). In line with Shuttleworth’s and Kasnitz’s broad approach I would add that, since all bodily conditions are phenomenologically experienced, then impairment and disability should also be thought of as simultaneously embodied states.

I am particularly influenced in taking this approach by the work of Pierre Bourdieu, whose notion of “habitus” has the potential to cut through the head-on choice between models that privilege “agency” and those, like the British Social model, that privilege “social structure.” In short, habitus refers to a socially constituted system of cognitive and motivating structures that provide both the individual and the group of which he, or she, is a part with a wide arc of predisposed ways of relating to, categorising, and responding to social situations (Bourdieu, 1990, p. 52ff). As the “embodiment of history” (ibid, p. 57), the habitus “makes possible the free production of all the thoughts, perceptions and actions inherent in the particular conditions of its production – and only those” (ibid, p. 55). Human action, then, is seen as being constituted through a mix of individually and collectively embodied constraints—which unconsciously limits the choices an individual may make—and freedom, within those constraints, to act.

Some have criticised Bourdieu’s approach as too socially reductionist in the same way this article criticises the social model of disability (Shilling, 1993, p.146; Farnell, 1994, p. 931; Comaroff, 1985, p.5). I would argue, however, that Bourdieu’s formulation allows for a more

subtle interpretation. The habitus does not pre-determine a particular course of action in response to a particular stimulus; rather, it limits the range of choices and makes certain responses more probable than others. I suggest that the embodied experience of leprosy within a particular social milieu creates its own habitus; that is, its own ways of structuring responses to the world. The particularity of this experience has implications for how social responses to leprosy are responded to and embodied.

To make the case for a more nuanced, situated approach to defining disability, in the next section I provide an ethnographic description of the leprosy community from where I draw my main examples. I then offer a summary of the socio-historical factors significant in the construction of leprosy in India before coming to the central part of the article: an exploration of the ways in which a disability might also be enabling, and how we might account for this apparent paradox.

Bethany³

The community where I did fieldwork was a self-established leprosy colony in Andhra Pradesh, five miles inland from the Bay of Bengal on India's south-east coast, around 200 miles north of Chennai (Madras) and the same distance east of Hyderabad, the state capital. Since the colonial phrase "leprosy colony" tends to conjure up the image of, in Goffman's terms, a "total institution" (1961, p. 11), the words "village" or "community" probably offer more appropriate frames of reference. Bethany was neither a hospital nor a leprosarium but, at least in its early stages, a squatter settlement of patients with leprosy who had been discharged from a nearby mission hospital. Cured of their biomedical disease but either too institutionalised (many had spent up to a decade in the hospital) to return home, or unwelcome because of the stigma associated with leprosy, the early settlers built makeshift mud and thatch homes on rail-

way owned wasteland, and eked out livelihoods from begging.

That was nearly half a century ago. In the intervening years the village has grown from an initial 30 inhabitants to a population bordering on 1,000. Around half of the population has had leprosy, the rest being their children and spouses. Of those directly affected by leprosy, 300 claimed to be disabled. Around 150 people still beg, but several social development programmes – started by various foreigners who came to stay in the village from the early 1980s – now provided work for around 300. There are also welfare programmes offering medical care, an elementary school, and food for those too elderly to work.

In 1999-2000 there were no other foreigners but myself in the village, and development projects were managed by a project co-ordinator appointed from within Bethany. However, much of Bethany's income continued to be channelled through overseas donors, and a management committee on which they (as well as villagers) were represented, ensured a continued close relationship between Bethany and "the foreigner."

The Social Construction of Leprosy

Leprosy, as a biomedical condition caused by the germ *Micobacterium leprae*, remains highly prevalent in India. 346,000 people, more than half of the world's cases, were registered for leprosy treatment as of 1 April 2003⁴. The national prevalence rate was 3.2 cases per 10,000 people. To put these statistics into perspective, by the World Health Organisation's (WHO's) reckoning, leprosy will cease to be a public health issue when it reaches a prevalence rate of 1 per 10,000. Although this view is hotly contested by many leprosy organisations as over-optimistic, it is clear that India still has a long way to go.⁵

Nevertheless, leprosy is entirely curable with drug therapies, and many people affected by

leprosy these days are successfully treated without any of the bodily changes traditionally associated with the disease. Indeed, Bethany's early settlers had all been "cured" – in the sense that *Mycobacterium leprae* was no longer present in their bodies – and this was why the hospital saw fit to release them back into the community. The fact that most of those discharged from the hospital – many of them bearing the physical marks of leprosy – were unable to return to their natal homes suggests that leprosy is more than just a biomedical condition. Leprosy in India (and elsewhere), in common with other forms of disability, is also a socio-historically constructed category.

For the most part, constructions of leprosy are negative. Defining someone as a "leper" can legitimate their rejection because leprosy has long been perceived, literally in the case of classical Hindu law (Strange, 1859, p. 155), as the manifestation of wrong-doing on the corporeal body. Wise, a nineteenth century scholar of the classic Ayurvedic texts, notes that "when a person dies with it Hindus believe that the person will be affected with it in the next life, unless he performs *praschitta*, penance" (1845, p. 258). *The Laws of Manu* (Burnell and Hopkins, 1971, p. xxiv) also describe leprosy as a consequence of bad *karma* in a previous life. Manu states: "[S]ome evil minded persons... for sins committed in this life, and some for bad actions in a preceding state, suffer a morbid change in their bodies." They "bear the marks of their yet unexpiated crimes in the human form" so that "an atrocious sinner becomes leprous..." (Strange 1859, p. 155, cited in Buckingham, 1997, p. 60).

The *Kanmakantam* – a medical treatise attributed to the medical sage Agastyar (Kandaswamy Pillai, 1979, p. 256, 264) – makes a similar connection between leprosy and negative behaviour. The latter includes "plucking an unflowered bud; killing animals; causing trouble to one's parents; destroying icons of gods; swearing at noble men; slashing down flowering plants in

a bower" (Akattiyar, 1976, p. 16, cited in Buckingham 1997, p. 61). As a consequence, "coin-like scaly patches appear on the skin – they decay and blood drips from them. [To cure it] the *karmas* have to be expiated" (ibid).

Missionary discourses of the mid-late nineteenth century reinforced this by appropriating the leprosy-deformed body as a metaphor for the diseased soul.⁶ Biomedical practitioners, in positing segregation as a means of disease control, institutionalised the labelling of "the leper" and his or her removal from the family home. For a time, the fear that leprosy might be hereditary also permitted the segregation of male and female "lepers". Mission hospitals created a parent-child type relationship between "lepers" and their mostly European carers; one which continues to shape the relationships people with leprosy have with foreign donors, volunteers and anthropologists in the present (cf Staples, 2005).

This morally negative construction of "the leper" as "a public nuisance" (Selections, 1896, p. 23) and as a potential source of disgrace to his or her relatives remains. Few people I spoke to in Bethany described leprosy in terms of *karma*, but, having converted in the Mission hospital to Christianity, some of them did describe leprosy as retribution for past sin. "I used to go with *so* many women," one young man recalls being told by a more senior male, "Made *so* many mistakes in my life. But look at me now." As he said this, the older man held out in demonstration what remained of his fingerless hands, and pointed down to the stumps of his feet. "I got all this as a punishment," he said, "So you watch out!" The ill-treatment one received as a consequence of leprosy, so perceived, was the fault of the individual sufferer, not the social institutions that reproduced that ill-treatment.

Local people, for example, sometimes use the leper label to stigmatise their neighbours in Bethany as "drunkards" and "madmen", and I have heard NGO workers refer to them (usually

privately) as awkward, psychologically disturbed and (less privately) as “obstacles to development” (cf Gardner and Lewis, 1996, p. 15). The “leper” tag does more than identify a disease; in South India it also carries highly negative connotations about people labelled with it.

Represented in this way, the social model appears to have much to commend it as a frame for understanding experiences of leprosy-related disability. The case of a friend I have described elsewhere (Staples, 2003b, p.307) provides a neat example. Kotaiah asked a surgeon to cut his leprosy-deformed fingers off in a straight line, so it would appear they had been injured in a machinery accident rather than as a consequence of leprosy. The fingers were physically more useful as they were; he could still ride a bicycle, for example. As he saw it, however, they would be less socially debilitating if they were removed altogether. His disability, from this perspective, was entirely socially constructed.

However, Kotaiah was dissuaded from going ahead with the surgery, which suggests he came to recognise the practical value of leprosy-deformed fingers over having no fingers at all. What this begins to suggest, then, is that while disabilities are most certainly defined in the course of social interactions, they are not entirely explicable within a framework of oppression. In the next section, I use ethnographic examples to show how people in Bethany, in developing a distinctively Bethany “habitus”, discovered a more explicit social value in the very bodily markings and deformities that simultaneously identified them as “lepers.”

Disability as Enabling

The Begging Tin as Passport

It is in the field of alms collection that my informants were most obviously enabled by leprosy disabilities vis-à-vis their neighbours in adjoining hamlets. The clawed hand, that stigmatised the leprosy affected person as “a leper” and saw him or her barred from many social spaces,

was symbolically transformed in begging contexts to become a vital resource.

Begging in Bethany tended to be conducted a long way from home, most popularly on the streets of Mumbai/Bombay, where up to 150 Bethany dwellers spent large chunks of the year. Although group alms collection had once been popular, most of the begging people I worked with in 1999-2000 now preferred to work alone or in couples. “It’s safer that way,” one experienced beggar, Raju, put it. “If the police suddenly appear, a single man or woman can get away more easily than a big group. It also means that we get to keep whatever we raise, we don’t have to share it out with the rest of the group.” Nevertheless, although they spent their days walking through or, in the case of those without legs, sitting on the streets of the city, in the evenings they congregated together at the makeshift settlement they had created in the Mumbai suburbs. This settlement had been formed on encroached railway land and, as a consequence, was regularly disturbed by the municipal authorities with water jets. Even so, by employing their own watchman, at least they had somewhere to keep their essential belongings while they were out begging during the day, and a place to cook meals and sleep at night.

The begging itself also followed a routine, as this extract from the field notes I made while staying with the group in Mumbai made clear:

By 7.30am, we’ve arrived at [that day’s begging location] by train. We had taken tea at the station with a group of Bethany people – maybe 15 in total – and then travelled together. Only [my research assistant] and I have tickets. Raju [who is going begging] shakes his rattle and begging tin and declares “this is my season ticket, my passport!” When he comes out with us at other times, when he’s not begging, he always buys a ticket. The group congregates again on a street corner once they get off the train; they take tea and,

once everyone is there, sit down on the pavement and pray together, the women covering their heads with their saris. Then they all set off, individually and in different directions, to work the streets of the surrounding area. Everyone has a rattle and a begging tin, the men have hats and the women all wear shirts over their saris and head scarves. In addition everyone carries a white shoulder bag made from sacking [which they] use to put alms in, especially gifts in kind (clothes, food-stuffs) and they keep a water glass and sometimes a bottle of water in there too.

As advised by Raju, while he goes down one street shaking his rattle and holding his can on his outstretched other arm (with bandaged hand), we take another route to [a nearby Catholic] church, where, he tells us, Bethany people will be working in shifts throughout the day...

...The first one we spot is Mariamma, going from car to car, asking the passengers for money – especially cars and taxis which are stopping to drop people off to go to church. She's wearing the "Bethany uniform": plimsolls, socks and headscarf, and carrying a rattle and a tin...

...[Later], talking to Raju on the way to our lunch stop, he claims that if one in a hundred people gives he feels grateful. Usually they give 50 paise or a rupee coin – occasionally Rs5 or Rs10 if he gets them with a longer story, and people in cars tend to give more often than passers-by in the street. He demonstrates his patter: "Please sir, I am a leprosy patient. God bless you, and your family, and your children. Give me one donation, one rupee, 50 paise, sir." And if they ask (as he said they often did when we talked the day before) why he's not working? He replies: "My life is spoiled because I am a leprosy patient sir. What can I do?"

...I ask him about different begging techniques: he says that some people just stand (or sit) at the roadside; some go from car to car; some walk long routes, going into shops on the way and asking for donations; and that most people use a mixture of all these approaches.

Begging, as the above suggests and as my informants continuously stressed, was not a soft option: it was physically hard work and demanding on its practitioners' health. Leprosy deformities, however, meant that it was relatively lucrative. Those identified as "lepers" were broadly categorised in Indian society as "deserving poor" (Caplan, 1999, pp. 291-292). Their disease implicitly conferred upon them a right to ask that was not available to other people in India (cf Staples, 2003a). Fellow passengers on trains, popular begging locations, frequently told me they were willing to give to those whose impairments prevented them from working or who performed tasks, such as sweeping out the carriage, but resented being approached by others. A clawed hand or leonine facial features that unequivocally spoke of leprosy regularly induced a positive response from alms givers because, I would suggest, these features evoked both compassion and fear. On the one hand, people gave because they felt pity for these social outcasts with spoiled bodies who could not make a living, as they perceived it, in any other way. On the other hand, people gave because prompt payment removed the sight of the "leper", seen as a possible source of physical and moral contagion, as rapidly as possible. Raju's efforts to bandage his hand before attempting to beg were clearly not wasted. The suggestion of an impairment increased his chances of success, all the more so if that impairment became a physical metonym for leprosy as a socio-biological phenomenon.

The reality of givers' preference for those with the greatest deformities is borne out by comparing the monthly incomes of those who begged in Bombay/Mumbai. "I can make between Rs3000 to Rs4000 per month," Mariamma told

me, “And that’s without deformities, just a few patches, and by wearing old clothes. Sambaiah [who has no legs and gets about on a trolley], can make Rs450 per day. Those with deformed hands *and* legs can make even more.” As a woman, Mariamma explained that she could make more money than an equivalent man, a statement with which others agreed. This was why many families sent their women rather than their men folk begging. The ratio of women to men at the Mumbai settlement when I spent time there was around 60:40. “A woman seems more vulnerable,” Rama Rao – the husband of a woman who went begging while he worked in Bethany – told me when I asked him why he thought this was. “And people think she doesn’t have as many opportunities as a man if she becomes destitute.” In short, there was a direct relationship between the level of disability (and being a woman was relatively disabling) and income that could be achieved from begging. In any case, monthly income was significantly more than that which could be made from working in NGO-sponsored income generation projects.

In terms of attracting money from donors, too, leprosy had an appeal beyond that provided by poverty or “neediness” alone. Many of the small hamlets that surrounded the leprosy community where I did fieldwork were at least as poor and in many cases poorer than Bethany, and yet none of them attracted the interest from overseas and local donors that the leprosy colony did. “No-one has to go hungry here,” my friend Rama Rao once told me during a general conversation about the difficulties faced by Bethany villagers. “They do sometimes in [the next village] though: they go out and do labouring work in the fields and with the money they make that day they buy rice. If they don’t work they don’t eat. Here nearly every family has some stock of rice in the house, even if we have to eat it just with pickles sometimes.” The rationale for being owed more by society than their healthy counterparts in other villages was that, because of the ostracism and geographical dislocation they had

endured as a consequence of leprosy, compensation was owed to them as a right.

It was also significant that the leper identity provided opportunities to other stakeholders. For colonial missionaries (and now indigenous evangelists), “the leper” was not only a site for salvation but a potential evangelist who could preach “the two-fold gospel of spiritual and physical healing” (Cochrane, 1927, p. 22). For Government organisations, NGOs and their employees, the “leper”, redefined in the present as a “client”, offers both a site for rehabilitation and jobs for leprosy workers.⁷ In recognising the opportunities they represented to other groups, my informants were able to negotiate social and economic advantages and to create new identities, beyond those achievable to other categories of rural poor, that offered dignity and self-respect. The fact that they recognised the commercial potential of their bodily condition was evident in Bethany from the recently erected signs prohibiting photography, designed to prevent images of them being used by NGOs for purposes that would not profit them directly (cf Staples, 2003b, p. 310).

In terms of direct benefits to those whose bodies communicated leprosy, the missionary construction of the “leper” has permitted an on-going special relationship with “the foreigner” that has been economically beneficial. The relationship also enabled my informants to deflect responsibility for their welfare onto what they constructed as an overseas, wealthy Christian “other”, who had a duty to help them. Church-links within India also provided “lepers” social capital with which to renegotiate identities as Christians.

Those with physical deformities that communicated the leper identity could also play on local fears of their apparently rotting leprous and, by association, corrupting bodies, both to reinforce the effectiveness of their street-begging and to make powerful protests to the authorities. The offer of people deformed by leprosy to

stage a sit-in at the police department to help my visa-extension application on a previous trip to Bethany is an extreme example of this. More subtly, appeals for rations, pensions and other Government grants were regularly strengthened by exposing body parts that could simultaneously evoke both fear and compassion at meetings with officials.

In individual cases, too, leprosy had been life transforming in positive as well as negative ways. Esther, for example, was not alone among the older generation of women when she described leprosy as “a blessing,” claiming it was through the disease that she had come to know the “true God.” More tangibly, Venkateswarlu had become more powerful than he otherwise would have done specifically because of his disease and the impairments with which it has left him. I offer the following case study, pieced together from a series of interviews Venkateswarlu gave me, by way of illustration.

Venkateswarlu’s Story

Venkateswarlu was the youngest son of a family of silversmiths who lived and worked in a large town less than 100 miles from Bethany. The stories he told me were self-consciously framed by a wider narrative of suffering, caused both by the physical effects of leprosy, and by the stigmatising and excluding actions of other people. Interview situations also provided an opportunity for him to make the case for leprosy affected people to be awarded compensation from Government and NGOs for that suffering. Despite offering a largely negative picture of his situation, however, a counter-narrative that ran through much of Venkateswarlu’s life history account was of successful campaigning and power gained not in spite of his leprosy but because of it.

Venkateswarlu became a resident in the mission hospital next door to Bethany in the 1950s as a result, he says, of being stigmatised by his sister-in-law, who would not allow him to eat from the same plates as the rest of the family.

Outward changes to his physical body did not occur until the 1970s. In the course of that decade he lost his nose, most of his fingers and his toes. In the early 1980s his eyesight also began to deteriorate. Although the drug therapy that became available at around that time prevented further deformities, Venkateswarlu was already physically unable to work, and spent much of that period begging. More recently, he has received support from one of the community’s welfare programmes, which provides him with a small monthly allowance and basic provisions.

Venkateswarlu has also been a vocal force in community politics, with few people willing to cross him openly. He had been elected four times as President of the Colony’s Elders, and in-between times had been involved from the peripheries, advising newer Elders on procedures, chairing community meetings and contributing to marriage negotiations. As a visibly leprosy affected man, Venkateswarlu was also the main speaker every year at a local rally and meeting to mark anti-leprosy day, an occasion he used to make the same case for compensation that dominated the accounts he gave me. More recently, he had also become the President of a state-wide leprosy association, which aimed to join with similar associations in other states to lobby Government at the centre.

“In Andhra Pradesh,” he told me, “There are 73 colonies, 20 are getting something from the missionaries or from other foreigners, but the rest are begging. Before the State Government used to pay us Rs.30 per month per person – Rs1 per day – and at that time we made contact with the other colonies, and elected a group of seven members, like a committee, to fight against the Government for more money. We wanted Rs300, at least. Also I spoke in some major cities, trying to get across to the public that we have come from families just like theirs: that we need help. For example, the Government could give some land and housing for patients... Now, [the pension] used to be Rs30, now it’s Rs75 per person. I went to the Assembly

in Hyderabad and I spoke to N T Rama Rao [the then chief minister] and sent letters to the Central and State Governments. Now they get Rs75.”⁸

Venkateswarlu’s role in bringing about the increase in State support for leprosy-affected people was by no means uncontested, but the claim had nevertheless brought him some kudos in the village. His membership of the state-wide association was also, some villagers claimed, a way of attempting to become one of the President of India’s appointees to the Rajya Sabha (Indian parliament’s upper house) where he could wield national influence.

The latter campaign was unsuccessful, indicating the limits of Venkateswarlu’s authority and influence beyond the perimeters of the leprosy colony. Nevertheless, his story illustrates how, in certain situations and from his own perspective, an institutionally recognised disability can become empowering as well as excluding. To frame it as a question: had Venkateswarlu not had leprosy and remained a part of his family’s business in his natal home, would he have achieved the same level of political authority? It is impossible to predict the trajectory his life might have followed had he not been stigmatised by leprosy (and Venkateswarlu was not prepared to speculate), but I would suggest that through his inclusion as a member of a nationwide group of leprosy affected people he had become more feared, respected and listened to (all qualities he found desirable) than he otherwise would have done. This was not about making the best of a difficult situation by responding to it positively or by over-compensating for a loss: it was about gaining advantage precisely because of his situation. If the phenomenon of embodied advantage through physical markings otherwise considered disabling was a particular feature of leprosy, this would in itself be interesting. As I shall show in the next section, however, there is evidence to suggest other forms of negatively construed bodily difference also enable in various ways.

Bogdan’s Freaks

It was in reading Robert Bogdan’s historical accounts of the American Freak Show that I initially became struck by the similarities between the situations he described and those I encountered in Bethany. I thus use Bogdan’s work here as an illustration of the ambiguous ways in which human difference might be experienced, before turning, towards the end of the section, to consider a wider literature that suggests enabling aspects of disability might be widespread.

A stress on exclusion, stigma and devaluation has dominated much of the debate in Disability Studies, and while Bogdan recognises the importance of these factors his account focuses more heavily on the ways in which the American Freak Show gave value to human difference. “Some were exploited it is true,” he admits, “But in the culture of the amusement world most human oddities were accepted as showmen” (1988, p.268). Advocating a sociology of acceptance to counter the emphasis on social exclusion, Bogdan’s layering of life history accounts demonstrates that, in the early part of the twentieth century, abnormality, like the clawed hand of untreated leprosy, was often a “meal ticket” as much as a handicap (1988, p.277). Subsequently, descriptions of human variation have become increasingly pathological, with different bodies medically reclassified as dysfunctional rather than as curiosities. As a result the Freak Show has become ever more marginalised. One of Bogdan’s case studies, taking us as it does to the core of contemporary debates over disability theory, is worth retelling here.

Otis “The Frog Man” Jordan, was a black man from Georgia, his nickname, presumably, a reference to his unusually formed limbs. His act, Bogdan recalls, was to roll, light and smoke a cigarette using only his lips. Until he was 28, he had eked a living from hawking pencils and other goods; his break came when he showed his cigarette trick to a carnival that was passing through town and was asked to join up as

a novelty act. He took up the offer, describing it as “the best thing that had ever happened” (1988, p. 280). In addition to enjoying the travelling and being accepted as a valued member of the group, the income had allowed him to buy a small house in his hometown. Having improved his life through participation in the carnival, Jordan now raised strong objections to the lobbying by disability activists to ban the Freak Show on the basis that it is degrading to disabled people (ibid, p. 281).

In considering the extent to which Jordan’s bodily difference was enabling rather than disabling, similar questions to those I asked in relation to Venkateswarlu’s case might be posed. What would his situation have been like without the bodily difference? Could he have made a good living? Bodgan’s evidence suggests Jordan’s options as a poor black man would probably have been just as limited and would almost certainly not have included anything as lucrative as joining the carnival. Jordan’s differences, in common with the other variations described in Bogdan’s book, were valued, both by the showmen themselves and the wider society. They also brought benefits that, from the performers’ perspective, exceeded the disabling effects of the difference.

This is not, I should stress, to be an apologist for the kinds of negative representations opposed by those who called for a banning of the Freak Show. What the difference of position between the two groups illustrates very pertinently is the tension between the interests of the individual and the interests of a wider community of disabled people. While Jordan felt his right to make a living in the way he chose was under threat, activists saw the exoticised representations of disabled people that were promoted by the Freak Show as damaging to disabled people in general. A similar tension exists between leprosy aid organisations and individual leprosy-affected people. The former aim to restore the dignity of leprosy affected people by de-linking associations between the condition and begging.

For the latter, begging is often a route to dignity through the accumulation of material wealth (Staples, 2004).

Watson (2002, p. 524) highlights a parallel tension between the British disabled people he interviewed, among whom there was little support for an identity politics based on the notion of a common group identity of disabled people, and the social model activists who argue for precisely that. For the activists, disability is conceptualised as a shared experience based on common interests (e.g. Barnes, 1990; Campbell and Oliver, 1996; Finkelstein 1993; Shakespeare, 1996). Kurzman’s observation from fieldwork with amputees that there is often a “hierarchicalization of disability” (2003a, p.2) suggests further problems with the social model approach. I turn to this, and other issues this inquiry has opened up, in the concluding section.

Discussion

This article has considered contexts in which disability might be simultaneously enabling and the issues that an investigation of those contexts reveals, particularly concerning the ways in which disability is defined and used. With reference to the latter, my aims have been twofold. Firstly, I wanted to highlight the problems inherent in a universal social model – in the singular – of disability. Secondly, I wanted to illustrate how theory induced through detailed ethnographic fieldwork might provide more workable alternatives.

Before I come to these, however, there are some important caveats to the case I have been making. Firstly, identification of enabling aspects within a disabling situation needs to be distanced from overly positive accounts, coloured by what Abu-Lughod has called “the romance of resistance” (1990, p. 41). Could I, in emphasising the potentially enabling effects of what are otherwise described as disabilities, be accused of highlighting “weapons of the weak” (Scott 1985; 1990) at the expense of the “tools of op-

pression?” Certainly, I have made use of Scott’s framework in the past as a way of reconceptualising the experience of leprosy-affected people from perspectives that go beyond narratives of stigma and oppression (Staples 2003a; 2003b; 2005). Here, however, I have been less concerned with resistance *per se*, than with the ways in which people might strategically maximise embodied advantages. These advantages need to be taken into account to provide more nuanced analyses of disability, within which people are not required to be *either* disabled *or* able-bodied. In short, my argument that disabilities can be enabling should not distract from the reality that they simultaneously, and by definition, also create disadvantages.

This brings me to a second caveat. In recognising the ways in which negatively perceived bodily differences might be positively utilised I want to avoid any suggestion that social processes of disablement can be justified. On the contrary, my argument is that attempts to overcome discrimination in general are compromised when the specific situations of people who have been disabled in particular ways are glossed with over-arching theory. “The job of those who want to serve people known as disabled,” as Bogdan puts it, “Should be to get behind the scenes, to know them as they are, not as they are presented” (1988, p. 279). The extent to which anyone is knowable beyond their multiple representations is, of course, debatable. Nevertheless, it is in uncovering more nuanced representations, based on observation of everyday life, that the social or cultural anthropologist can make the most significant contribution to the inter-disciplinary arena of Disability Studies.

What has also emerged through this inquiry is the need for more nuanced theory. Social model definitions of disability are problematic because they are predicated on an assumption of biological abnormality – on “impairments” – that simultaneously undermines the notion on which the theory is centred: that disability is entirely socially constructed. These criticisms

of the social model have been well-rehearsed elsewhere (see, for example, Tremain, 2002, pp. 33ff) and continue to dominate much of the traffic on an e-mail list dedicated to discussion of the social model.⁹ Here, I limit my critique to the following points.

Firstly, a theoretical model that denies the direct relevance of embodiment to a definition of disability renders the term all encompassing in terms of *who* might be included, taking in lesbians and gay men, black people and women, for example. At the same time, it renders the term too narrow in terms of *how* it categorises these people once labelled. While there is some merit in an inclusive approach, inasmuch as other socially oppressed people might have experiences in common, the notion that virtually all of us are disabled reduces the potency of “disability” as an identifying category for the purposes of activism. More significantly, in imposing (or in taking on) an identity that assumes oppression, those who are disabled are denied agency and are categorised by what they cannot do or are prevented from doing, rather than by what they can do. This identity often becomes seen as separate from and more important than other personal identifying factors, such as gender, ethnicity, religion, class or caste, with which a disabled identity inevitably mingles. My informants were not just “lepers”; they also identified themselves as Christians in relation to local Hindus; they were located within networks of familial relationships; and they had identities related to their relative status within the leprosy community. In addition, as my ethnographic examples have illustrated, bodily differences are actually much more flexible to interpretation and relative to the broader circumstances in which they are located at particular times than a model that reduces disability to oppression will allow. While leprosy is certainly disabling in India, that is not to deny that its marks might also be socially enabling in particular contexts.

This brings me back to the central paradox of how that which is defined as disabling can also

be enabling. The answer, as I have shown, is that this is not paradoxical at all. Rather, the ways we have used the terms have served to straitjacket our thinking. Disability, in the senses that it has been defined both medically and by the British social model, is too generalising a term. For one thing, it is inadequate to differentiate between states of being that might demarcate one as different and evoke particular responses from others. For another, it falsely limits the perspectives from which we are encouraged to examine the experiences of a person so labelled. Kurzman's informants, for example, did not consider themselves disabled, but—as a chapter title in his Ph.D. dissertation summarises it—as “able-bodied if not total-bodied” (2003b).

One way of extending thinking beyond this either/or choice between disabled and abled is to utilise more fully in Disability Studies Bourdieu's idea of “habitus” (1977; 1990), as outlined in the introduction to this article. Such a formulation allows for the possibility that aspects of a disability might offer advantages, without insisting that those who gain from those advantages are necessarily conscious of manipulating them. Social constructions of leprosy, for example, are embodied in the habituated action of proffering an out-stretched, fingerless hand to solicit alms in the course of a typical begging transaction.

An additional, and wider, solution, within which Bourdieu's analysis should play a useful part, lies in abandoning a grand theory approach to disability altogether, instead using detailed ethnographic research into particular cases to induce or suggest suitable theoretical approaches for particular contexts. Such an approach is not only more theoretically satisfying, it is also important from a policy perspective. Existing interventions have tended to follow two routes. On the one hand they focus changing or adapting the disabled person's body, using anything from prostheses to plastic surgery to electric shock treatment, to enable the person to fit into existing society. On the other hand, more enlightened approaches aim to address so-

cial attitudes towards disability and to promote a more universally accessible environment. Both routes generally fail to incorporate the positive aspects of an otherwise disabling situation that might disappear when well-meaning interventions change those situations. Leprosy affected people without bodily marks, for example, make less money from begging, while Otis “The Frog Man” Jordan and his fellow showmen faced losing their livelihoods because of changing attitudes towards the Freak Show.

My suggestion is not that individual or small group perspectives are always prioritised over those of the wider society. Rather, it is that policy makers centrally incorporate ethnographic particularities into building solutions. Plans for the eradication of leprosy as a biomedical condition, for example, need to include genuinely viable alternatives to begging, identified by leprosy-affected people themselves, which replace not only the higher earnings but the freedoms and self-respect achieved through begging. They also need to include a social space for those already disabled by leprosy, like the people I worked with in Bethany, for whom eradication is an irrelevance. More ethnography, in India and elsewhere, points the way to going beyond ethnocentric analyses based on a narrowly defined dichotomy between impairment and disability.

*An earlier version of this article was presented at the Western Social Sciences Association (WSSA) Annual Conference 2004 in Salt Lake City, Utah, an event I attended with generous support from the British Academy and the School of Oriental and African Studies, University of London. I am grateful to Gary Linn and other contributors to the conference for their comments. The fieldwork on which the article draws was funded by the UK's Economic and Social Research Council (Grant R00429924418), as was the post-doctoral fellowship during which it was written (Grant PTA-026-27-0342).

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- Busby (1997) and Staples (2003b).
- ³ I have provided far more detailed descriptions of this community and its development – under the pseudonym Anandapuram – elsewhere (Staples, 2003a & b; 2004 & 2005).
- ⁴ All statistics quoted in this paragraph are from the World Health Organisation's site. Retrieved March 26, 2004, from www.whoindia.org/leprosy/02-epidemiology.htm.
- ⁵ A Congress of International Leprosy Associations, held in Paris in 2002, concluded there was no evidence leprosy will die out at a predefined level of prevalence rate, and the statistics painted an overly rosy picture by including Western countries where the prevalence rate is virtually zero. See the webpage <http://www.lepra.org.uk/review/june02/supplement/contents.html> to download a full copy of the Congress's report, also published in *Leprosy Review* 2002, 73, S3-S62. The Congress took place 25-28 February 2002 in Paris, France. See also Staples (2004) for further debate around the official discourses on leprosy eradication and management.
- ⁶ See, for examples of how leprosy was portrayed in a comparable way in European medieval literature, Skinsnes and Elvove, 1970; Brody, 1974; and Stephen, 1986.
- ⁷ The International Federation of Leprosy Associations' (ILEP's) guidelines for socio-economic rehabilitation prefer the term 'client' to the many others applied to those who have or have had leprosy (see, for example, Gopal, 1999; Nicholls, et al. 1999).
- ⁸ As of January 2000, when the interview took place.
- ⁹ See the jisc-mail list "Disability-Research" online via www.jiscmail.ac.uk.

Endnotes

¹ For a more detailed outline of the social model that developed out of the UPIAS definitions – still the dominant paradigm in interdisciplinary studies of disability – see Oliver (1990) and Barnes, Mercer & Shakespeare (1999).

² For a more detailed critique of Cartesian dualism as universally applicable, see, for example, Marriott (1989),

A New Perspective: School Counselors with Disabilities and Non-Disabled School Counselor Views of Counselors with Disabilities Effectiveness

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Abstract: A literature review about the effectiveness of counselors with disabilities was conducted. Interviews were also held with two graduate students in a Master's level graduate School Counseling and Guidance program and two school counselors currently employed by a public school to obtain anecdotal evidence in support or negation of the literature. One graduate student has a disability, the other does not; one employed school counselor has a disability, the other does not. Most interviewee responses imply school counselors with disabilities might be more effective than school counselors without disabilities because of probable higher levels of empathy due to difficult challenging life experiences.

Key Words: school, counseling, disability

Introduction

Although information about counseling individuals with disabilities is commonplace, data about counselors with disabilities is scarce. It is important to discuss how school counselors, both with and without disabilities, view school counselors with disabilities effectiveness as counselors in a school system. It is also necessary to discuss what accommodations and/or modifications can be provided and what service agencies can support school counselors in a public school system. Looking more closely at these issues will help ensure individuals responsible for school counseling programs scrutinize their systems to be sure that schools, a microcosm of society, represent the diversity of the community as a whole. This will support students to

embrace all the diversity within themselves and surrounding them.

Current information about counselors *with* disabilities is scarce. There seem to be two reasons for the absence of information. First, search engines often do not differentiate between counselors with disabilities and counselors working with individuals with disabilities. The most accurate key word search involved using the term "counselors with disabilities" and then weeding out extraneous information. The second most accurate key word search was using the term "disabled counselors". Second, recent research on this topic does not exist. Some studies date back 30 years, concurrent with the beginning of the Disability Rights Movement and the return of Vietnam War veterans with disabilities in need of counseling services. More recent articles date only to the 1990s. Therefore, it is important to note the uniqueness of this article and how its message is important in the 21st century.

Overview of Literature

In an overview of the literature available regarding counselors with disabilities, little data is available specifically regarding school counselors. Much information about counselors with disabilities discusses rehabilitation counselors and post-secondary education counselors. The reviewed literature has been generalized to include school counselors.

Counselees appear to share two general thoughts about counselor effectiveness regarding counselors with disabilities: the additive point of view and the subtractive point of view (Miller, 1991). All literature will be prescribed to that of either Miller's additive or subtractive perspectives.

In the additive point of view, counselors with disabilities have an advantage in a counseling situation due to having a disability. This perspective is supported by several research studies dating back to 1973. In 1991, Nosek, Fuhrer

& Hughes, of the Baylor College of Medicine, note, "Counselors with disabilities were rated more favorably overall than counselors without disabilities, particularly when the counseling content was disability-related and when counselors were depicted as nonprofessional." (p.153). They also note that, "When the topic involved requesting personal assistance, a pronounced concern for some persons with disabilities, disabled subjects attributed substantially greater credibility to a disabled counselor" (p. 160). The theory that people with disabilities prefer to work with counselors with disabilities is part of the peer counseling philosophy of some schools of independent living (Nosek, Fuhrer & Hughes, 1991; Strohmer & Leierer, 1996).

The additive point of view is further supported by research conducted by Brabham and Thoreson (1973) in which both students with and without disabilities prefer to discuss personal problems with counselors with disabilities. Using the Barrett-Leonard Relationship Inventory, which measures patient-perceived empathy, Mitchell and Allen (1975) conclude counselors with disabilities are rated significantly more positively on all therapeutic values: empathic understanding, positive regard, unconditionality of regard and congruence. Mitchell and Frederickson also note significant counselor preferences exist for physically disabled counselors over counselors without physical disabilities due to a perceived improved ability to understand and empathize. In a study on self-disclosure, Mallinckrodt and Helms (1986) note that "counselors in several of the disability conditions were rated as being significantly more expert and attractive than able-bodied counselors" (p. 343). Finally, in a study conducted by Toner and Johnson (1979) of sixth and tenth grade students using a person perception instrument, "The disabled counselor was preferred to the nondisabled counselor, regardless of the sex of the counselor or the sex and grade level of the student" (p. 402).

In the subtractive point of view, counselors with disabilities are seen as disadvantaged due to having a disability. This perspective is also supported by several research studies. At the forefront, researcher Douglas Strohmer conducted several studies that supported this perspective, although the strongest evidence is noted in older studies. The most recent of Strohmer's research endeavors is presented in an article, *The Effects of Counselor Disability Status and Reputation on Perceptions of Counselor Expertness, Attractiveness, and Trustworthiness* (Leierer & Strohmer, 1998). In this article, Leierer & Strohmer present their "Implications for Theory," which states: "A counselor's disability will not necessarily guarantee higher ratings on attractiveness, expertness, and trustworthiness; in fact, a client can be influenced negatively by a counselor's disability" (p. 284). In another study conducted by Strohmer, *The Effect of Counselor Disability, Attending Behavior, and Client Problem on Counseling* (Leierer & Strohmer, 1996), the authors note that "disability status may exacerbate the client's perception of the counselor's skill. However, when counselors with a disability use poor attending skills, they are seen as being less attractive than other counselors. Therefore, by having proficient counseling skills, counselors with disabilities can dramatically augment their social influence as a therapist" (p. 92). In a 1996 study, *The Importance of Counselor Disability Status: What We Know and What We Need to Know*, Strohmer and Leierer note: "There is some evidence that counselor disability status is important when the problem being discussed in counseling is directly related to the counselor and the clients' shared disability status" (p. 108). Finally, in the oldest of Strohmer's studies, *Effects of Counselor Disability Status on Disabled Subjects' Perceptions of Counselor Attractiveness and Expertness* (Strohmer & Biggs, 1983), ratings of physically disabled subjects of counselor expertise are lower when the counselor is shown as having a disability than when not having a disability (Nosek, Fuhrer & Hughes, 1991; Miller, 1991). "These results raise some doubts about

the validity of the argument that disability condition is a salient group membership characteristic directly related to more favorable counselor ratings by disabled clients” (Strohmer & Biggs, 1983, p. 206).

The subtractive point of view is further supported by research conducted by Allen and Cohen (1980) in which non-disabled counselors are preferred by non-disabled persons. In a study conducted by Cash and Kehr (1978), counselors were individually judged as either physically attractive or physically unattractive by female subjects. Although physical disability was not equated to physical unattractiveness, researchers have used the study to support the subtractive point of view by citing the conclusion: “Unattractive counselors were judged to reflect less desirable traits and engendered weaker commitment and less expectations than did identical behaviors attributed to physically attractive or anonymous counselors” (Cash & Kehr, 1978, p. 336). Finally, Miller (1991) also notes, “Stereotyped prejudice against persons exists and that obviously disabled persons evaluate themselves and are evaluated by others more negatively than are able-bodied persons” (p. 348).

Personal Communications: Anecdotal Data Received Via Interviews

The purpose of this research is (a) to determine how school counselors, both with and without disabilities, view the effectiveness of school counselors with disabilities, (b) to discuss what accommodations and/or modifications can be provided and, (c) to explore what service agencies are available to support school counselors in a public school system. Anecdotal data was collected to achieve these goals. To attain this data, eight separate interviews were conducted with four school counselors. Two of the school counselors have disabilities. Pamela Brown, a 34 year old female graduate school counseling student attending the University of Hawai'i at Manoa on Oahu, the state's most populated island, is of Caucasian decent and medically diag-

nosed with severe Repetitive Strain Injury (RSI). Mark Ting is a 34 year old male school counselor from the island of Maui, of mixed Asian (Chinese and Japanese) and Pacific Islander (Hawaiian) descent, who is Quadriplegic. The other two interviewees are non-disabled. The first is Joshua Kimura, a 35 year old male school counselor of Japanese descent, also from Maui, and the second is Sharon Soares, a 27 year old female University of Hawai'i graduate school counseling student who self identifies as Mixed-Caucasian (Chinese and Portuguese). The participants' names have been changed. They have been given a last name of the same ethnicity as their real last names. The first set of interview questions does not ask respondents about disability, while the second is specific to issues about counselors with disabilities. Interviewees were not privy to the second set of questions previous to responding to the first. The first set of questions included the following:

1. What expectations do you have of being a school counselor?
2. What made you decide that this is a profession you wanted to pursue?
3. What traits do you have that would/does make you an effective school counselor?
4. What do you think some of the challenges might be/are to being a school counselor?
5. Do you feel that you possess traits that other people don't that would/does make you a more effective school counselor? If yes, what are those traits?
6. How could a public school system, such as the Department of Education as a whole and individual schools, help school counselors to reach their best potentials as effective helpers?
7. What other resources/agencies are available to assist school counselors to be able to perform their job duties in the most effective manner possible?

8. What kind of tools/resources *should* be available for school counselors so that they may do their jobs to the best of their abilities?

The second set of questions included the following:

1. What is your definition of disability?
2. What is your definition of diversity?
3. Do you identify with the disability culture? If yes, do you feel that the disability culture is also a diversity culture?
4. Do you prefer people-first language or disability-first language?
5. What is the name of the disability that you have? What is the definition of that disability? What is the nature of that disability?
6. Does the disability limit your life activities? If yes, in what way?
7. Do you feel that a person with a disability may possess traits that a person without a disability may not possess that would make them a more effective school counselor? If yes, what are those traits?
8. What parts of a disability may be a challenge to being a school counselor?
9. Do you think there are any differences between a school counselor with a disability versus a non-disabled school counselor?
10. Do you feel a school counselor with a disability, would be better able to counsel students with disabilities than a non-disabled school counselor?
11. How could a public school system, such as the Department of Education as a whole and individual schools, help a person with a disability to reach their best potential as a school counselor?
12. What other resources/agencies are avail-

able to people with disabilities to be able to perform their job duties in the most effective manner possible?

13. What kind of tools/resources should be available for school counselors with disabilities so that they may do their jobs to the best of their abilities?

Both counselors with disabilities and non-disabled counselors appear to have the same expectations of the types of counseling skills they are able to contribute to their chosen profession. All school counselors interviewed said they expect to advocate for their students by working with students, teachers, administrators, parents, families and the community at large. Interviewees also conduct individual and group counseling sessions and prevention and intervention programs (P. Brown, personal communication, March 2, 2003; M. Ting, personal communication, March 4, 2003; J. Kimura, personal communication, March 7, 2003; S. Soares, personal communication, March 11, 2003).

There is a marked difference in the way school counselors with disabilities reply to the question, "What made you decide that this is a profession you wanted to pursue?" Both counselors with disabilities, Brown and Ting, note becoming disabled had some effect on their choice to become school counselors. Brown notes that after the final stages of her injury, she "couldn't do anything except talk and listen." She felt that "school counseling seemed like it clicked." Ting notes, "It was actually because of my accident that I became a school counselor. After [the] accident [I] had to kind of regroup and figure out what I could still do." Brown and Ting each had different careers previous to the injuries that led to their becoming permanently disabled.

All interviewed school counselors mention similar traits they possess to be effective counselors, such as compassion, empathy and understanding, a love of working with children/students, being good listeners, being analytical, and being outgoing. The school counselors with dis-

abilities also add their life experiences of having and living with a disability as positively contributing to effective school counselor traits. Ting feels “overcom[ing] the challenges of having a disability help[ed] to build character.” Brown notes her life experience, as a whole, put her “head and shoulders” above a lot of other school counselors.

Responses to the question, “What do you think some of the challenges might be/are to being a school counselor” varies. Three school counselors mention not being able to help clients as much as they would like. Ting seems to focus more on the aspects of his disability regarding challenges. He notes issues of accessibility and possible negative peer relationships could impede school counselor success.

When asked the question, “How could a public school system, such as the Hawai‘i Department of Education, as a whole, and individual schools, help school counselors to reach their best potentials as effective helpers?” all respondents note concerns unrelated to disability issues. These include the following: allowing for both creative differences and autonomy, treating counselors as professionals, providing funding for better student to counselor ratios, higher pay, practical and useful trainings, sufficient work-space, clerical assistance, and appropriate materials and curriculum. Both graduate student school counselors note professional associations, such as the American School Counselors Association, the Hawai‘i School Counselors Association, the American Psychological Association and the Play Therapy Association, as possible resources and agencies that can provide counselor assistance, whereas both school counselors note more community-based organizations for support such as Maui Youth and Family, Upward Bound, Pacific Resources for Education and Learning, and professional peers.

Interviewees were asked the question, “Do you feel that a person with a disability may possess traits that a person without a disability may

not possess that would make them a more effective school counselor? If yes, what are those traits?” Three respondents imply that people with disabilities have traits non-disabled people do not possess that would make them more effective school counselors. These traits revolved around the ability to empathize more easily due to having a disability themselves, especially when counseling students with disabilities. However, both Brown and Ting also mention they believe a non-disabled counselor could reach the level of counseling skills and effectiveness as a counselor with a disability without becoming disabled themselves. It appears that both counselors with disabilities feel life experiences as a whole are what makes a person a more effective counselor.

When interviewees were questioned about what types of challenges there might be for a school counselor with a disability, both counselors with disabilities seem concerned about being physically able to restrain a student that may need to be restrained for the safety of both his or herself and others. Ting notes that “being able to restrain a student [that] tells you they are going to kill themselves or a violent student” may be difficult. Brown says, “I feel physically vulnerable [if] a kid needs physical restraint.”

In response to the question, “Do you feel a school counselor with a disability would be better able to counsel students with disabilities than a non-disabled school counselor?” three individuals imply that there could be some advantage for school counselors with disabilities. Responses range from having a mild advantage, “Someone with a disability [could] break the ice [better] than someone without [a disability],” to emphatic responses from both disabled and non-disabled respondents, “Yes, definitely. I would have the perception that I could identify better and I could create the perception that I could identify better,” and, “Yes. They could share some things that they have done to help them through. [They] can offer real, practical [counseling advice]. They’ve been there and

Table 1: Resources for Counselors with Disabilities

National Center for the Dissemination of Disability Research	http://www.ncddr.org/
The Office of Special Education and Rehabilitative Services	http://www.ed.gov/about/offices/list/osers/index.html?src=mr
Recording for the Blind and Dyslexic	http://www.rfbd.org/
U.S. Department of Justice, Americans with Disabilities Act	http://www.usdoj.gov/crt/ada/adahom1.htm
Talking Books Program, National Library Services for Blind and Physically Handicapped	http://www.loc.gov/nls
Associates for World Action in Rehabilitation and Education	http://www.awareusa.org/
American Foundation for the Blind	http://www.afb.org/
National Federation of the Blind	http://www.nfb.org/
American Council of the Blind	http://acb.org/
Web Accessibility Initiative	http://www.w3.org/WAI
The Access Board	http://www.access-board.gov/
IBM Accessibility Center	http://www-306.ibm.com/able/guidelines/web/accessweb.html

Source: Pennington, D.A. (2003). Resources for counselors with disabilities. *Counseling Today Online*, 45(8). Retrieved March 22, 2003, from <http://www.counseling.org/ctonline/Resources0203.htm>

done that.” The aforementioned responses seem to support Mallinckrodt and Helms’ additive point of view of self-disclosure (1986). However, the non-disabled school counseling graduate student feels, “It would be like saying that a non-disabled counselor would be able to counsel non-disabled clients better than a disabled counselor can.”

In response to a question about employer support of people with disabilities, all respondents mention some accessibility concerns. ADA compliance, architecturally accessible schools, barrier-free environments and assistive technology, are some specific items mentioned. Note that an online article by Pennington (2003) notes the American Counseling Association can help to provide assistance for “counselors with disabilities who are seeking ways to accommodate their disabilities in the field” via the ACA Careers hotline at 317.403.0269 or via the website at <http://aca.convio.net/site/PageServer?pagename=career>.

Finally, when asked what types of tools or resources are available for counselors with disabilities, both non-disabled school counselors are unsure, while both counselors with disabilities could mention only a few, including Vocational Rehabilitation and the ADA. Although the interviewees seem to lack more in-depth knowledge about resources available to individuals with disabilities, Pennington’s article, “Resources for Counselors with Disabilities” (2003), outlines several online resources that may provide useful information for people with disabilities (See table 1).

Conclusion

In support of the additive point of view, both school counselors with disabilities feel they possess traits other people may not necessarily have that would make them more effective school counselors. Although one of the counselors with a disability is concerned about appearing arrogant, she feels that her life ex-

periences enhanced her school counselor traits: “Having a major disability and recovering from it, having panic attacks and anxiety attacks, [having] been through the therapy process, gives you an advantage, [a] better vision of what counseling is” (P. Brown, personal communication, March 2, 2003). The other counselor with a disability has a similar response, “Coming from a position where I have been prejudiced against, labeled and misunderstood, I can relate to [students] better” (M. Ting, personal communication, March 4, 2003).

Literature can be found both in support of disability status adding to counselor effectiveness and in support of disability status subtracting from counselor effectiveness. However, all interviewed school counselors seem to feel counselors with disabilities may have traits more effective in counseling both students with and without disabilities. The interviewees seem to ascertain those traits, which include empathy and self-disclosure skills, as having been acquired from overcoming new obstacles and life experiences related to a disability.

Miller (1991) notes both additive and subtractive points of view can be seen from the perspectives of both school counselors with disabilities and non-disabled school counselors. However, recent studies, such as that conducted by Nosek, Fuhrer and Hughes (1991), supporting the additive point of view, may be closer to the truth. It appears that both disabled and non-disabled real-world school counselors do indeed feel having a disability does add to counselor effectiveness.

The views of both school counselors with and without disabilities are necessary to create a successful counseling program that utilizes the strengths of all of its individuals. Identifying what accommodations and/or modifications can be provided and what service agencies are available to support counselors in schools will help build on these strengths, thereby fortifying the system of support for all students. Finally, this support will aid in the promotion and acceptance of diversity by students within educational sys-

tems, as well as the communities of which they are a part.

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Working and Caring for Children with Chronic Illness/Disability: Stories of Disconnection, Cruelty and “Clayton’s Support”¹

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Abstract: This paper reports the findings of an exploratory, qualitative study of the life and work of people who are, concurrently, parents of a child with chronic illness/disability, and working full time. Nine women shared their experiences about the demands of caring for a child with chronic illness/disability while working full time. In light of the demands constantly placed on these women as they manage their multiple roles, it was of particular interest that their stories shared feelings of disconnectedness from others, as well as frank recollections of the cruelty and thoughtlessness of partners, family, friends, colleagues and strangers. They also reported their experiences with “Clayton’s support” - the support you get when you are not getting support. These stories are shared in an effort to ameliorate the continuing challenges faced by these women.

Key Words: chronic illness, disability, carers

Working and Caring for Children with Chronic Illness/Disability

The purpose of this paper is to share a cluster of emergent themes from a recent qualitative study. The study was concerned with the experiences of women who worked full time and, concurrently, cared for a child with a significant chronic illness/disability. The paper commences

¹ The author gratefully acknowledges financial support for this project, via an industry partnership grant between the Children’s Hospital Education Research Institute (CHERI), Trauma Research International Pty Ltd and the University of Western Sydney.

with a contextualisation of the problem. This is followed by an outline of methodological choices. Then, data is shared that depicts the cluster of themes confirming problems for these women relating to social support (and its absence). These include, (a) feeling disconnected, (b) thoughtlessness and cruelty, and, (c) “Clayton’s Support”. The paper concludes with a discussion about social support, and its whimsical nature, before suggesting why these needs should be addressed.

Living with chronic conditions can be very difficult for the child involved, and for their parents and siblings (Martin & Nisa, 1996). This paper addresses what working parents-especially working mothers-face when caring for children with chronic illness/disability while also trying to hold down a full time job. For the purposes of this study, a “child” is defined as a person between the ages of birth to 18 years. A “chronic illness/disability” is a long term health problem or disability experienced by the child for at least 6 months. This is a significant, ongoing illness/disability, requiring ongoing medical or professional intervention (via pharmacological or other treatment, visits to medical or other professional practitioners, or hospitalization) to treat acute episodes and/or ongoing problems associated with the illness and/or disability. The focus of this study is on the *challenges presented to the carer who is also working full time*, rather than the child’s experiences with illness/disability.

Children with chronic disease and illness are a significant group of the population (Martin & Nisa, 1996). Newacheck (1994; cited in Melnyk et al., 2001) reports approximately 31% of children under the age of 18 years have one or more chronic illnesses. Although illness and disability tend to be associated with the aging process, children are at a significant risk of having a disability or long-term health condition due to accidents, environmental factors or through being born with a particular disorder (ABS, 2002). Of particular interest are conditions that occur more frequently in this age group, such as asth-

ma, attention deficit disorder/attention deficit and hyperactivity disorder (ADD/ADHD), intellectual and developmental disorders, and hearing or speech impairment (ABS, 2002). Of the 3.9 million children in Australia aged between 0 to 14 years in 1998, almost one in seven had a long-term health condition (594,600 or 15%), with boys (18%) more likely to be affected than girls (13%) (ABS, 1999).

Overall, as a result of advances in scientific knowledge and technology, the number of children with a chronic illness is increasing (Gibson, 1995). Examples of children's medical diagnoses may include: cerebral palsy; muscular dystrophy; asthma; cystic fibrosis; diabetes; myelodysplasia; hydrocephalus; cleft palate; burns; cancer, or other physical disability as a result of trauma or congenital anomalies (Burke et al., 1999). As with adults, children with chronic illness/disability are not necessarily faced with acute, life threatening situations (although they may be); the central concern is the longer term "care" of the illness (Melnik et al., 2001). In this study, children had conditions such as severe epilepsy, varying intellectual and physical disabilities, attention deficit and hyperactivity disorder (ADHD), Down syndrome, paraplegia and autism.

Methodology

For this exploratory, qualitative study, a relatively small number of participants were interviewed (nine) who were living the phenomenon under investigation. The numbers for this study were kept small on the basis that smaller numbers of respondents in qualitative studies allow for more penetrating insights. Purposive sampling was used to recruit participants. Respondents could have been either male or female although, of interest, all participants referred for participation were women. Respondents needed to have been engaged in full time employment (or study), or have been in full time employment during the last 12 months. They also needed to

be parents of a child with a significant chronic illness/disability.

Respondents were recruited via a word-of-mouth, snowball technique. Success has been experienced elsewhere with this recruitment technique, especially given the small sample size and the sensitive nature of what is being investigated (See, for examples, Watters and Biernacki, 1989; Vickers, 1997, 2001). The investigator(s) contacted "intermediaries", asking them to get in touch with potentially eligible participants. Colleagues, friends, and family known to the researcher were asked if they knew anyone who might be a likely candidate for participation. No one referred declined participation. This was a three-stage qualitative study, as follows:

- Stage 1: In-depth interviews from a *retrospective* perspective focusing on "What *did* you do/have you done?"
- Stage 2: In-depth interviews including clarification of issues/themes; a *prospective* perspective; responses to vignettes. The focus was on "What *would* you do in the future?"
- Stage 3: Culminating Group Experience. The focus was on asking respondents "What do you think?" especially in terms of the emerging themes.

Data from all stages was used to develop the themes that emerged. Here, a cluster of related themes is reported: feeling disconnected; cruelty and thoughtlessness, and "Clayton's Support".

Feeling Disconnected

The stories from respondents reflected a life different from many. The women in this study all reported their tremendous struggle balancing work and home life, especially with the enormous physical and emotional burdens placed upon them as a result of their caring responsibilities (Vickers, Bailey & Parris, 2003; Vickers, Parris & Bailey, 2004). All reported, one way or another, feeling different, disconnected or apart from those with whom they worked and related. For example, Evalyn, a 40 year old mother of two, works full time in a university environment in a senior management role. She is married, and while she reports a supportive relationship with her partner, has experienced considerable difficulty dealing with the many challenges that her son's severe epilepsy and consequential intellectual disability have presented. Evalyn confides she does feel different from those around her:

Evalyn: I do feel different. I guess on the whole people are pretty compassionate. They are very compassionate but I just don't think they really understand, you know, my life. And, I guess they don't have the same perspective on life as say someone with a high support needs child has. Like, my child is nine years old now but for another parent with another nine year old child, they probably think, "I've got another nine years of where my child will live at home, stay at home." But I don't know what the future is for my child, what will happen to him and that's something that really worries me, you know, what will happen to Kevin. I obviously can't care for him forever ... So there will be a time when I can't care for Kevin and he will most probably live longer than I will. So, I'm always worried about the time when I can't look after him. And I don't think anyone, I guess they have an idea but they don't really understand unless they've lived it or are

living it. [nervous laugh from Evalyn].
(Evalyn, #1: 33)

Dolly also reported feeling "disconnected" from those around her, especially other mothers of children with disabilities she came into contact with at her daughter's school. Dolly, recently separated from her husband and now alone in caring for her only daughter Maggie, felt overwhelmed at times; different and disconnected from those around her. Maggie also has severe epilepsy and a resultant intellectual disability. Dolly raised the issue of not being able to team up with other mothers of children with disabilities for support because of her heavy work schedule, rendering her unable to spend time, for example, at school functions to get to know the other mums better. Dolly owned (in conjunction with her ex-husband) a Human Resources Consultancy firm, a senior role, requiring her to work long hours. For Dolly, working full time is what sets her apart from others in a similar situation:

Dolly: A lot of the parents there are either, they're nearly all single mothers. So many of the fathers have bailed because they haven't been able to handle it, which is really interesting. And a lot of the mothers don't work. They're on pensions or maintenance or whatever else. So, without seeming precious, they're not corporate women. They're sort of more "mums" that might have two or three other children, and they've had a Down's [Child with Down's syndrome] or they've had a child with a disability. And they're either married and their husband's supporting them to be at home or they're single mums who are living on maintenance and pensions and are able, again, to be more flexible. I'm sure some of them work but most of them seem to have lots of flexibility. (Dolly, #1: 88)

Dolly's disconnection stems directly from her inability to be with women in a similar situ-

ation, to share with them, to rely on them, to have the flexibility they apparently have with their caring responsibilities. She continues:

Dolly: Look, I think as a person with children like this, it's really hard working. Maggie's got an Easter Hat thing today, and I can't be there for it... And it would be really nice to go. I went to the swimming carnival last week, but could only stay for an hour, or half an hour... But I do feel almost discriminated against... And last year I was able to go swimming, taking Maggie swimming. So I volunteered and Steven [Dolly's former partner who works with her in their business] was being really supportive of this, of me going down and spending an hour. But it took probably more like two and a half by the time you drive down, you walk the kids from the classroom to the pool, you change them, you swim with them for half an hour, and then you get them dressed, and then you take them back to the classroom. It's a couple of hours and then you come home. And then you have a shower and get dressed and come to work, so probably more like three hours lost all up in that exercise, which is almost half a day's work. But [sigh], I got a little award saying, "Thank you for your participation." And school and the principal just generally they favour more involvement. They really actively encourage you to be really involved, which would be really nice. But then there's that trade-off, like I can't afford to feed her if I can't [work].

Researcher: Do you get a sense that they appreciate, for you, the enormity of taking half a day out of your working week?

Dolly: No, I don't think they do. No, no. (Dolly, #1: 86-87)

It was Dolly who was the one who introduced the notion of being "disconnected". She explains:

Researcher: So you feel quite different from them [the other mothers]?

Dolly: Well, I feel a bit disconnected...

Researcher: Disconnected?

Dolly: Yeah. Well, when I went to swimming it was great because I actually got to meet a couple of them. But even things like, "Can you stay and have lunch?" Well, I *couldn't*. But they all stayed and had lunch with each other. So, the couple of times I did that, it was lovely and then I felt bad because I wasn't working. So it was this constant guilt thing. (Dolly, #1: 89-90)

This comment coincides with Dolly and others confirming their need for strong support networks and a notable lack in this area. Dolly confirmed she had no real network of support, other than her mother who had recently been asked by Dolly to move out and no longer continue in her caring support role (Dolly, #1: 36). Dolly had, for instance, no clue as to who was going to care for her child during the upcoming school holidays (the following week), when she had a full diary of work appointments scheduled (Dolly, #1: 37). This sense of disconnectedness, with colleagues, with friends, with partners and with other mothers, was shared by many of these women. During the culminating group session, both Leah and Evalyn confirmed the magnitude of this issue. Leah said:

Leah: Yes... I was really looking forward to being able to talk with other people about the experiences and how they managed things. When Margaret [the researcher] said there was that third phase [of the research project], I thought, "Oh good," because I don't really talk to anybody else. There isn't an association

that embraces our situation. So I thought it would be really good to just talk with other people about what their experience was. (Leah, Culminating Group Seminar: 8)

Cruelty and Thoughtlessness

What was striking in the stories of respondents was that all were able to recount one or more incidents where people had said or done things that could only be construed as either terribly thoughtless or very cruel. The stories that follow include incidents with partners, family members, friends, colleagues and complete strangers. Respondents were asked if there were any particular comments or incidents that came to mind relating to their caring for their child with a chronic illness/disability - either positive or negative. Evalyn had this to say about someone she barely knew:

Evalyn: One person said to me, “How could two really intelligent people have a child like Kevin, like yours?” And I just couldn’t believe she said that. I didn’t say anything, I just said, “Mmm-mmm.” I just couldn’t believe someone said that to me. (Evalyn, #1: 53)

Dolly also reported a very callous remark, from her friend about her daughter with an intellectual disability being better off going to sleep and not waking up:

Dolly: Well, yes, it was just the most horrific thing. A girlfriend of mine – and I say that extraordinarily loosely [laughter] –she would always be extremely over the top about Margaret. Oh, you know, “I don’t know how you do it. I don’t know how you cope.” ... She rang me one day and said to me, “Oh, how’s Maggie?” “Oh yes, she’s going quite well.” And something good had happened at the time and I was feeling quite happy about it, some little improvement. And she said

to me, “You know, sometimes I think it would be better if Maggie just went to bed one night and didn’t wake up.” I just couldn’t believe it. I mean, I could barely speak. And I said to her, “I can’t talk to you. I have to go.” And I came home and I just *howled*. And my husband was, “She’s never setting foot in our house again. (Dolly, #1: 28)

At the time of our interviews, Dolly had recently separated from her partner. She spoke during the interview of wanting to be in a relationship again. However, Dolly’s friends had some thoughtless remarks to share with Dolly about her future dating prospects, related to her daughter Maggie’s disability:

Dolly: A number of people have said to me... “Are you going to think about dating?” “Yes.” I really loved being in a relationship. I loved the partnership. I loved being married. And I would like, whether I’m married or not is irrelevant, to go back into a partnership again. And I’d actually like, I’d really love, to have another child... And a couple of people have said to me, “Oh, it’s going to be really hard for you to find someone who’ll take Margaret on.” [Pause, Dolly shifts uncomfortably in her chair]. And one person said, “You’ll know if they really love you if they take Margaret on.”

Researcher: Did you say anything to that?

Dolly: No, I was a bit “gob-smacked” [shocked] to be perfectly honest. (Dolly, #1: 65-66)

Cate describes how her colleagues have stopped talking to her since finding out her son has autism. What is more extraordinary about this situation is that Cate works in a center that supports people with disabilities. One would expect that people who work with people with disabilities on a daily basis might be less discom-

forted by knowledge of a disability or contact with people with disabilities, and more sensitively disposed towards those who have them, or care for people so placed. Of interest, Cate also cares for her brother with a disability who lives with her:

Cate: Finally, when I went through the whole thing of the evaluations and stuff like that, then I was like, “William has autism.” Then after that, we didn’t talk any more. Now we still don’t really talk. People don’t really, we talk a little bit: “My daughter’s going to kindergarten now. She’s doing this now.” They’ll bring in their kids, and the kids are like, “Hi, how are you? What’s going on?” But William says nothing. Nothing. Sometimes I’ll bring him in and he’ll visit, and they’ll visit with him, but we don’t talk in an excited way like we used to. And it’s OK. It’s totally OK.

Researcher: Does it bother you?

Cate: Yes, kind of. It’s kind of like you would think that my co-workers, they know me... and they know about my brother. They know they can approach me. (Cate, #1: 21-22)

Cate is clearly very hurt by her colleagues’ behaviour, even though she states that it is “OK” for them not to talk to her. Sally shared similar stories of her colleagues’ insensitivity. In the first instance, Sally reports one of her colleagues wanting to gossip about her disabled child, immediately after the child was born. In the passage that follows, Sally is describing the very traumatic period immediately following the birth of her child. Sally’s daughter was born with hydrocephalus, a significant facial disfigurement and cleft palate, and a significant intellectual disability. As one can imagine, Sally had a lot to digest immediately following the birth of her daughter:

Researcher: You’ve mentioned some special friends that you can obviously really count on. Are there any friends or colleagues that have particularly disappointed you?

Sally: Yes. One *beautiful* example. [Laughter]. This one woman. When Natalie was first born and she was transferred to Randwick [hospital]. Because I’d had a Caesarean, I wasn’t able to go. I got a day pass on the Wednesday, so I hadn’t seen her from the Saturday [when Natalie was born] to the Wednesday, apart from this hideous polaroid shot I had at my bedside. I can remember Janice, my good friend, saying, “Chris [one of Sally’s colleagues] wants to go and see Natalie.” And I said, “What for?” And [then] I said, “She wants to go and have a look!” And I said, “No!” And it was really interesting that I could even reason at that stage of all the emotional, I could actually read what she was up to. She wanted to “sticky-beak” [a slang term describing one who prys into another’s business] so she could go back to work, big-note herself because *she’d* seen the baby – because everybody at work knew... [Sally replied], “I haven’t even seen her yet. So no, she can’t.” So I went to see [Natalie] on the Wednesday, but the sneaky bitch went on the Friday. She did; she went and did it!

Researcher: Even though you’d said “No”?

Sally: Yes, even though I’d said “No.” (Sally, #1: 35)

Sally also recounted the real absence of understanding from her family, in particular, her partner’s parents. What she describes below was also during the period shortly after her baby was born:

Sally: But yes, I had lots of visitors, lots and lots of visitors, people from work,

friends, family. My parents couldn't really cope. Peter's [Sally's partner] parents I don't think understood at all.

Researcher: Why do you say that?

Sally: They're very religious, so it was all about, "God will make it better." And it was kind of like, "Oh, you just don't get it!" And I guess that's probably really unkind, because I tend to be a very practical, while it was devastating and all that kind of stuff, it was, "Well, here it is; just deal with it and get on with it."

Researcher: It must have been very – "distressing" is perhaps a bit too strong – but it must have been very uncomfortable to hear things like that?

Sally: I think for them I was, "Oh, you're just stupid" [laughter]. I just dismissed it. I'm sure Peter's father thought that it happened because I smoked, because I had the odd cigarette.

Researcher: Oh no. It was "all your fault?"

Sally: Yes, it was "all my fault." But that's OK. Again I thought, "If that's what you're comfortable with," you know, "That's OK." My parents, I think that for a long time, and probably still now, my father struggled with the imperfection. Because for many years, every phone call was, "Have you spoken to the plastic surgeon? Have you spoken to the plastic surgeon? She'll be psychologically scarred!" I felt like saying, "She'll only be scarred because you're going to make her scarred. Nobody else is." (Sally, #1: 13-14)

Sadly for Sally, the years ahead did not become easier. She reports below some very cruel and thoughtless incidents involving her and her daughter from complete strangers. Readers will be surprised just how many of these stories Sally could relate:

Researcher: Has there been any particularly negative situations to do with Natalie's condition which spring to mind?

Sally: ... [Laughter] Well, I guess I've had things like – probably before she had any cranio-facial reconstructive surgery – we get used to [how she looks], but you could see other people with their jaws to the ground. You'd be at [a large suburban shopping mall], and the kids would drag the whole family over for a viewing, going, "Look, look, look!" Point, point, point. It was unbelievable.

Researcher: And what did you do when that happened?

Sally: I just thought, "Oh whatever." But I was lucky, because Natalie had well-developed language really, really young. It wasn't just language that I could understand; it was stuff that anybody could understand. So it was good, because she'd come and say, "They're looking at me." And I'd say, "Well, you go over and say, 'My name's Natalie. Hello.'" And you'd just see these people freak; they'd "scarper" [a slang term meaning to depart hastily] or they'd turn bright red on the spot with embarrassment. I can remember there was this little old lady who asked me if I'd hit her. I just was stunned and went, "No." Then only two weeks after that, I had another little old lady say to me, "Oh, did you hit her?" And I just went, "Yes, the sledge hammer missed her forehead and got her nose." Like, duh.

Researcher: It's just so appalling...

Sally: [Laughter] And the ice-cream man. When I was buying ice-cream: "Oh! Oh! What happened to her?" It was like, "She was born like that. You can stick your ice-cream!" Depends on whether I'm having good days or bad days whether I –

Researcher: Engage and have some –

Sally: Yes, or just tell them to piss off. I can remember the man that came to quote for awnings at my place ... not long after Natalie was born. I had this *delightful* [sarcastic] old man come and quote for my awnings. Natalie was asleep and then she woke, and I said, “I just need to go and get my baby.” He was obviously a religious man, I think, and he sort of said, “The devil works in mysterious ways. He’s certainly thrown a spanner in the basket here.” [The term “spanner in the works” is a slang term for an impediment or annoyance]. And I just thought, “You’ve got to be kidding me.” And I said, “It’s rather unfortunate for her. I’ll get on with life and get on with it, but she has to endure and look like this for the rest of her life.” Because he was going on about God, and I said, “Well, I think God sucks at the moment. Because this little kid has to endure this stuff all the time.” But that kind of, “Well, God’s chosen you because you’re obviously a very special person.” She was only a few months old; it certainly wasn’t anything I wanted to hear. I just thought, “Don’t give me that shit!” (Sally, #1: 22-23)

What was particularly disturbing about Sally’s story here, were the number and voracity of ugly and cruel incidents she could bring to mind on the spot. She did not pause; she did not have to think about the question. She was able to rattle off numerous hurtful incidents without any difficulty at all. Given the obvious need for support in her life, the hurtful comments and behaviours she had so routinely faced were astounding.

Clayton’s Support

² The only assumed “obligation” of support in caring for the child was from the child’s father.

“Clayton’s support” is defined as the support you get when you are not getting support. This concept borrows from the advertising campaign for a non-alcoholic beverage called Clayton’s, where consumers were encouraged to indulge in the drink they are having when they are not having an alcoholic drink. Many respondents confirmed the existence of “Clayton’s support” from many sources: partners, family, friends and colleagues. Clayton’s support tended to come in the form of support being offered (or reasonably anticipated), but when the time came to act on the offer or obligation,² the support was not forthcoming. Below, are some examples. What is especially troubling is that for these women with caring responsibilities for a child with a chronic illness/disability, who also worked full time, their need for social support was higher than most. Evalyn reports her bitter upset when a family member, her brother-in-law, would not mind her child so she could attend church with her family. Church attendance with her family clearly meant a great deal to her:

Evalyn: I found that I couldn’t go to church with Kevin, like, listen to a sermon. And one day, I actually had the hide to do a roster for my family; who went to church. And I said every month, I’d like to be able to sit in with Mathew, and be a family, and listen to the sermon. And my brother-in-law said, “We can’t do that, because what about our own family? Who’s going to look after *our* kids when we’re looking after *your* kids?” It was really, he was really negative about it. And I was just devastated. I was absolutely devastated. And then he, after that, I mean, after that he actually apologized. [Evalyn becomes very upset at this point and starts to weep quietly]. (Evalyn, #1: 54)

Cate shares her experiences trying to get some child-minding support from her mother. Cate’s mother had a disabled son herself (Cate’s brother, Brian, who Cate now cares for):

Cate: My mother's 66 and I know that she would be... when I think of her, I look at her and I say, "You should be able to watch William" – that's his name – "you should be able to watch Billy no problem because you had Brian." But she doesn't, and I'm not sure why. I think it's because she's just kind of jaded. I waited a really long time to have kids, and Billy's only four. I'm 38, so that tells you how long I waited [laughter]. And she's 66, and I just think she isn't committed about him. I don't think she wants to deal with it. I think she loves him, but I just can't expect her to come and watch him. Where before I had him, I kind of had this thing in my mind and we talked about it, "Mum, are you going to be able to help out? Are you going to be able to come over and stay if we want to go out? You know, will you watch the kids?" "Yes, yes, yes, I'll do that." But when it came down to it, it's not turning out that way. (Cate, #1: 3)

Not only does Cate not get support from her mother, she does not get support from her partner, Colin, either. Not only has Cate overheard Colin tell his mother he was "disappointed" in their disabled child, Cate explains she cannot rely on Colin to care for Billy because she is fearful that he might lose control and hurt him. Consequently, she finds herself having to drop everything at work from time to time, to return home. Cate ultimately avoids leaving their disabled son alone with his father.

Cate: We knew something was up with William. Once I heard [Colin] say that he was disappointed about it, and that was when he was talking to his mother on the phone, and I heard him say it. And that was kind of hard to hear. And I already said that I'm afraid he'll try to hurt Billy one day in anger and frustration. But ultimately I'm not sure if I trust [Colin] alone with him over extended periods

of time. So the way I deal with it is that I make sure he [Billy] has care. Meaning, the babysitter is there rather than my husband. And there's never a time when he has to watch that's over three hours. And I am the controller of that; I am the master. That's something I took upon myself. He said to me, "I can't watch these kids. I can't take it; it's too much. Billy's too uncontrollable. He stuck his hand in his diaper and put poo all over the wall. I can't take it." And there's always a day when the daycare's closed and I've got to work, and he's got both of the kids home. There have been days when he's called me and said, "Listen, I can't take it. You need to come home *now*." And I'll go home. And it's rare, but I always make a point – I say to him – "*You* have to call me and tell me that before something happens. That is your out. You *need* to call me." So he understands. I don't really trust him alone with him for overnight and stuff like that. Like when I had the second baby, I had to be in hospital overnight, and he was home with Billy, and that was really, really hard. Because I asked my mum to stay but she couldn't. But it was fine.

Researcher: Does he know that you have those reservations about his control?

Cate: I don't know. We never talk about it. I never sat down and said, "I don't trust you." I just kind of manufacture our schedule so that it doesn't occur. (Cate, #1: 20-21)

For Cate, not only was support for her in-home duties lacking, her work life was often interrupted unexpectedly and she felt unable to leave her disabled child with his own father for any length of time. She shared one particularly worrying incident. Both Cate's children (a two year-old and an intellectually disabled four year-old) had been left at home alone. Their father had

gone out to purchase alcohol for himself (Cate, #1: 64). Cate's situation and caring responsibilities appear overwhelming. While working full time, she must single handedly care for her son Billy who has autism, her grown brother with a disability, her unemployed husband, and her able-bodied two year-old. We have already seen Cate's colleagues are not especially supportive, nor her mother or her husband. Cate had this to say about approaching her mother-in-law for assistance:

Cate: I had to go away twice. Once to bring the kids over there so that Colin's Mum could get used to being alone with [Billy]. And then a couple of months later I could actually go and be able to drop [Billy] off there for a couple of days at a time, because she was intimidated by him too. She was, "*What am I going to do with this four year old kid who doesn't know how to talk, and still uses a diaper?*" Plus I paid her some money, so that always helps... they don't have any money, so they were like, "Whoo-hoo!"... And that's what it took. That's what it took. That's what I had to do. (Cate, #1: 6; researcher's emphasis)

To complete the picture of Cate's overwhelming situation, and the absence of social support she experiences, I include this last passage, where she explains that her employer-sponsored daycare center (which is, I remind readers, an organization that provides support for people with disabilities) denied her son access. Her son, apparently, was "just too much trouble":

Cate: The worst thing was when the employees were told that this was a daycare that you can use for your kid. They said, "You can use this daycare for your kid, and it's going to be great because you'll get this discount on daycare. And it's going to welcome kids with disabilities." And I thought that was just awesome. And then when they started it, I said,

"Why don't I send my son to it?" And the person who was running the daycare at the time said that they couldn't handle my son, even though he wasn't even yet two. And they just said that he was too hard to work with for the staff. And they said, "No." And I went to them in writing. I said, "Can you please tell me why you're denying me this?" And the problem I think was that the person running the daycare was a financial guy. He was head of the business office at the time. I don't really think he had very much interest in actually helping kids; I think he was interested in the bottom line. And he was, "Well, this kid's just too hard." But that was the hardest thing. And even that wasn't that big of a deal. It made me grow; it made me branch out into the community for daycare. (Cate, #1: 10-11)

Cate's story is reflected in many other respondents' experiences, although she is the only one who reports support withdrawal from her mother, partner, in-laws, colleagues and the employer-sponsored day care center, concurrently. For Charlene, her experience of Clayton's support was through her ex-partner [the father of their disabled son] who actively worked *against* her, as she struggled to cope with supporting and caring for her two very young children--one of whom had become a paraplegic because his father had run him over as an infant:

Researcher: And do you have the support of your ex-husband for Jamie?

Charlene: I did *not* at the time. My ex was very non-supportive, and he was very hostile.

Researcher: About the cause of the accident?

Charlene: No. My ex-husband ran over Jamie. So he was very guilty. He was very non-supportive of me. When I filed for divorce, he got a lawyer and filed that

I was an unfit mother. And the fact that I had shown that the previous five years of income tax, the only person in our household that earned a living was me - that he hadn't worked - helped me. Jamie had a home teacher who had come into our home and wrote a letter saying that she had observed the children at home and that I was a good mother. But I still had to go through court and take care of that. (Charlene, #1: 10)

Conclusion

The question of social support has always been a vexing one in our communities, especially as it pertains to people with disabilities, or those people caring for others with disabilities or chronic illness. We know victims of life crises sometimes have difficulty gaining the support they desire and need (Silver et al, 1990, p. 397). We also know that not all social ties may be supportive (Hobfoll and Stephens, 1990, p. 454; Vickers, 2001) and that social support may have a mixed effect (Hobfoll and Stephens, 1990, p. 461; Vickers, 2001). We have certainly seen that to be the case here. These women are in dire need of social support. Unfortunately, the literature is distressing in confirming those in greatest need of social support may be least likely to get it (Silver et al., 1990, p. 398). Further, we also know the supportiveness of social ties waxes and wanes as stressful events are confronted and take their toll on the resources of those involved (Hobfoll and Stephens, 1990, p. 455). Perhaps one possible explanation for the sense of disconnectedness and the experiences of "Clayton's support" reported may be that these women continually need to call on support, thus draining sources of goodwill.

However, that does not explain active attempts to thwart these women, to make life more difficult for them and their children, and it certainly does not explain the numerous acts of cruelty and thoughtlessness reported here. The thoughtlessness demonstrated may be a function of the feelings of vulnerability and

helplessness evoked in potential helpers and beliefs about appropriate reactions to display towards people experiencing life crises (Silver et al., 1990, p. 398; Vickers, 2001). Having a child with a serious chronic illness or disability would certainly constitute such a life crisis. However, being a product of social relations, social support is likely to have costs and benefits associated with it (Hobfoll and Stephens, 1990, p. 455) and may be dependent upon the perceptions of others of the individual's *need* for support (Sarason et al., 1990, p. 18). The problem may lie, for example, with how to present the problems to others: "If they display their distress and report difficulties in coping, they may drive others away. But if they fail to exhibit their distress, they may not signal a need for support" (Silver et al, 1990, p. 398). In other words, the way these women choose to display their needs for support may contribute to the lack they are experiencing. How much help should they say they need? If it seems too much, they may frighten potential helpers away. If they seem to be handling their lot-as these women did-perhaps others are unaware of their need. It is acknowledged that "social support is not a bottomless well" (Hobfoll and Stephens, 1990, p. 465) and frequently, people who are potential givers of support may not know how to react when dealing with people during a life crisis (Silver et al., 1990, p. 398). The sobering conclusion is reached that these women, and those like them, cannot necessarily depend on those closest to them for support, due largely to the unacknowledged nature of their situation.

Sadly, our ability to imagine the illness experience and to empathise with those who are ill is severely limited (Morse and Johnson, 1991, p. 1; Vickers, 2001). Denial of illness and its consequences by those closest to the person concerned can be frustrating and angering (Szasz, 1991, p. 168). We have seen here that even supportive relationships may be characterised by negative exchanges (Hobfoll and Stephens, 1990, p. 462). However, we have also seen very unsupportive contexts where these women need to continue and survive. What is required is ap-

appropriate recognition of the needs of these women for support, at home and at work, by partners, families, friends and colleagues. Policymakers need to acknowledge, when making workplaces accessible to people with disabilities, that they also need to consider the needs of workers who are caring for those with chronic illness/disability to alleviate their trauma. The stories above flag serious and ongoing challenges for these women: surviving on a daily basis; progressing their careers (and, perhaps even, holding down their jobs); maintaining a cordial relationship with co-workers, and keeping a semblance of “normality” in their family functioning and interpersonal relationships. Acknowledgement of such concerns provides an important first step in ameliorating these women’s lives.

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Essays and Creative Works

A Disabled Woman's Journey

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Abstract: This is the story of the author's journey from an early childhood characterized by severe physical and cognitive disability to an adulthood devoted to challenging distorted views of disabled persons. The author's goal is to be among the disability studies scholars who impart at schools and at places of employment understanding of and respect for persons with disabilities

Key Words: Cretinism, Peer Abuse, Disability Studies

I embark on revealing my own experience with both physical and psychiatric disability with one purpose. That is to emphasize the dire need for disability studies to be integrated not only in the college-level curriculum, but in the curriculum and lesson plans from high schools down to primary schools. Such programs would make it possible for disabled children and adults to be perceived as part of a diverse population rather than as objects of derision. True access involves not just open doors but open arms.

About six months after my birth, at the end of 1944, my mother was confronted with an infant who did not eat, defecate, or show any intellectual growth. On the basis of one course in college physiology my mother suspected I had a non-functioning thyroid gland. No physician would believe her. She was told to go back to the kitchen. In 1946 she took me, by this time a bloated blob with a protruding tongue, to Duke University. There my mother was vindicated when I was diagnosed as a cretin, a person without a functioning thyroid. If not diagnosed in early infancy, the infant becomes a cretin dwarf, physically and mentally retarded. Upon diagnosis, I was immediately given desiccated thyroid which replaces the thyroid hormone. Within

one month my appearance was normal. Due to the lateness of the diagnosis, the prognosis was guarded. "She will be physically normal, but probably mildly retarded. Ultimately it is up to the mother and God." One of the physicians, however, gave my mother some hope when he told her of a rehabilitated cretin infant who became a doctor.

My mother and father clung to that hope even though I could not walk and was incontinent until I reached the age of four. My parents read to me constantly. Then a spark was ignited in my dim awareness and I began to read. By the time I was eleven I could read books on psychiatry in my parents' library. Due to my lagging physical prowess no children would play with me. Books became my consolation. I erected a fortress of fantasy to survive.

From the time I was seven until I was fifteen, I was persecuted by my cousin Judy and by school children. After a dance recital in which I tried my best, my cousin laughed at me and said I moved like a cripple. After school I would hide behind the trees to avoid the taunts of the other children who called me "freak" and "cripple." At summer camp my ineptness caused my teammates to lose baseball games. For this I was beaten brutally and often scratched and bitten. The brutality of my peers must be viewed in the light of the times. It was the 1950s, a decade of rigid conformity. I recall my neighbor's daughter had epileptic seizures as a young child. The children in her neighborhood would kick the girl when she lay on the ground after a seizure.

Although I never fought back, I was consumed by hatred and revenge. I prayed my tormenters would die. To this day, I disintegrate emotionally when I am demeaned by others. Suddenly I revert to the anguished child hiding behind the trees. I can never forgive a blow to my ego.

In high school I began to sing and act in plays. This was the only happiness I knew. Despite my clumsiness on stage, my acting and

singing talent moved the audience deeply. Admiration soothed, and to this day soothes, the deep wounds beneath the surface. Thus, I decided to become a star and to teach a lesson to all the children who had humiliated me.

When I left my hometown and went to college, I no longer had to engage in sports. For the first time I had friends. My singing was also admired; however, a small role in an opera revealed again my problem with clumsy movements and inability to take stage directions. I was nevertheless unwilling to face the reality that a stage career was out of the question for me.

After I had been graduated with honors from college in 1966, I went to Germany to train my voice further and to forge a career. Within a few months I saw singers far more talented than I could not find steady jobs. I became a medical translator and teacher of English and translation methods. Moreover, I developed my talent for singing in many voices and languages. After a few years in Germany I had a full-time career as a teacher and two part-time careers. I felt fulfilled professionally and garnered a great deal of admiration. Nevertheless I was plagued by depressions which I could not understand. I began to read books on psychology, especially the work of Alfred Adler. I then came to understand how correct my father was when he said that even if we do not live in the past, the past lives in us.

In 1973 I returned to New York, found a job as a translator with a publisher and went to graduate school. By 1986 I had been awarded a Master's degree and a Ph.D. in German literature. Before I sat for the orals, I noticed I was gaining weight and had trouble staying awake to study. My hair was growing sparse and I had trouble retaining information. My "thyroid specialist" had not given me enough medication. Without any medication, I would have reverted to a vegetative state. It is important for people with disabilities not to place unquestioning trust in our "expert" physicians. We often know our bodies and minds better than anyone else. An-

other physician had overdosed me and I nearly died of high blood pressure. I now know the signs of both extremes and my current physician listens to me, rather than basing her prescription solely on the blood tests.

With my thyroid once again functioning, I passed my orals with flying colors and then wrote my dissertation. The doctoral degree did not yield the results I had envisioned. For several years I taught German as an adjunct, but I could not find a full-time job. During a German session of the 1990 Modern Language Association I was told by a professor of German that my credentials were outstanding but I would never find a full-time job. "You are a woman, middle-aged, and from New York," he explained to me.

Due in part to my frustration at not finding the professorship I sought, my recurrent depressions became increasingly severe. Since 1988 I have been under the care of a psychiatrist. Although my medication keeps me quite stable, a severe blow to my self-esteem triggers a break-through episode. Despite the distress I have never been rendered dysfunctional.

By 1990 my publisher employer was selling the firm. Thus, I decided to go to law school and become an attorney in the area of employment discrimination. My special interest was in disability discrimination. From 1987 on I had been publishing articles on various aspects of disability. The story of my rehabilitation came out in 1987. By 1991 I had published in the medical journal *Epilepsia* a study on the depiction of epilepsy in literature and film. Owing to this research I gained international recognition in the epilepsy community. Although I have no seizure disorder, I identified deeply with the stigma and rejection most people with epilepsy experience both professionally and personally. The success I had with my research gave me the courage to embark on a law career at the age of 48.

At law school I initiated the first "Society for Disability Law" and did my writing requirement on the epilepsy defense. Upon graduation

from law school I worked pro bono on my first case. She was a criminal defendant who had terminal lupus. I succeeded in obtaining a dismissal of the indictment in the interest of justice. Until I found a steady job, I earned my living as a free-lance legal researcher and writer. Most of my assignments involved disabled clients.

Finally I found a position as Disability Rights Coordinator at a major New York City criminal justice agency. I still work there and derive a great deal of fulfillment from my job. Despite the paramilitary nature of the agency I still manage to accommodate a significant number of employees. When I cannot provide the accommodation an employee seeks, I try to soften the blow by strategizing with the respective person as to what new career path might be appropriate. Sometimes I just listen to the employee cry out the pain.

At present I am also pursuing a graduate degree in forensic psychology. Continuing my studies is a joy, rather than a burden. I ski with my mind. My intelligence is a miracle and I never tire of proving myself worthy of that miracle.

Reading through my psychology journals, I came upon an issue devoted to disability. This was when I read of the remarkable pioneering work of Dr. Simi Linton and her colleagues. Suddenly I knew what to do when I retire from the City: The revolutionary movement of disabled academics as well as grass roots fighters is my home of the future.

It is February 7, 2004. As I write this account, I am recovering from hip replacement surgery. After the initial agonizing pain, I began rehabilitation at the Rusk Institute of New York University Hospital. There what had initially seemed to be a great misfortune turned out to be a blessing in disguise. Before my injury I had sympathy with people who use wheelchairs. However, it was only when I could not move, could not go to the bathroom or dress myself that I came to appreciate the courage entailed in fighting for access. Today putting on my socks

and taking a shower on my special bench are victories. All of this I had taken for granted until my fall. Now I cannot go down the stairs to the subway. Now I must often in vain hail taxis which will not stop when they see me with my walker. I called Simi Linton from the hospital and told her what insight I was gaining from my experience and how much my determination to be an active part of the disability rights movement had increased. At Rusk Institute I made another discovery. I felt completely at home with my fellow patients. We were the majority in this setting. Our physical and occupational therapists were young men and women who gave us unceasing encouragement and showed unending patience.

There are an increasing number of people who feel the old and disabled are a drain on society. These "Darwinians" believe the world should belong to the strong. During my most recent attack of depression, a young man told me he would assist me in suicide if it were legal. He informed me that "since all depressed people are weak and will eventually commit suicide, they should be helped to do it efficiently so that their organs can be harvested." And yet, it is the existence of the weak and needy which brings forth compassion in the strong who can see beyond cold financial considerations in regard to the elderly and disabled.

When I was about fourteen I wrote a poem called "Lonely Child." Although I lost the words to the poem, I still recall that depicting that forlorn little girl, once myself, constituted an act of healing. Today participating in a course on disability studies is healing. Writing this essay is healing. Pain is rendered productive in service of transformation. Like a fearful horse I often wade in the quagmire of old injuries. Yet, I know I must rise above the past so the lonely child dwelling within me may find peace at last.

My journey continues towards my goal of becoming part of the disability studies community. The inclusion of disability studies will en-

able others to view disabled persons as part of a mosaic in which beauty is found in asymmetry as well as in symmetry. Incorporating disability studies into the lives of children and adults will bring us all one step further in the journey towards our own humanity.

Irma Jacqueline Ozer is a Lecturer/Researcher on Disability Rights at the New York City Department of Correction. Because of her childhood experiences, her studies and employment have been devoted as much as possible to disability issues. Her singing and acting background has been utilized in singing cabaret benefits for disabled homeless persons. She is presently pursuing a degree in psychology to be utilized in counseling disability groups and further research on the treatment of the physically disabled by psychologists.

Disability and Academe: Views from Both Sides of the Teacher's Desk

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Abstract: Personal history of going through higher education as a blind person and a thirty year career of teaching, counseling, supervising and administrating is used to illustrate changes and constants in the ways academe deals with a disability.

Key Words: teaching, disability accommodations, blindness

I was born blind, and I have experienced 20 years of education as a student, and 30 years of teaching, counseling, and administrating. My blindness has shaped my views on education from both sides of the teacher's desk. The only two teachers with visible disabilities I ever had were my resource room teachers who taught me Braille. This might have something to do with the fact I received almost all of my education from elementary school to graduate school before Public Law 94-142 and long before the

Americans with Disabilities Act. But even since the ADA, I can count very few fellow denizens of the groves of academe with disabilities. Therefore, I have made up the rules as I have gone along, and I learned a lot about human nature for which I never got credits or grades.

Early on it became clear to both my parents and me that my success in life was much more likely to be in the classroom than on the playground. I was chosen captain of the spelling bee team but never captain of the dodge ball team. When I was ten, my parents, possibly hoping to inspire me to be a scientist like my father, took me to meet Dr. Nemeth, the blind math professor who invented the Braille math and scientific notation system.

In high school I participated in a two-week summer school at a local university for gifted science students. I learned a lot about just plain coping away from home and can vouch for the benefit to disabled students of this kind of transition experience. One of the skills I learned was what to do when your reader does not show up. I enlisted my brother to read the material I needed for my course project on the making of the first hydrogen bomb. What would Freud say about this subject choice by a socially inept, young blind girl trying to go through the separation and individuation conflicts of the teen years?

When it came time to venture forth from the home nest, something in me knew I would need to make a complete separation from an overprotective family. My parents pointed out there were four good colleges in my hometown and I could go to any of them. I chose to go to Michigan State, eighty-six miles from home and to stay there almost twelve months a year, graduating in three years.

I loved the freedom of being one of about twenty blind students on campus. At first I stayed far away from other blind students, having adopted society's attitudes that blindness was something to be ashamed of and overcome.

But during my second year, I began to hang out in the room set aside in the library for reading aloud to blind students. There I learned such useful skills as using a nail file to jimmy the door to get to the women's restroom nearby instead of going halfway across the library to ask someone to let me in. I also had enlightening discussions with other blind students about such topics of the sixties as, "Do you see colors when you're on an LSD trip?" and, "How do you run from the cops when using a cane and participating in a street demonstration?" Student development, including pride in my identity as a blind person, came with reading assignments not available from Recordings for the Blind.

Readers deserve a large amount of credit for helping me get through school. I never had the funds to pay them; so all the hundreds of hours to get through from freshman year to dissertation preparation were volunteered. In college, the only Braille book I had was calculus; many were not available on tape either.

At Purdue where I did my graduate work in clinical psychology, there was no reading room set aside for reading aloud to the blind, so we used back corners and a couch in the women's bathroom outside the psychology reading room. Statistics and Freud, among others, were read to the tune of flush, flush. Some of my volunteers did not know statistics, so would say, "There's this long S-shaped curvy symbol here." But they showed up and they read.

Working and volunteering were important parts of my education. I worked washing dishes in the dorm cafeteria, gaining opportunities to play in the muck and earn money at the same time. My favorite volunteer activity was working at local crisis phones. One day during some volunteer training, I suddenly realized why I shone at this work. I was used to relying on voices to get information; not having visual cues was no problem!

Most faculty members I had were accessible and helpful long before they "had" to be because

of ADA and other laws. They met my requests for accommodations by reading tests aloud and reading aloud what they wrote on the board. A few did not try and made it clear they wished I was not in their classes. In these situations, I stayed, probably more out of stubbornness than out of a genuine thirst for knowledge.

One gentleman tried much too hard to level the playing field. My hindsight views him as a caring liberal of the sixties variety. He was reading me his multiple-choice exam and when I told him my answer for a question was "a", he told me that was wrong and I should try again. I said "No. My answer is 'a'." He stated he was just trying to help and why not guess again. I said something about not caring if it was wrong, "just mark 'a'." He did, muttering he could not understand why I would take no help. I felt royally insulted and ready to fight his condescending attitude.

A tough area for me in both undergraduate and graduate school was statistics. In undergraduate school I had an Indian teacher who spoke with a British/Indian accent. By the time I translated in my mind what she was saying and wrote it down using my slate and stylus dot by dot I was light years behind. Again in graduate school, the book was not in Braille or on tape, so volunteer readers and weekly tutorials from the professor got me through. Bless the professor, he even provided coffee for the tutorials; compassion can be found in statistics faculty members!

Fast-forward to over 30 years of a rewarding career in the academic world, teaching, counseling, supervising and administrating college counseling centers at four different universities. One major change in the way I do my work is because of the advent of talking computers. I can grade student work submitted electronically, read professional journals online, and scan text material into my computer. My university provides the job accommodations of buying software that enables the computer to read every-

thing on the screen out loud and hires a work/student to read to me five hours a week. We skim through pounds of books, journals, and paperwork that fall into my mailbox each week. What has not changed is my driving desire to know as much as I can in my chosen field. Occasionally, I grudgingly accept that blind or sighted, one cannot read it all, but I keep trying. Librarians have been great friends and enablers of my bookaholic tendencies. At each university where I have worked, I had a cataloguer friend who pointed out good new books to me in my areas of interest. The books get carted to my office, the student reader reads the table of contents, and I pick out chapters to mark and take home and scan to read in my copious “free” time. The most frequent words I say to the readers are still “next paragraph” and “look for the results.” So many books and so little time! (Especially when you consider it takes at least twice as long to read something out loud) Do not ask me what the Thursday television line-up is; my ears are in a book.

Academe, whether before or after the Americans with Disabilities Act, has been grudging in my experience in its acceptance of those of us with visible disabilities, even at the bottom rungs of adjunct lecturer and assistant professor. After receiving my doctorate in clinical psychology, I sent out over 150 resumes before getting any interviews. I had written about my blindness in my cover letter stating it limited me only in my ability to drive between branch campuses. I received back many laudatory letters pronouncing me “amazing” but not for them. Finally I garnered an interview at a campus that turned out to be my future employer. Their way of dealing with the many questions that could quite reasonably occur to sighted folks about how a blind professor would handle the day to day demands of teaching was to ask: “What would you do if someone shot up heroin in class?”

When I asked, stalling for time, “Is this common?” they assured me it was not but still wanted to know what would I do. I suggested it

would probably cause a stir from other students and I could notice the stir and ask what was going on. The closest I came was a shouting match between a Black Muslim and a white racist.

I have never had the kind of discussion I would like to with blind faculty members from across the country about classroom management, but here are my solutions to a couple of common problems: cheating, and recognizing students.

In the area of academic honesty, I take the hard line quickly and firmly. I inform students in my syllabus and on the first day of class that academic dishonesty will not be tolerated and anyone found cheating will be given an “F” on that assignment. I inform them again at the beginning of the test and have a sighted proctor patrol the aisles. In the one incident of cheating I know about, the proctor grabbed a napkin from a member of one of the university’s athletic teams with multiple-choice answers written on it. I gave the student the grade he deserved, but think it was later changed by a more forgiving or sports-minded department chair. Somehow the word spread at that university that my Seeing Eye dog knew who cheated and had tipped off the proctor. At least the dog got some respect.

Recognizing students and forming personal relationships with them is an important part of teaching but is hard for me. By mid-semester I usually know about half my students in a class of forty. Some are easy: the three males in a 30 student psychology of women class; the bright talkative “stars”; and a few at the bottom of the class about whom I worry perhaps more than they do. The middle is a blur. Being able to read their e-journals myself and write back comments has helped in promoting more personal faculty-student relationships.

In teaching the psychology of the exceptional child class, I have had the opportunity to make my exceptionality part of the curriculum. These students learning how to be professionals working with disabled clients first must figure

out how to work with a professor who is blind. Most of the students come into the course kindly disposed towards “those unfortunates.” It is my agenda to have the students leave the course with empathy and skills to become impassioned allies for exceptional clients, friends and coworkers. Teaching in the nice, polite, hard working Midwest, I try to not sound too angry when discussing discrimination or too sarcastic when a “disabled superhero overcomes disability” story hits the news. One of the sensitization exercises I use early in the term is to have students report in class on images of exceptional individuals they find in magazines I hand out. Needless to say, “There aren’t any” is the most common report. This provokes wonderful discussions of hidden disabilities, the “beautiful people” pictured in magazines, and what is beauty anyway?

To get a picture of how my disability comes across to students, I asked them anonymously to write about this in a psychology of the exceptional child course. The students said having a professor with a disability added to their knowledge of the practicalities of living with a disability in ways a textbook could not teach. As one student said, “They (people with disabilities) can do the same things I do, just in a different manner and with a little bit more effort.” Students also reported an attitudinal change toward “looking past the exterior to the person inside.” At first the facts that I did not make eye contact, that students had to just speak up instead of raising their hands to be called on and that a dog was in the classroom caused some consternation. As the semester went on, these differences just became parts of the classroom ambience. One student felt advantaged in that she did not have to groom herself before coming to an eight a.m. class because I would not see her. One wonders why peer pressure did not keep her combing her hair anyway?

From my fifty years of teaching and learning, the major conclusion I can draw is: academe is just like the rest of society, still grappling with how to deal with the one out of seven of us with

disabilities. I get irritated at not being provided with electronic copies of documents before meetings even though I have repeatedly asked for them. I need to draw a deep breath and remember that no matter on which side of the desk we are, we are all still learning.

Katherine Schneider is an emerita senior psychologist and coordinator of training at the Counseling Service of the University of Wisconsin-Eau Claire. In retirement she enjoys guest lecturing on disability issues to a variety of university classes and community groups. She may be contacted at: Counseling Service, University of Wisconsin-Eau Claire, Eau Claire, Wisconsin 54701 or Schneiks@uwec.edu.

Commentary

Are Britain’s Higher Education Institutions Prepared for Prosecution in September 2005 Due to Their Lack of Disabled Access?

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Key Words: disabled access, higher education, SENDA

In September 2005, Britain’s higher education institutions become liable to prosecution if a student or staff member believes there to be disability discrimination relating to access to buildings, facilities and other areas. This is because the Special Educational Needs and Disability Act 2001 (SENDA) made educational institutions responsible for implementing Part IV of the Disability Discrimination Act 1995 (DDA). This research note presents a case study constituting an audit of one university. Finding that, despite a programme of access, the university lacks many features that would be expected, the study is offered as a shot across the bows to

administrators in UK higher education institutions.

Responsible university bodies have known for many years about the required changes to physical access at institutions. The Disability Rights Commission (DRC) has provided a range of advice, guidelines and prompts to encourage advanced preparation (see www.drc-gb.org). Those guidelines included recommendations for institutions to undertake audit-surveys to assess their preparedness, and the DRC commissioned several case studies (see e.g. NFER 2003). The case studies tended to examine work that had been done at institutions whereas here we report on what remains to be done. Since the university assessed here is unlikely to be an isolated case, we feel the issue warrants the attention of a broader readership.

Part IV of DDA 1995 obliges universities to change various physical features to eliminate disability discrimination with respect to access. Part M of the 2004 version of Building Regulations, *Access to and Use of Buildings*, provides specific guidelines regarding physical access and other requirements. Information in that document was used to develop a template for an audit-survey. A summary of relevant aspects of the regulations will illustrate areas covered by the survey and provide the context for what follows. Key relevant aspects were:

- *Site boundaries and car parks* should preferably be level. Where not, there should be a gentle gradient over a long distance or a series of shorter parts with steeper gradients. If the gradient is too steep it should be ramped. The surface should be easy to travel on, there should be room to approach the building, and it should be well lit.
- *On-site parking and setting-down* should be near entrances, with sufficient room for a wheelchair-user to enter and leave the car, and space to travel to the entrance.

- *Ramped access* should have as shallow gradient as possible. There should be support on both sides of the ramp, and room to manoeuvre and open doors.
- *Stepped access* should have a warning well in advance. It should have a non-slip surface and handrails. *Handrails* should be easy to grip, spaced away from walls and at a convenient height.
- *Accessible entrances* should be clearly sign-posted, recognisable, and have weather protection. The threshold should be level. If universal access cannot be gained at the main entrance, there should be an alternative.
- *Doors* should be accessible to all, wide enough for all to enter, have visibility panels and shut when not in use. Automatic doors are preferred. Manual doors should stay open long enough for entrance or exit, have enough room for a wheelchair-user to manoeuvre and open the door, well positioned handles and clear instructions. Power entrance doors should have clear controls. For glass doors, it should be obvious whether they are open or shut.
- *Entrance lobbies* should be big enough to manoeuvre a wheelchair or pushchair, be free from hazards, and have a doormat.
- *Entrance halls and reception areas* should be easily accessible. Reception desks should be an appropriate height for wheelchair-users and allow close contact with a server for lip reading. Information about the services in the building should be well signed.
- *Internal doors* should preferably not have self-closing devices, so they stay open for longer.
- *Corridors and passageways* should be wide enough for wheelchair manoeuvring and to allow people to pass a wheel-

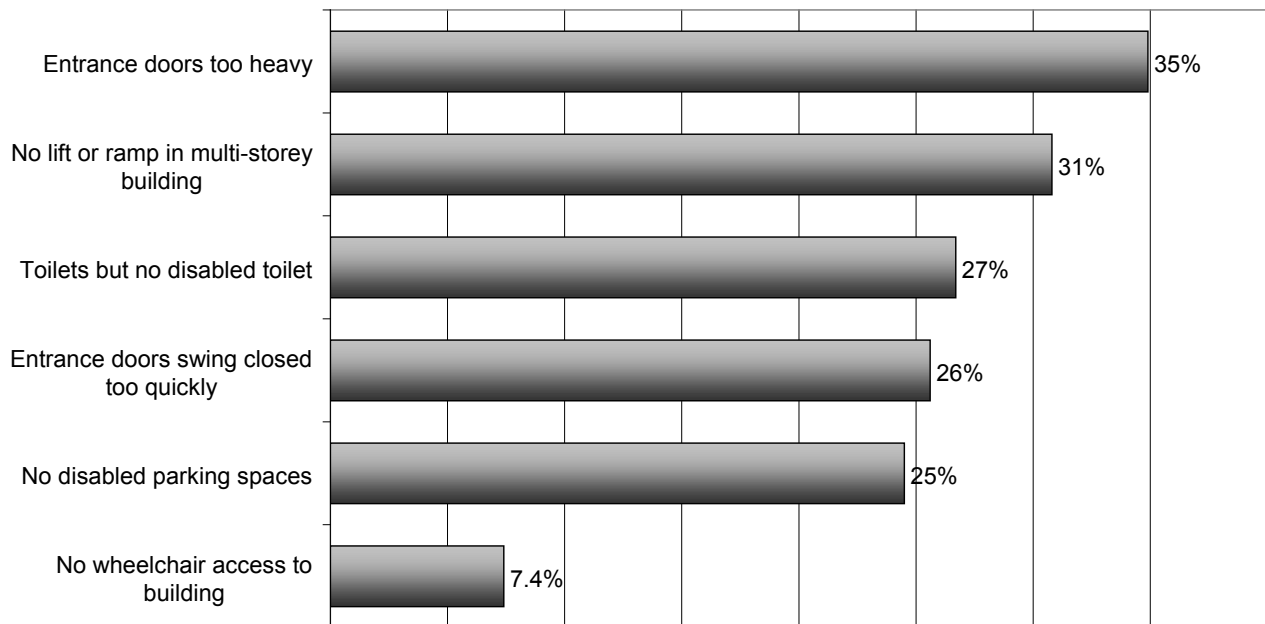
chair-user in the corridor. They should be well lit, have a contrast between the walls and floor, and have good acoustic design.

- *Internal lobbies* should allow a wheelchair-user to be clear of one door before opening the other.
- *Passenger lifts* are the most suitable for vertical access as all can use them. They should be well signed within the building, allow enough space and time for a wheelchair-user to enter or leave the lift, and should allow room for a wheelchair-user and at least one other passenger. Audio and visual information about lift usage should be provided.
- *Lifting platforms* are an alternative to passenger lifts. They should have reachable controls and audio and visual information. *Wheelchair platform stair-lifts* are only for exceptional circumstances, and are only suitable with correct instruction

and supervision.

- *Internal stairs, ramps and handrails* should meet the same standards as the external ones.
- *Aids to communication* can be many things. Practical aids include braille, loop systems and assistive listening devices, good lighting, good signage, designs that allow close contact with service providers to facilitate lip reading as required, and appropriate floor materials for people with visual impairments.
- *Wheelchair-accessible unisex toilets* should be easily reached, and have enough space for a wheelchair-user to approach, transfer and use the sanitary facilities. Cubicles should have horizontal and drop-down support rails, have room for manoeuvring and allow the user the opportunity to be able to wash and dry their hands whilst sat on the toilet. They should have an accessible pull-cord

**Figure 1: Discrimination against Wheelchair Users
(% of relevant buildings)**



alarm for emergencies, and provide paper towels as well as a hand-drier because not everyone can use the latter.

The *Building Regulations* provided the principle reference point for the development of the present audit-survey. The research site was a mid-size university campus in the southwest region of the UK. The university is anonymous for present purposes as the intention is not to chastise this particular university which is likely to represent the rule rather than the exception. In fact, during the research it became evident that this university had undertaken a deliberate programme of modification to physical features, and it is therefore possible that it represents institutions which are at the “better” end of the scale in terms of meeting the requirements.

The survey detailed here was conducted independently of the university body with responsibility for tackling DDA issues. Hence, the survey has the credibility of independence, but was limited to areas which did not require official access. As a result, lecture halls, accommodation and areas requiring special access were not surveyed. In relation to some specifics including corridor and door widths, door weights and speeds, a judgement on their appropriateness was made by an adult female who passed through, or tried to pass through, in a wheelchair. The audit-survey was complemented by a small number of in-depth interviews with disabled university staff members, though only a brief glimpse of the interviews is given in what follows.

Table 1: On-Campus Access Discrimination Against Wheelchair-Users

Location (n=number of relevant buildings)	% of relevant buildings
Car Parks	
No disabled parking (49)	25%
Of buildings with disabled parking (37):	
Poorly signposted spaces	81%
No added space width	46%
Parking is away from entrance	41%
Main Paths to Buildings	
Path indistinct from road (42)	38%
Path uneven	28%
Path obstructed	19%
No handrails for change in path level (22)	86%
Wheelchair Ramps to Buildings	
No wheelchair ramp (54)	39%
At least one ramp handrail missing (33)	76%
Building Entrances	
Door too heavy for wheelchair-user (43)	35%
Door swings closed too quickly (43)	26%
Unclear door instructions: push/pull (54)	72%
Reception desk at inappropriate height	44%
Multi-storey buildings (n=26)	
No lift	31%
No ramp between floors	100%
No rear-wall mirror in lift (13)	31%
Disabled Person's Toilet	
No disabled toilet (49)	55%
Toilets but no disabled toilet (30)	27%
Door does not open outwards (22)	41%
Door not easy to lock/unlock (22)	27%
No drop rail next to toilet (22)	23%
No emergency assistance pull cord alarm (22)	36%
Washbasin, soap dispenser and hand-drier not in reach from toilet (22)	59%
Absence of paper towels or hand-drier (22)	100%

Two acknowledgements are necessary prior to the presentation of findings. First, since field-work was conducted in early 2005, the university in question could, in theory, have subsequently addressed some of the issues raised herein prior to September 2005. Second, the findings presented here concentrate upon potential transgressions of DDA. We note that the university did meet many of the requirements and had clearly undertaken a programme of physical design changes to address the issue. Perhaps what follows should preferably be viewed as assessing the shortfalls that could be overcome with further iterations and additional resources.

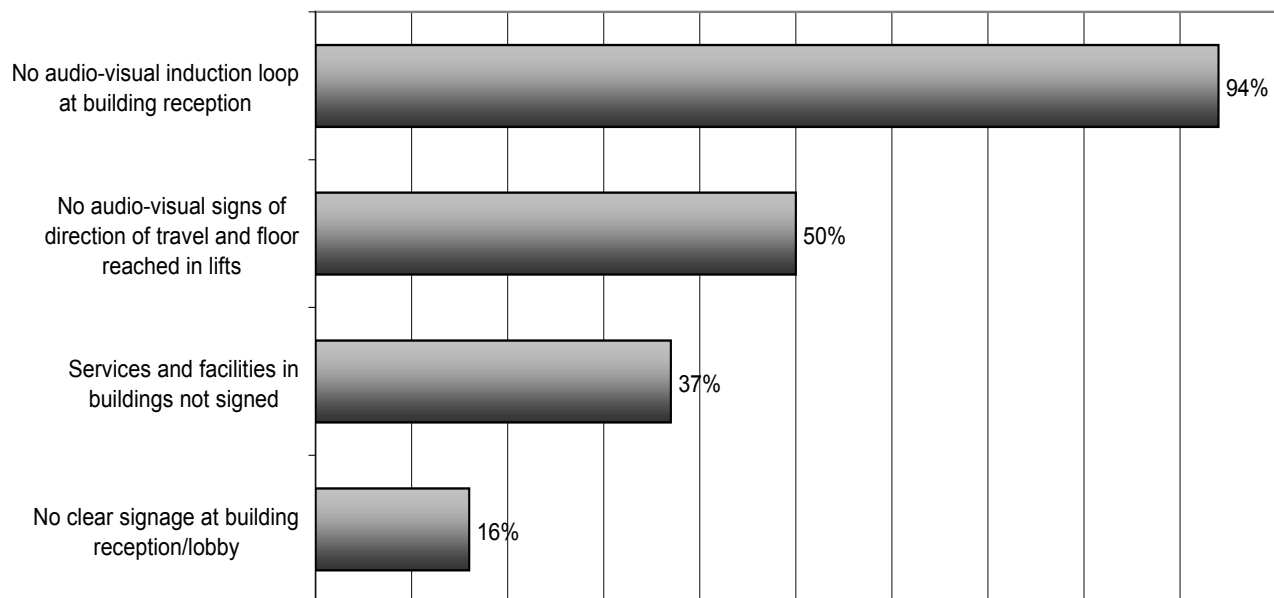
Key findings of the audit relating to discrimination against wheelchair-users are summarised in Figure 1 and Table 1. Table 1 contains more information than is discussed in the text. Key findings relating to discrimination against persons with sensory impairment are shown in Figure 2. The number of relevant buildings or entrances is given in the table and figures. Forty-nine buildings were surveyed, five of which had two main entrances for a total of fifty-four main entrances.

Four of the fifty-four main entrances (7.4%) surveyed did not allow independent access by a wheelchair. Although this is arguably the most blatant exclusionary practice, other indicators suggest exclusion is more widespread. Many buildings did not have access ramps, and well over a third of main access doors were either too heavy or too speedy for wheelchair-users, thus presenting difficulties and requiring, at best, a belittling request for assistance. One interviewee observed:

“You have to actually take a run at them [the doors] to make them open. I went to a graduation at [a different university] about two summers ago and in the Department of English at [that university] they had pressure pads on the wall. So you just hit the pressure pads by each fire door and they open. So that would be a good thing to have for wheelchair-users at [this university].”

Since almost a third of multi-storey buildings did not have a lift or ramp to non-ground floors, wheelchair-users were effectively excluded from

**Figure 2: Discrimination against Sensory Impairment
(% of Relevant Buildings)**



these buildings. A quarter of on-campus car parks did not have disabled spaces, while others suggest tokenism due to either the absence of additional space for wheelchair manoeuvres (46% of car parks with disabled spaces) and/or a prohibitively long distance between the disabled space and the relevant building (41%). One interviewee complemented a particular building, although it is the implied exclusion from others that is arguably most apparent:

“I try to organise most of my meetings in this building [because] this building is very good. I think this building might be an example of good practice around the university.”

Many of the main paths to university buildings did not meet requirements. Paths were often indistinct roads, uneven and/or obstructed. Where paths changed levels, the vast majority (86%) did not provide handrails for wheelchair-users as recommended by the Building Regulations.

Only four in every ten entrances had a wheelchair ramp, and three quarters of these were absent at least one handrail. In addition to doors being too heavy or closing too quickly for the non-Olympic wheelchair-user, there were few clear Push/Pull instructions at doors. Almost half of reception desks were of an improper height for use by wheelchair-users who did not have monster truck tyres. While almost a third of multi-storey buildings did not have a lift, those which did often failed to have a rear-wall mirror, thereby potentially restricting the vision and egress of wheelchair-users.

Over half of the 49 buildings that could be accessed (55.1%) did not have a toilet for disabled persons. This does not necessarily indicate discrimination however, as some buildings did not have toilets of any kind. Of buildings with toilets for non-disabled persons (arguably the preferable denominator), a quarter did not have an accessible toilet (8 of 30). Where accessible toilets existed, none of them met all aspects of

the *Building Regulations*. Many cubicle doors inappropriately opened inwards, and around a quarter had what the survey deemed ‘problematic’ (overtly awkward) locks. A quarter of cubicles lacked the necessary handrails, close to 60 percent did not have the hand-basin within reach of the toilet, and none had both paper towels and hand driers (a regulation because not all users can use driers).

Survey information was also gathered on physical access for persons with sensory impairments, of which a brief overview is given here. The *Building Regulations* note the importance of direction signs and information signs, the need for which was noted by one staff member who was interviewed:

“Because I’m deaf, I don’t always ask where things are because if I get someone who speaks softly or quietly I can’t hear them. So I will really look for signage. It needs to be clear so I can see where I’m going and I don’t need to ask anyone.”

Key findings relating to discrimination against the sensory impaired are shown in Figure 2. Hardly any campus buildings had an induction loop in reception, though the presence in some instances indicates that there was institutional knowledge of this facility. However, with only half of buildings exhibiting directional signs, and over a third failing to sign their services and facilities, there was a clear suggestion of discrimination against persons with hearing impairments. In some instances, even where it was clear that some effort had been made to improve access, it had not succeeded:

“Unfortunately there has been a new sign put up showing the layout of the campus. I don’t find the fonts big enough. It’s not clear. I would like to see more definition. I want to see where I am at that moment in time. I think that could be looked at and redeveloped.”

A sentiment echoed by a colleague:

“Quite often the numbers on doors are put up high and they are quite small. So signage in buildings is another one [problem][for me. In the Institute of [a particular academic discipline], I go along on tip toes trying to get up to the sign. And that building’s just been re-done!”

This case study does not profess to examine all access requirements that would eliminate disability discrimination. The emphasis here was upon highlighting this important contemporary issue by identifying problematic areas. There were many instances of good practices that are not discussed herein for reasons of brevity. Methodologically, the case study further demonstrates the utility of the observational audit-survey method. A tick-box observational survey requires relatively few resources, and is a useful monitoring technique to complement interviews and verify statements of university bodies.

While the likelihood of prosecutions in September 2005 may appear small, and the likelihood of class-action suits smaller, the consequences of either would be, at the very least, bad publicity for the administrators and institutions involved. This should make senior university administrators sit up and think, and perhaps revisit their programme of physical design change to ensure it is sufficiently comprehensive.

It is possible that universities could claim that they are not required to meet the specifications of the Building Regulations. There appear to be two possible get-out-of-jail-free loopholes that they might seek to exploit. The first is that institutions could claim the legislation only requires them to make “reasonable” adjustments (a term used in the Disability Discrimination Act 1995), and that this is therefore a subjective judgment call. The second is that institutions could claim they are only required to be “responsive” to requests as they arise after September 2005 (again, the term “responsive” was used in the official documents). However, both potential loopholes are illusory. Both are con-

tradicted by the wealth of information, advice, guidelines and codes of practice that have been provided, as well as the evidence that some steps have been taken in the right direction. The Code of Practice of the Disability Rights Commission notes that responsible bodies have a clear *anticipatory duty*:

“Failure to anticipate the need for an adjustment may mean it is too late to comply ... when it is required. Lack of notice would not of itself provide a defence to a claim that an adjustment should have been made” (DRC 2002; 54-5).

Whether or not it is deemed “reasonable” for responsible administrative bodies to knowingly and systematically exclude disabled persons from higher educational institutions may therefore prove to be a matter for the courts to decide.

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Emily Godson graduated from the Department of Social Sciences at Loughborough University in 2005 having prepared a research thesis focused upon disabled access. The thesis formed the basis for the present study.

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Disability Classics

First Grade

Bob Segalman, Ph.D.

In October 1948, one month before Truman beat Dewey, and more than 25 years before federal law (I.D.E.A.) guaranteed an education to people with disabilities, I became the first child with a severe disability in Sioux City, Iowa to be mainstreamed. Born with cerebral palsy, I could walk leaning on others and could talk so that only Mom, Dad, and a few others could understand me.

In those days, such children in Sioux City either attended special classes or received home instruction; but the school social worker, Mrs. Bowers, promised to help find a normal class for me to attend. My father was the counselor and director of a Sioux City social agency and had helped some of her clients, so she was glad to help me in return.

I was almost six and was very interested in starting school. I could read a little and remember nagging Mom to teach me more. Miss Bowers spoke to several first grade teachers in neighborhood schools, until she met Miss Erskine who was interested in having me in her class. Miss Erskine had just the right kind of class for me: her class was slower than the other

three first grade classes at that school. This class would take two school years to complete first grade work, and I would be the smartest child in the class, sometimes an important compensating benefit for a child with a disability.

I started school in October and must have known that I had to sell myself. On Halloween I gave everyone in the class a card and had Mom put a stick of gum in each one. When anyone asked me about my walking I said, "I can't walk well, but I can tell time." I would then show them Grandfather's big pocket watch and explain how to read it. They soon forgot about my walking.

When I began school, I attended only two hours a day so I would have time to get used to the routine, and the other children could get accustomed to the unusual child in their midst. I got tired at first, but gradually my stamina grew, and within six weeks I was able to attend all day. Mom stayed with me in class all the time at first just to translate my speech for Miss Erskine, but Mom's attendance became less necessary as Miss Erskine began to understand me, and as I began to do well academically after a month or so Mom no longer needed to come with me. All through school, though, Mom took the initiative in getting to know each of my teachers and encouraging them to call at the onset of any problem. I never felt awkward about this as it just seemed to be another dimension of my special circumstance.

My success in first grade gave my parents enormous joy. They saw it both as a signal of my eventual independence and as evidence that they would not need to educate me at home. For me, this first year was the onset of a completely mainstreamed education.

Because so few pupils with disabilities were mainstreamed then, there was almost no opportunity for me to meet them. In grade school I rarely came across other disabled pupils and often wondered if there were others. I met a few at several summer "camps for the handicapped",

but most of them had educational or mental handicaps leaving us with little in common. I always left those camps after a few days because I could not stand being treated as a “disabled child”.

Once, when I visited my grandparents for two weeks, I attended a special class for children with orthopedic disabilities in their community. Much time was wasted in naps and arts and crafts with little actual learning. I spent the entire two weeks worrying that I would fall behind in my class at home. I had a similar experience when I spent two weeks at a rehabilitation center during my junior year of high school. My teachers at home had written out detailed daily homework assignments. For the first few days of rehabilitation program I would stay up until 11 p.m. each evening to finish my homework, then the staff started giving me tranquilizers. They viewed my industriousness as a neurotic symptom.

Throughout high school and college, I was the only student with a disability in attendance. I grew up being the only different one wherever I went; that helped prepare me for a life of employment. That is, throughout much of my career, I have been the only person with a disability in my work unit.

Because none of my teachers had taught a child with a disability before and because I attended school before teachers’ colleges developed special education curricula, I had the advantage of being judged on my merits rather than on arbitrary standards or on the performance of pupils with disabilities who preceded me. I was lucky to have been placed in a mainstream class, where I was forced to work up to my potential.

My long-term ambitions were still greater than those that many of my teachers had for me. Perhaps that had something to do with my perception of my disability. People told me I was disabled, that my speech was slurred, and my walk clumsy and slow. Yet when I spoke I heard the words in my head as I said them, so

they sounded clear to me. My walk seemed slow to me but it did not seem clumsy as I always looked straight ahead and could not see my legs twisting. With my strong self-confidence I could not understand how my disability might block success.

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Reviews

Book Review

Title: *The Hospital Poems*

Author: Jim Ferris

Publisher: Main Street Rag, 2004

Paper, ISBN: 1-930907-52-4, 54 pp.

Cost: \$14.00 USD

Reviewer: Steven E. Brown

Jim Ferris’s poems move me. That is the highest praise I can offer. In this selection of thirty-eight poems, divided into three sections, “Child of No One,” “Soul Music,” and “The Treatment,” the reader follows Jim from early childhood to the present, while he dissects his hospital experiences and his evolution from a child with a difference to a writer with a disability.

In a first section poem, “Meat,” Ferris writes: “Between four and five they bring down the meat/ from recovery...” (p. 5) a commentary about how hospitals treat patients and how patients engage in their own observations about hospitals and medical treatment.

In the final poem of the book the author includes a self-indictment of what some term a “crip hierarchy.” In “Biological Determin-

ism,” Ferris starts: “Jockeying for position” then writes, “Only one can win.” He does not. He misses finding the girl of his hospital dreams, who “was the light/ we yearned to buzz around” and who is surrounded by the competition by the time Ferris arrives. Yet, he concludes, as must we all, with or without disabilities, as we move through life, he must plan on “getting up again, again.” (p. 54)

One can critique poetry, like all art, by all sorts of standards. But at the most fundamental level, they both still revolve around the concept, “I know what I like.” These poems have depth, movement, and emotion. I like them. I recommend you get to know them as well.

Monograph Review

Title: *Lights...Camera...Attitude! Introducing Disability Arts and Culture*

Publisher: Ryerson RBC Institute for Disability Studies Research and Education, Ryerson University (Toronto), April 2004

For more information, see www.ryerson.ca/ds

Reviewer: Steven E. Brown

This monograph is an excellent introduction to the current state of disability arts and culture, especially, but not only, in Canada. The Ryerson University disability studies research team of Jihan Abbas, Kathryn Church, Catherine Frazee, and Melanie Panitch, divide this monograph into chapters about arts and culture in the context of political change, mis/representation of disability in the arts, audience responses, and moving forward. They also include a section on disability arts and culture links.

The authors do a skillful job of combining introductions to this material with more sophisticated analysis, providing jumping off points for both beginners to these concepts and more experienced disability arts and culture participants and observers. A good example of both

these attitudes are seen in the following description of audience reactions to performances by artists with disabilities:

“At this point in their evolution, ‘soothing’ confirmations may be what most audiences want or can understand of disabled artists/performers. And yet, as we discovered, to witness a performance in this genre is to be challenged and made uncomfortable as much as it is to be affirmed and uplifted. What this suggests is that ‘changing attitudes’ is not an instantaneous and happy enlightenment arising from new and better information. Consciousness-raising about a group of people so negatively situated with respect to mainstream culture for so long can be troubling and difficult work. Disability Arts and Culture is at its most politically potent precisely here, in revealing this fallacy” (page 41).

The accompanying DVD, I found disappointing. First, it was not captioned, so anyone committed to using it who is also committed to universal access, is out of luck. I understand from correspondence with one of the research team that a captioned version is in the works. Second, it is a genuine sampler, with no complete entries. I found this extremely frustrating and disappointing. My recommendation: Get the booklet and hope that complete performances will be eventually released on DVD.

Music Review

Title: *Alive*

Musicians: Sax as Sax Can (Klaus Kreuzeder and Henry Sincigno)

Publisher/Distributor: Trick Music, 1992/1999

Available at: <http://trick-music.de>

Reviewer: Steven E. Brown

I first learned about Klaus Kreuzeder when I traveled to Germany in the mid-1990s. Although, I had a chance to attend several festivals celebrating disability culture, I seemed to always just miss his performances. But whenever I asked anyone about music and disability in Germany, Klaus Kreuzeder's name always came up. A few months ago a German friend arrived in Hawai'i. I had asked him if he could bring some music by people with disabilities. He brought the compact disc of *Alive*.

This is the kind of music I would like if I had no clue who the musicians were. It is scintillating jazz, with Kreuzeder playing soprano and alto saxophones and a sopranino, and Sincigno strumming acoustic guitars. The amazing part of this combination is that Kreuzeder is a wheelchair-using polio survivor. While many polios (as they call themselves) have difficulty breathing, Kreuzeder is wailing away on these instruments. In fact, there is one particular song in which he holds a note for a long time—a minute or two. It seemed every time that particular stretch of music played, my wife came in the room and felt blasted by the music.

Kreuzeder, who left Sax as Sax Can for a solo career in the late 1990s also seems to have a disability consciousness. This live recording was made in a variety of venues, including the 1996 Paralympics in Atlanta and Soweto, South Africa school for children with disabilities. The music on this disc contains no lyrics. It's straight jazz, with homages to great composers like Dave Brubeck and Hoagy Carmichael with *Take Five* and *Georgia on My Mind*. The remainder of the thirteen songs are original compositions.

I highly recommend this music to anyone who likes jazz. It will get your juices flowing.

Book Review

Title: *Missing Pieces: A Chronicle of Living With a Disability*

Author: Irving K. Zola; new foreword by Nancy Mairs

Publisher: Temple University Press, 2003 (reprint of 1983 edition)

Paper, ISBN: 1-59213-244-8

Cost: \$17.95 USD

Reviewer: Mark F. Romoser

Irv Zola's classic "Missing Pieces," is subtitled, "A Chronicle of Living with a Disability." Oddly, when Zola arrives at a Dutch village called Het Dorp -- simply, "The Village" -- he does not consider himself to be a person with a disability, despite the use of leg brace, back brace, and cane.

Het Dorp is no ordinary Dutch village. It exists to provide people with significant physical disabilities a place to live, semi-independently. Zola, a professor of sociology, has come to Het Dorp during an exchange professorship in Leiden. Not content merely to observe, he asks to be treated as a resident of Het Dorp. The journey truly begins when he puts down his cane and sits in a wheelchair, with "an unaccustomed plop" (p. 52).

It's all here in this world-within-a-world. People who have had accidents consider themselves superior to those with progressive diseases because they're not at risk for becoming "more disabled". Oddly, for this purpose, polio was considered an "accident"; people in 1972 knew nothing of post-polio sequelae (p.53, 83). Sexuality, too, simmers beneath the placid surface of Het Dorp. When Zola catches sight of raven-haired Marlene, the same fellow who dated in high school using crutches is astonished to find himself attracted to a woman who uses a wheelchair (p. 53)!

In her foreword to this new edition, Nancy Mairs insightfully points out that nothing like Het Dorp exists, or could exist, in the United States, with its historical antipathy toward fund-

ing of social programs. Why, then, is there a feeling gnawing away at Zola that something is missing at Het Dorp?

The lesson Zola learns, taught most effectively by the few married couples at Het Dorp, is that at the end of the day, Het Dorp is an institution. If and when that day comes, *Missing Pieces* will stand as an important historical document of the institutional era: of everything such an institution could be, and more importantly, that which it could never be.

Book Review

Title: *Listening in the Silence, Seeing in the Dark: Reconstructing Life after Brain Injury*

Author: Ruthann Knechel Johansen

Publisher: University of California Press, 2002

Cloth, ISBN: 0-520-23114-7, 217 pp.

Cost: \$24.95 USD

Reviewer: Kelly D. Roberts

Listening in the Silence, Seeing in the Dark: Reconstructing Life after Brain Injury is a mother's story of a teenager, Erik, who has a traumatic brain injury (TBI). This thought-provoking book looks at life after brain injury primarily from a mother's perspective, while exploring the impact on the entire family. *Listening in the Silence* is a must read for persons working with people with brain injuries, family members of those with brain injuries, and persons with brain injury.

Near the end of Erik's sophomore year in high school, he was a passenger in an automobile accident that left him in a coma. He registered at the least responsive level on the Glasgow Coma Scale showing no motor response, no eye-opening, and no vocal response. He was in critical condition for three weeks and diagnosed with TBI.

The author presents the process involved in reclaiming and reconstructing self after brain injury. She takes the reader through this process from learning to walk, remembering family members, learning to read and write, to more personal things like re-developing a personality and interpersonal and social skills.

The author leaves the reader knowing that science still has a lot to learn about how the miraculous brain functions and the long-term prognosis for individuals with TBI. While "there is no predictability in the course of recovery from TBI," (p. 16) Erik, with the support of his family and friends, is able to recover, attend and graduate from college, establish new relationships, and obtain and maintain satisfying employment. Although Erik does not return to his "old self" he does regain physical and mental capacities that are close to his pre-accident condition.

From the bleak view of staff from the medical institutions, who did not provide much hope, "On two or three occasions the medical director, neurologist, psychologist, and even the social worker urged us to face the reality of Erik's condition and go home more [conveying their belief that Erik would probably not recover]" (p. 111), to the continued hope of family members, the book takes the reader through this life altering ordeal and provides insight into human development and resiliency.

Book Review

Title: *Home Bound: Growing Up with a Disability in America*

Author: Cass Irvin

Publisher: Temple University Press, 2004

Paper, 2003 ISBN: 1-59213-220-0

Cloth, 2003 ISBN: 1-59213-219-7

Cost: Paperback - \$19.95 USD; Hardcover - \$59.50 USD

Reviewer: Steven E. Brown

Whenever I desired to break from reading Cass Irvin's book, I was unable to do so. Her story kept calling me.

It's a fascinating description of growing up with a disability in the American South in the 1940s, 50s and 60s. Individuals from other countries might perceive a monolithic US experience, which we in the US know is not accurate. My life, as a young person with a disability, born about six years later than Irvin, in Michigan in the US Midwest region, reflects a quite different experience. Even so, we both arrived at similar junctures, promoting disability rights and culture.

Some of what I found compelling in the book included Irvin's descriptions about her experiences at Warm Springs, Georgia, the rehabilitation center for those with polio, made famous by Franklin D. Roosevelt (FDR). She felt so much at home there that she writes, "It is a paradox to think that an institution can be liberating, but for me it was. I was not confined there as I was when I was home" (page 51). To me, this sentence sums up a lot of the American disability experience: we can be confined or liberated, no matter who we are, no matter where we are, no matter our dis- or a-bilities; it's a juxtaposition between our internal and external environments and for Irvin as a child, freedom was found at Warm Springs.

Many more descriptions of how a timid young girl became an adult advocate are found within this book. What makes it different from many other autobiographies is how Irvin stretches her own life's experiences into those of a community of people similar to her. The following exchange when Irvin tells a friend she found a publisher for her book signifies why lots of people should read this life story:

"Are you going to tell them how hard it is to be a cripple?"

"Yes, Jewell."

"Are you going to tell them it doesn't have to be this way? That it's because of their stupid prejudice and their stupid belief that we don't matter? That that's what makes it so much harder than it has to be."

"Yes," I answered. "I'm going to try" (page 168).

The part of the book I liked least was what seemed to me extraneous detail. For example, I don't really need to know the author brought a doggie bag home from a restaurant dinner for her sometime boyfriend (page 156). There are also a number of typos and missing words, particularly in the last chapter and a half, which seemed unusual for a university press book. But these are niggling points. The big picture is many of the stories we've been sharing with one another, in the disability rights movement, for the past thirty years or so, are now being perceived as interesting to people outside of the movement. This is incredible progress. And yet...while we move forward, we seem to continually stumble on ourselves along the way.

Irvin writes:

"Franklin Roosevelt hid his disability from the public simply because he knew what public perception could do to his image. He did not hide it from Winston Churchill because he did not fear Churchill's perceptions. Churchill knew he was capable, a leader and a peer. And to people who were close to him, he was grand just the way he was" (page 169)...

As are we all. If only we would pay attention. This book will help achieve that goal.

Book Review

Title: *The Difference that Disability Makes*

Author: Rod Michalko

Publisher: Temple University Press, 2002

Paper, 2003 ISBN: 1-56639-934-3

Cloth, 2003 ISBN: 1-56639-933-5

Cost: Paperback - \$22.95 USD; Hardcover - \$59.50 USD

Reviewer: Steven E. Brown

The author, who is legally blind, describes how he perceived lack of sight, both as a child developing vision problems, and as an adult, living with blindness and teaching sociology. Michalko is well-known for his explorations of this territory, and of his life with his guide dog, Smokie, to whom this book is dedicated *in memoriam*.

I have not read Michalko's other books, but I did recently read *Disability, Self, and Society* (Toronto, University of Toronto, 2003), by his partner, Tanya Titchkosky. This is relevant because some of the same scenarios, for instance, the one with which this book opens, are described by each other, but with their varying perspectives. So while I was familiar with the story leading off the book, I was not familiar with his particular perspective. That distinction between the views of two people gets at a lot of Michalko's interests.

The author describes his book as an interrogation of the process of "identity formation and the social and political significance of our stepping into our identities" (page 5).

The Difference that Disability Makes clearly inspects how disability impacts Michalko's life and studies. Some of it will seem familiar to those who have been studying disability for a few years and some of it will raise new questions. Since identity seems to be American society's most pertinent topic of current debate, it is well worth exploring this book to see how a thoughtful surveyor of this terrain moves along his journey.

Book Review

Title: *Many Ways to Be Deaf: International Variation in Deaf Communities*

Editor: Leila Monaghan, Constanze Schmalting, Karen Nakamura, & Graham H. Turner

Publisher: Gallaudet University Press, 2002

ISBN: 1-56368-135-8

Cost: \$69.95 USD

Reviewer: Sally Y. Nhomi

Many Ways to Be Deaf provides glimpses into deaf communities around the world, and throughout history, from 17th Century Britain (Rachel Sutton-Spence) to contemporary circles of deaf peers and diverse families in the United States (Ceil Lucas and Susan Schatz). It illustrates that internationally, there is still controversy about how to equip deaf children with appropriate and adequate forms of language and literacy skills, and tensions between desires to standardize sign language forms and calls for allowing authentic and diverse forms of expression. Leila Monaghan provides an excellent overview of international forms of deaf culture in the introductory chapter to the book.

Every language has a political history, and issues of nationalism and community identity are reflected in the place of sign language in each country. Deaf culture is widely seen to be inferior to Hearing culture in Austria (Franz Dotter and Ingeborg Okorn), and sign languages are divided by linkages to particular spoken languages within multilingual societies in Switzerland (as reported by Penny Boyes Braem, Benno Caramore, Roland Hermann, and Patricia Shores Hermann) and in South Africa (as described by Debra Aarons and Louise Reynolds). Schools for the deaf have also shaped signed languages and deaf culture, sometimes in idiosyncratic ways. For example, Barbara LeMaster describes how segregated boys' and girls' schools led to the

development of separate forms of “boys” and “girls” sign languages in Ireland.

Particularly in rural parts of Africa, Asia and Latin America, rich and poor deaf individuals see highly unequal educational opportunities, medical supports and technologies, and basic quality of life expectations. Constanze Schmalzing laments how, in one Nigerian community, deaf and hearing residents who long shared manual gestures for communication are seeing the gradual loss of their common language as American Sign Language (ASL) is learned and favored by a privileged minority. Calls for limiting the intrusion of ASL and for preserving the heritage of locally derived signed languages run through articles describing deaf communities in Brazil (by Norine Berenz), South Africa (Aarons and Reynolds), Nicaragua (Richard Senghas), Thailand and Vietnam (James Woodward). Contrastively, Karen Nakamura (who writes on Japan) and Michael Pursglove and Anna Komarova (who report on Russia) critique societies which deny civil rights for deaf individuals along standards upheld by American Deaf activists.

While most of the book’s chapters are by hearing researchers who explore cultures different from their own, Donald Grushkin shares, in very personal terms, feeling caught between the hearing and Deaf communities in the U.S. as an individual who is hard of hearing. A highlight in the volume is Jean Ann’s evocative account of her experiences at a Taiwanese school for deaf children. Ann probes her own (American-influenced) beliefs and research agendas as she allows readers to listen alongside her to the diversity of individual voices she draws out during her school visits. She provides not only a rich and sensitive portrait of a school and its community, but thoughtful reflections on her roles as observer, researcher and individual.

Many Ways to Be Deaf is highly recommended for those with interests in anthropology, sociology, signed languages, deaf culture, language politics and/or comparative education.

Book Review

Title: *The Study of Signed Languages, Essays in Honor of William C. Stokoe*

Editor: David F. Armstrong, Michael A. Karchmer, & John Vickrey Van Cleve

Publisher: Gallaudet University Press, 2002

ISBN: 1-56368-123-4, 298 pp.

Cost: \$59.95 USD

Reviewer: Sally Y. Nhomi

During the 1950s, William Stokoe convinced sceptical language scholars that signed language could have all of the complexity, structure, precision and expressiveness of any spoken language, established sign language as a subject worthy of scholarship, and helped legitimize the teaching of sign language to deaf children. Appropriately, this volume offers eclectic examples of the ways with which signed languages might be studied, and a variety of reasons *why* signed languages should be studied. It should appeal to anyone with general interests in language studies, sociology and/or cultural studies, as well as to researchers of signed languages or Deaf culture.

Included are historical and theoretical perspectives: Douglas Baynton describes social trends with which respect for signed languages varied in the U.S. during the 1800s. Roger Fouts and Gabriel Waters, Adam Kendon, Scott Liddell and Sherman Wilcox critique academic prejudices which have inhibited research on signed languages, such as biases in language origin theories and tendencies for “language” to be conceptualized as something spoken and heard. Frank Wilson shares the theory that human development of the ability to manipulate hands with skill enabled new forms of interpersonal cooperation, and suggests that gestures accompanied the earliest forms of human language.

Other essays address issues of diversity: Ceil Lucas, Robert Bayley, Mary Rose and Alyssa Wulf describe how age, ethnicity, gender, religion, community membership and educational and professional status can affect how an individual uses Sign Language, and, in turn, shape the individual's stature within the community of Sign Language users. For example, graduates of Gallaudet are said to use "elite" signs that are often unknown outside Gallaudet. From a different vantage point but drawing similar conclusions, Glenn Anderson describes the need for increasing respect for the linguistic integrity of the sign language used in Black Deaf communities. Britta Hansen details how Danish deaf children in isolated communities require bilingual mastery of sign language and literacy skills. The potential benefits of teaching sign language to non-deaf children are also explored: John Bonvillian reports on trials involving children with autistic disorders. Olga Capirci, Cristina Caselli, Jana Iverson, Elena Pizzuto and Virginia Volterra find that teaching manual gestures and spoken words simultaneously can enhance language development in early childhood.

Carol Padden and Jennifer Rayman close the book with a call for continued research on American Sign Language (ASL) toward perpetuating its heritage, pondering how to do this while allowing for diversity, growth and change. That questions which are universal among custodians of languages are being raised with regard to ASL indicates considerable progress since Stokoe's day. I think he would be pleased.

Book Review

Title: *Queer Crips: Disabled Gay Men and Their Stories*

Editors: Bob Guter & John R. Killacky

Publisher: Harrington Park, 2004

Paper, 2003 ISBN: 1-56023-457-1

Cloth, 2003 ISBN: 1-56023-456-3

Cost: Paperback - \$19.95 USD; Hardcover - \$39.50 USD

Reviewer: Steven E. Brown

Like the earlier *With the Power of Each Breath*, (Pittsburgh and San Francisco: Cleis Press, 1985), edited by Susan E. Browne, Debra Connors, and Nanci Stern, an anthology about women with disabilities—almost two decades old now--this is a pathfinding work.

Queer Crips includes stories from people trying to find their way in their own worlds—and in ours. These gay (mostly) men (mostly) explore lives trying to determine how to combine their sexuality and disability identities, or lacks thereof. Authors range from proud to be gay, but not to have a disability, to the reverse, and many colors of the rainbow in-between.

In the next-to-the last of the book's thirty-five pieces by twenty-nine authors, Eli Clare, who's described as a "transgendered poet, rabble rouser, and author," (page xiii), writes that he(?) seeks, "places...where we are encouraged to swish and swagger, limp and roll, and learn the language of pride. Places where our bodies begin to become home." (page 215) A sentiment with which those of us struggling with our "disabled" bodies can often identify.

Co-editor Bob Guter, whose interviews with a variety of characters, are one of the book's highlights, states in the anthology's final piece, "We who are accustomed to being medicalized, analyzed, evaluated, counted off by statistical standards, are tired of being passengers. We are determined to drive this vehicle that is our lives" (page 224).

I cannot think of a better way to begin, conclude, or be in the middle of our existences.

This book, as far as I know, is unique. It won't stay that way. There are too many similar stories to tell. But as the first of its kind, it will, like *With the Power of Each Breath*, remain at the frontier's edge.

As a classroom tool, it has the ability to awaken intense discussions; as a book, it belongs in every disability rights library; and as literature, it belongs in all the other ones.

Book Review

Title: *Sexualities: Personal Lives and Social Policy*

Editor: Jean Carabine

Publisher: The Policy Press in association with The Open University, 2004

Paper, ISBN: 1861345186, 176 pp.

Cost: \$29.95 USD

Reviewer: Cassian B.K. Kimhan

This book is the first of a four part series examining the relationship between social policy and personal lives. The theme of this text centers on sexuality. While sexuality is thought by many to be a private affair, Jean Carabine and others reminds us that sexuality is intricately linked with social policies and laws, as well as cultural norms and attitudes. Throughout Carabine's review the reader is encouraged to examine how social policy affects sexuality and vice versa. Most of these discussions take place within the context of the United Kingdom. However, this phenomenon is applicable among many developed nations.

There are discussions on homosexuality, teenage pregnancy, and single parenthood. Possibly the most interesting discussion within this text is Margrit Shildrick's chapter on sexuality among persons with disabilities, a subject which is usually taboo. The author discusses not only the dilemmas persons with disabilities face when wanting to express their sexuality, but also how social policies at present often prevent them from doing so. The personal testimonies and discussions within this chapter are intriguing and offer a rare insight into society's biases against persons with disabilities. It is often for-

gotten that persons with disabilities have sexual natures too. This chapter is a good reminder of this truth and offers some insight into how society can provide more appropriate care in this domain.

While the text could be dry at times, the readings and directed activities found within would be appropriate within an educational setting focusing on the development or impact of social policies or even in a review of the relationship between sexuality and society.

I would recommend this book as an enlightening review of how social policies influence everyday lives, even in the privacy of one's bedroom.

Book Review

Title: *Replaceable You: Engineering the Body in Postwar America*

Author: David Serlin

Publisher: University of Chicago Press, 2004

Paper, ISBN: 0-226-74884-7

Cloth, ISBN: 0-226-74883-9

Reviewer: Steven E. Brown

David Serlin gives nuance to the 1940s and 50s in this book about modern medicine and social change and perception in the United States. Serlin's primary chapters utilize one aspect of medicine and a primary protagonist to focus on broader changes during this period.

Serlin's chapters are progressively more risqué. He begins with a veteran of World War II and describes how the development of a hand prosthetic is meant to heal both the soldier's physical wounds, and integrate him into his proper social milieu. This theme that recurs throughout the book. He follows this chapter with a description of a group of women known as the Hiroshima Maidens. These Japanese victims of the American atomic bomb attack on

Hiroshima traveled to the United States to undergo new innovations in plastic surgery to try to regain their place in Japanese society. From here, Serlin moves into two figures, who in some ways, are radically different: Gladys Bentley, and Christine Jorgensen. Bentley was a notorious lesbian performer at the height of the Harlem Renaissance in the 1920s who claimed to become a heterosexual woman with the treatment of estrogen therapy in the 1950s. Jorgensen was an ex-soldier who became the first well-known male to female transsexual in the U.S. Serlin's analysis of Bentley and hormone replacement therapy covers a lot of territory, including a complex life that seems to have been mostly oversimplified in previous depictions. With Jorgensen there seems to be more of a focus on her public persona than the complexities of her life.

Serlin ends with a concluding chapter describing how artist Andy Warhol fits into this picture. The book makes the point that:

“...medical procedures and technologies enabled individuals to emerge victoriously from the closets of shame and pathology into which they were typically forced, and provided new narrative possibilities heretofore unanticipated by the vast majority of Americans” (161).

A person with a disability reading this work might conclude that not much has changed over the years. Medical miracles are still, as they were then, being touted as cures for all kinds of social ills. Sometimes they seemed to work; sometimes they did not. Serlin's subjects found, as have many of us, that there is a difference between perceived medical healing and social acceptance. Which leaves all of us wondering why in some cases, difference is so heralded, and in others, so reviled?

Book Review

Title: *Aging With A Disability: What the Clinician Needs to Know*

Editors: Bryan Kemp & Laura Mosqueda

Publisher: Johns Hopkins, 2004

Paper, ISBN: 0-8018-7817-9, 307 pp.

Cost: \$24.95 USD

Reviewer: Patricia Duffley-Renow

Increased life expectancy as a result of advances in medical treatment and technology has also extended the life span of individuals with disabilities. Clinicians, caregivers, and individuals with disabilities need to be aware of cognitive, physiological, and “Quality of Life” factors that may be affected as a result of the aging process.

Aging With A Disability: What the Clinician Needs to Know, takes a comprehensive look at aging in individuals who have a disability. The editors have extensive backgrounds in geriatrics and rehabilitation. They provide not only their perspectives but also those of aging and disability from individuals with disabilities.

Stated goals of the book include: “The desire to influence rehabilitation practice and to make practitioners aware that aging is a lifelong process not one that begins after a certain age. It is written primarily for clinicians but individuals who have disabilities and their caregivers will benefit from it as well” (p. 4). The book provides a comprehensive view of living with a disability and possible changes from aging. Changes may occur sooner in individuals with disabilities. Being aware of some dynamics of the aging process may enable a person with a disability, clinician, or caregiver to prepare for those changes.

The book is divided into five sections. Within each section are several chapters. Vignettes by individuals with disabilities are dispersed throughout the book to remind the reader that individuals with disabilities lives are affected by these changes.

Section One focuses on the perspective of an individual who lives with a disability and

continues with the family's perspective. Section Two introduces physiological changes and "Quality of Life" issues for families and caregivers. In Section Three, treatment options are discussed and functional changes are addressed that pertain to specific impairments, working as we age, and assistive technology. The section on assistive technology is limited to wheelchairs and daily living devices. This area needs to be expanded to include devices that can assist in the work environment and devices that can enhance quality of life, such as augmentative communication devices. Specific conditions are discussed in Section Four, but there is a lack of information on sensory impairments and neuromuscular disease. The book concludes with discussion of health care policy and opinions from providers and consumers of this service.

In closing, *Aging With a Disability: What the Clinician Needs to Know* is a primer on disability issues for clinicians. It should be included in Vocational Rehabilitation Programs as required reading. Information for the book was derived from research studies and discussions with individuals with disabilities over the past twenty years. Awareness of the aging process can help individuals make informed choices about their vocational goals and prepare for the future. Family members and caregivers of an individual with a disability will find this book valuable as an ongoing reference.

Book Review

Title: *What Psychotherapists Should Know About Disability*

Author: Rhoda Olkin

Publisher: Guilford Press, 1999

Paper, March 2001 ISBN: 1-57230-643-2

Cloth, 1999 ISBN: 1-57230-227-5

Cost: Paperback - \$24.00 USD; Hardcover - \$45.00 USD

Reviewer: Beth Omansky

Divided into fourteen chapters, this book provides an overview of disability laws, social history, and definitions; attitudes and stereotypes experienced by disabled people; family dynamics; psychotherapeutic treatment approaches, and "special" issues in therapy with disabled clients. There is a chapter on assistive technology as well, which seems to be extraneous to the central themes of the volume.

Olkin compares and contrasts the "moral model" (punishment for sin), the "medical model" (traditionally used in human services), and the "minority model," which she believes is synonymous with the "social model" of disability. However, this assertion fails to recognize the centrality of materialism in the classic social model.

Especially considering the pervasiveness of multicultural theory and practice in applied human science education and training, it is understandable that Olkin prefers the minority model, which claims that disabled people are treated by society in similar ways to racial and cultural minority groups. The "minority model," is about "prejudice, discrimination, and stigma (p. 24). Through the use of tables and accompanying explanations, Olkin draws parallels between disabled people and other minority groups' experiences, i.e., "pressure to assimilate," "subjects of eugenics," "hate crimes," "inappropriate use of tests," "under-representation in professions," "separate but unequal," "affective regulation," "unemployment," and the "body as reflection of self" (pp. 28-34). Using "person first" language throughout the text, Olkin states that it is preferred in the United States, but then wisely advises helpers to "[m]odel your language after that used by the client" (p. 40). While I find typical disability "etiquette" guidelines objectionable, Olkin's chapter on this topic contains practical, concrete, useful "general rules, e.g., "Don't stare," "Think about the temperature in your office," and when dealing with a personal assistant, interpreters, or family, "Be clear about who is the client" (pp. 190-200).

However, when it comes to actually doing therapy with disabled clients, Olkin reverts to the medical model, writing that the therapist needs to determine how the client's disability "in clinical practice, assessment of functional level – and any ways the therapy itself might be affected by this – is a crucial initial step (p. 40).

Despite some limitations, *What Therapists Should Know* is a refreshing addition to a body of literature which usually lacks any alternative to the medical model. I hope that Olkin will produce an updated edition which reflects current thinking in the disability community. All in all, it is a very useful volume for teaching alternative ways to perceive disability.

Book Review

Title: *Hotel Ritz-Comparing Mexican and U.S. Street Prostitutes: Factors in HIV/AIDS Transmission*

Author: David J. Bellis, Ph.D.

Publisher: The Haworth Press, 2003

ISBN 0-7890-1776-8, 128 pp.

Cost: \$18.00 USD

Title: *Women's Experiences with HIV/AIDS: Mending Fractured Selves*

Author: Desirée Ciambrone, Ph.D.

Publisher: The Haworth Press, 2003

ISBN 0-7890-1758-X, 213 pp.

Cost: \$20.00 USD

Reviewers: J. Gary Linn & Carol Bompert

David Bellis's *Hotel Ritz-Comparing Mexican and U.S. Street Prostitutes* and Desirée Ciambrone's *Women's Experiences with HIV/AIDS* are complementary studies. Together they provide the reader with a continuum of women with HIV and/or at high risk for acquiring HIV. Bellis's work describes the sexual and drug us-

ing behavior of street prostitutes in California and Mexico who (particularly those in the United States) are outside of the healthcare system. Ciambrone moves up the social ladder and into the social service and medical care systems. She discusses the life experience of a predominantly white, and educated, group of women who received drug therapy and support for their HIV illness.

Bellis successfully targets policy makers, substance abuse and behavioral AIDS researchers, and caregivers. His rich international data set and insightful sociological analysis of the interrelationship of sex work, drug abuse, and HIV support compelling arguments for the reform of antiprostitution and antidrug laws in the United States. Ciambrone provides valuable information on the lived experience of women with HIV for caregivers and convincing empirical support for the theory of biographical disruption, which should be of considerable interest to medical sociologists and health psychologists.

Bellis increases our understanding of the interdependence of sex work, drug use, and HIV in two distinct social systems in two countries; while Ciambrone helps us to understand the daily lives of HIV infected women in the United States who are provided medical and social services. Both books are extremely interesting for a variety of reasons. Bellis simultaneously works at multiple levels (individual, community, national, and international) and focuses our attention on the critical linkages tying together prostitution, drug abuse, and HIV illness. His analysis is written from a thought-provoking critical perspective. Ciambrone, with her highly detailed qualitative interviews, provides us with a uniquely intimate view of women's experiences with the problems of stress and coping with HIV. She writes from a sensitive feminist perspective.

Unfortunately, these important studies are not widely accessible to people with disabilities. They have only been published in a regular font

size. No large print, Braille, or audio versions are currently available. Although they presently have these limitations, they are both reasonably priced.

We recommend Bellis's book for policy makers at all levels of government, a wide range of substance abuse and behavioral AIDS researchers, and caregivers and social service providers. It should be especially useful for persons working in the criminal justice system.

We recommend Ciambrone's monograph for social science researchers working in HIV/AIDS; especially those interested in qualitative research, feminism, and women's health issues. It also will be very useful for caregivers (especially those in psychological and support services) and undergraduate and graduate students of nursing, social work, sociology, and public policy.

Book Review

Title: *Making Self-Employment Work for People with Disabilities*

Author: Cary Griffin & David Hammis

Publisher: Paul H. Brookes, 2003

Paper, ISBN: 1-55766-652-0, 242 pp.

Cost: \$35.00 USD

Reviewer: Steven E. Brown

The authors have drawn on their extensive experiences working with individuals living on SSI and SSDI to create an excellent handbook about self-employment while working within the Social Security system. On first going through the book I was disappointed that more was not included for those on SSDI. I emailed one of the coauthors, David Hammis, and we began a lengthy and interesting email exchange. David indicated while more information about SSDI was needed, there was also more about SSDI in the book than I realized. More importantly, in the course of our conversations I wondered if he

would respond to other readers with questions and he enthusiastically welcomed such correspondence.

My other major criticism of the book was I could find virtually nothing on what someone would do if they could not obtain, or afford, health insurance and did not have both Medicare and Medicaid. Dave agreed this was a serious issue and thought it should be addressed in future editions.

Having said all that, I highly recommend this book to anyone who wants to become self-employed. The authors provide a detailed process, and many examples, for how to do this. Chapters include, "Person-Centered Business Planning," "Business Feasibility," and "Marketing and Sales Tactics." Each chapter offers glossaries of terms, textual content and interpretations, and examples of actual individuals the authors have assisted to develop successful self-employment strategies. Forms and resources are also included as separate chapters. Anyone on SSI and SSDI who wants to become self-employed, or those working with such individuals, would benefit from having this book as part of their library.

Book Review

Title: *The Decline in Employment of People With Disabilities: A Policy Puzzle*

Editor: David C. Stapleton & Richard V. Burkhauser

Publisher: W. E. Upjohn Institute for Employment Research, 2003

Paper, ISBN 0 88099 259-X

Cloth, ISBN 0 88099 260-3

Cost: Paperback - \$22.00 USD; Hardcover - \$45.00 USD

Reviewer: Mark F. Romoser

This volume comes from the Upjohn Institute for Employment Research in Michigan, while the editors are experts in disability policy from Cornell University. Thus, this is an attempt to explain the startling decline in employment of people with disabilities from both the labor market and the disability studies perspectives. It will make interesting, and certainly thought-provoking, reading for those in the fields of vocational rehabilitation and rehabilitation counseling, and anyone else interested in the employment picture for people with disabilities.

One chapter is devoted to the provocative thesis that the culprit is the Americans with Disabilities Act (ADA) itself. Supposedly the ADA's protections cause business to be more wary of hiring workers with disabilities, who would be entitled to rights under the ADA and might then be difficult to fire at will. Author Thomas DeLeire took leave from the University of Chicago to serve on President George W. Bush's Council on Economic Advisers, a fact not mentioned in the book. Another chapter restates this sentiment right in the title, "Is It Time to Declare the ADA A Failed Law?" Its conclusion: probably not.

Still another chapter focuses on increases in benefit entitlement programs, specifically Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). It does not, however, discuss the implications of people who are marginally employable choosing SSDI, and especially SSI, over low-wage employment with limited benefits. This is not a good situation either for people with disabilities or for society at large. In general, the editors could have included more discussion of changes in the American labor market that might be hurting workers with disabilities. A good starting point would have been the gender gap: essentially all of the decline in employment has been among men with disabilities. It could be that women with disabilities are more likely to be employed in low-paying, part-time, but readily available, positions in the retail and food service industries.

The subtitle "A Policy Puzzle," is particularly apt. The book offers more in the way of thoughtful, if sometimes controversial, discussion about this perplexing decline in employment than it does in terms of proposing workable solutions. One hopes these will come in another volume in the not-too-distant future. In the meantime, this book should serve as a starting point for a debate that is long overdue.

Book Review

Title: *Student-Directed Learning*

Author: Martin Agran, Margaret King-Sears, Michael Wehmeyer, & Susan Copeland

Publisher: Paul H. Brookes Publishing, 2003

Paper, ISBN: 1-55766-621-0, 122 pp.

Cost: \$25.00 USD

Reviewer: Rhonda S. Black

For far too long, students, especially those with disabilities, have been viewed as passive recipients in teacher-led classrooms. The authors of *Student-Directed Learning* are making strides in changing "who holds the chalk?" by providing practical strategies for changing classroom environments into more collaborative communities.

Student-Directed Learning is one of five books in the *Teachers' Guides to Inclusive Practices* Series, available from Brookes Publishing. Other books in the series include *Behavioral Support*, *Collaborative Teaming*, *Modifying Schoolwork*, and *Social Relationships and Peer Support*. This book is practitioner-friendly while being based on solid research findings. Most notable are the visual icons, text boxes, and other organizational features that make information easy to find and follow. For example, the first chapter begins with four student snapshots, each with an icon of a camera, a bold heading, italicized writing, and plenty of white space. An introductory paragraph follows explaining how stu-

dent-directed learning strategies would benefit the students in the snapshots. Next, a text-box section defines differences between teacher-mediated, student-mediated, peer-mediated and technology-mediated instructional strategies. Each strategy has a different picture icon to help illustrate the point (teacher at chalkboard for teacher-mediated, peers working together for peer-mediated and so forth). This section is followed by a discussion of various student-directed learning strategies clearly marked with headings and brief but thorough explanations. The next section highlights advantages of student-directed learning, again with subheadings, nice spacing and concise, yet thorough, explanations. Finally, there are two textboxes, one titled "What the Research Says" which summarizes two meta-analytic studies of self-management in a simple bullet list accessible to practitioners, parents and researchers; the second summarizing student involvement in the Individualized Education Program (IEP) process as mandated by the Individuals with Disabilities Education Act (IDEA).

The remaining chapters, *Antecedent Cue Regulation and Picture Cues*, *Self-Instruction*, *Self-Monitoring*, *Self-Evaluation and Self-Reinforcement*, and *Success in the Inclusive Classroom and Access to the General Curriculum* follow a similar format. Each chapter includes student snapshots, visual examples and step-by-step guides to implementing the concept discussed. Each chapter also includes easy-to-read "What the Research Says" bullet-list summaries of the research, and "Voices from the Classroom" textboxes providing advice from classroom teachers. Numerous flow charts, checklists, and self-evaluation forms are provided throughout the book to bridge the research to practice divide.

This text would be a good resource for school personnel in general or special education, elementary or secondary schools, and college classes in general or special education.

Book Review

Title: *Aidan's Way: the Story of a Boy's Life and a Father's Journey*

Author: Sam Crane

Publisher: Sourcebooks, Inc., 2003

ISBN: 1-57071-903-9

Cost: \$18.95 USD

Title: *A Will of His Own: Reflections on Parenting a Child with Autism*

Author: Kelly Harland

Publisher: Woodbine House, 2002

ISBN: 1-890627-19-4

Cost: \$16.95 USD

Title: *Karen*

Author: Marie Killilea

Publisher: Dell Publishing Company, Inc., 1952

ISBN: 1568490984

Cost: \$25.25 USD

Reviewer: Fred Pelka

"I don't believe that cerebral palsy children have any mentality."

So spoke a leading physician of his day, a specialist whom the Killilea family consulted in the late 1940s to determine the best treatment for their daughter, Karen. It was in large part to challenge such abysmal ignorance, such stunning arrogance, that Marie Killilea wrote her memoir, *Karen*, published in 1952. The book was a breakthrough in educating the general public about the nature of CP, and the real (as opposed to the mythic) struggles of families with disabled children. Along with a series of other memoirs, it also rallied parents to join what were then fledgling organizations such as United Cerebral Palsy

Associations and the ARC. Shunned by their neighbors, patronized by the medical establishment, and all but ignored by local governments refusing to educate their children, these parents would in time be largely responsible for some of the most significant victories claimed by the disability rights movement: *PARC v. Pennsylvania*, the first recognition by US federal courts of the right of children with disabilities to a public school education; the Individuals with Disabilities Education Act; and the deinstitutionalization movement of the 1970s.

Now a new generation of parents are writing their stories, separated from Killilea by half a century and the advent of the modern disability rights movement. Two of these memoirs, *A Will of His Own: Reflections on Parenting a Child with Autism*, by Kelly Harland, and *Aidan's Way: The Story of a Boy's Life and a Father's Journey*, by Sam Crane, show both the impact and the limits of that progress.

Take, for instance, de-institutionalization. The Killilea family was urged to send Karen to an institution, which in the 1940s generally meant a "state school" such as Willowbrook or Pennhurst, massive residential facilities notorious for their squalor, neglect, and abuse. Deinstitutionalization may have freed tens of thousands, but the urge to separate disabled children from their parents remains. Having been told that Aidan's diagnosis ("Agenesis of the corpus callosum") means the boy will never walk, talk, or see, he will be "severely mentally retarded" and prone to seizures, the Cranes are urged to consider "putting Aidan away in an institution." "I was stunned," Sam Crane writes, "By how quickly some could conclude that my son, not yet a year old, was hopeless, his life lost, and that he should be excluded from the love of his family and friends" (Crane, 65). Crane confronts this dismissal of his son's worth in many guises, from the professional colleague who advises him it would be more "merciful" to let Aidan die, to the insurance company physician who rules Aidan's only food source, a prescription formula

delivered through a g-j tube, is "supplemental" and thus not covered by the HMO. Crane wins this particular battle, but notes how a family with fewer resources might have succumbed to this blatant attempt to cut costs at the expense of the life of a disabled child.

"It's not just money that distorts our view of human worth," Crane notes. "Social status, cultural attainment, physical beauty: all of these and more creep into our calculations of an individual's value" (Crane, 249). Crane catches himself as much influenced by the myths of disability as those around him. He and his wife are at first willing to sign a DNR (Do Not Resuscitate) order recommended by their hospital, should Aidan need to use a ventilator. They rescind the order only after being confronted by a physician who tells them that being ventilator dependent is not the-fate-worse-than-death they assumed it to be. It's one measure of the movement's progress, and a demonstration of the rightness of the slogan "Nothing about us, without us," that this particular physician happened to have CP. (If being able to survive medical school is any indication, it would seem that people with CP "have a mentality" after all).

Sam Crane, like Marie Killilea, has written a straightforward narrative, beginning at Aidan's birth and moving along more or less chronologically. Harland's book, by contrast, is a collection of essays, or "reflections." She prefaces these with an extended quote from nature poet Mary Oliver, with whom she shares both style and outlook. For Oliver, "What I write begins and ends with the act of noticing and cherishing" (Oliver, 99). Harland, pondering her son's autism, starts from this same stance of awareness and affection. Will's autism compels him to crave ritual and predictability, to regulate his sensations to the point where they can be integrated. Instead, he's confronted by the overwhelming confusion of modern life. Harland empathizes with her son, anticipating what will "set him off" into a panic or frenzy. In the process she also manages to convey how unnatural

an environment is the typical city (in this case Seattle), how unforgiving our modern life is of those who think or act or perceive differently from the “norm.”

Like Killilea, both parent-authors go a long way in explaining the particular issues of parents whose children have significant disabilities. Harland and Crane go further, however, in sharing their more intimate struggles and confusion. Harland, for instance, writes with great feeling of the guilt – what we might call the “internalized oppression” – of parents who are encouraged to blame themselves for “what went wrong.” Crane takes it an important step further by putting this urge to blame in a political context. He analyzes, for instance, how parents of kids who need alternate public school services get pitted against the rest of the community, how certain segments of our society begrudge the very existence of people with disabilities.

Killilea, a devout Roman Catholic, like the other authors possess a strong element of spirituality. For Harland, her acute focus on the “here and now” in the service of her son becomes a form of Zen “mindfulness,” while Crane draws heavily from Lao Tzu and the Chinese Taoist tradition. “Disabled people” he concludes, “are not marginal to the human experience, they are central to it,” (Crane, 68-9) and one of the most powerful passages in his book is his refutation of Peter Singer’s “utilitarianism.”

Both Crane and Harland have written for a general audience, but their books would be appropriate texts in any disability studies course at a high school or college level. (For that matter, *Karen* is also still worth reading, despite the occasional lapses into sentimentality). I would urge, however, that they be used as supplements to, and not substitutes for, texts by disabled writers themselves.

References

Oliver, M. (1999). *Winter hours: Prose, prose poems, and poems*. New York: Houghton Mifflin.

Book Review

Title: *Creativity and Collaborative Learning: The Practical Guide to Empowering Students, Teachers, and Families*, 2nd edition

Editor: Jacqueline S. Thousand, Richard A. Villa, & Ann I. Nevin

Publisher: Brookes, 2002

ISBN: 1-55766-578-8

Cost: \$49.95 USD

Reviewer: Katherine T. Ratliffe

The authors –investigate strategies in creative problem solving and collaborative learning to create and support inclusive school communities. Theoretical discussions lead to strategies to include diverse children in classrooms and social communities in schools.

The book is divided into three parts. The first addresses inclusion through exploration of common issues such as involving families in education, fostering school friendships, multiculturalism, and universal access to the general education curriculum. Theory, research, and best practices of these concepts are discussed and grounded with concrete examples. Specific techniques are suggested to improve practice such as MAPS (Making Action Plans) or the Osborn-Parnes Creative Problem Solving process, tools that can assist individuals, their families and friends to connect with each other and discover possibilities available to them. These strategies are presented with specific instructions and templates.

The second section of the book examines creativity and collaborative learning more in depth, describing problem-solving methods,

cooperative group learning, facilitating creative thinking, peer tutoring, and partner learning. Ideas to address student disruptions and troubling behaviors are suggested through examples and case scenarios.

The last section provides specific strategies and adds lesson plans for implementing the above methods in the classroom. Lesson plans include academic objectives, skill performance, and evaluation.

It has been said that inclusion is nothing more than good teaching for all students. This book is written to aid all students. It primarily targets teachers, but family members will benefit from reading it by becoming better advocates for their children through understanding, evaluating, and making informed suggestions for their children's education. The flow and organization of the book are slightly confusing because so many ideas are presented in different ways, however, it provides a valuable compilation of theory and strategies, and is written in an accessible style. Its value is in the application of general education theory to support the education of a diverse population of students, and in the specific strategies described to apply that theory.

Book Review

Title: *Reflections from a Different Journey: What Adults with Disabilities Wish All Parents Knew*

Author: Stanley Klein & John D. Kemp

Publisher: McGraw-Hill, 2004

Cloth, ISBN: 0071422692, 224 pp.

Cost: \$18.95 USD

Reviewer: Mike Reynolds

Klein and Kemp's book is a refreshing anthology geared towards new parents or parents of young children with disabilities. Far from offering the same gloom and doom my folks were told by "the expert" doctors, the stories

here show a realistic, enlightened, enjoyable and humorous, yet incredibly honest view of growing up with a disability. The work accomplishes what it sets out to do, demystifying the diagnosis of disability. In showing people with disabilities as humans who have the same goals, desires and dreams as every child, not only does the book speak to parents, but also furthers the available literature in the realm of disability culture. For anyone active in the disability rights community, authors who are peers, such as Gregor Wolbring and Mike Ervin, provide valuable information about their lives.

This work, while intended for parents with disabilities, is a solid read for anyone with a disability. Many of the shared challenges we face, such as acceptance in school, getting proper education, and struggling to live independently and figure out our own paths in life are addressed. The price of the book is small in comparison to the many times one would look at it for advice, check for a different way of doing something, or just for a relaxing read.

After reading this, I realized my mother would love this book and plan on purchasing it for her as a holiday gift, if only to confirm the popular notion that fighting to keep me included in my peer group was the only way I'd live independently – she was right, as were the parents in this book.

Book Review

Title: *Educating the Disabled: Enabling Learners in Inclusive Settings*

Author: George R. Taylor & Frances T. Harrington

Publisher: Scarecrow Press, Inc., 2003

Cloth, ISBN: 0-8108-4614-4

Paper, ISBN: 0-8108-4616-0

How to Obtain: www.amazon.com or www.scarecroweducation.com (15% discount)

Cost: Paperback - \$33.95 USD; Hardcover - \$43.95 USD

Reviewer: Judy Riffle

George R. Taylor and Frances T. Harrington wrote *Educating the Disabled: Enabling Learners in Inclusive Settings* for administrators in charge of educating people with disabilities. Specifically, the book pertains to “directors of special education, supervisors, consultants, superintendents, principals, coordinators of education, research directors, psychologists, counselors, social workers, site-based management teams, and teachers aspiring to become school administrators” (p. vii). This book is a good review for those already knowledgeable about special education, a thorough introduction for those with little background in this area, and an effective textbook for graduate school leadership courses. In addition, research based reform practices are outlined; strategies for effective change, team-building, and involving all stakeholders are included. For instance, the authors cite Michael Fullan’s change philosophy as being helpful to administrators, and stress the importance of such items as using research-based educational practices, sharing a common focus, and keeping high expectations for all students.

Taylor and Harrington focus on how administrators can facilitate inclusive classroom settings using a team approach. Some school administrators do not thoroughly understand special education or why they should consider inclusion as an option, but this publication is a great start to a possible paradigm shift in their thinking or as a straightforward reform tool.

Chapters span from effective teacher development, fair student assessments, encouraging cultural awareness, special education laws and court cases, making accurate decisions about student placements and goals, the inclusion debate, involving parents and community, and reporting student progress to parents. Tools such as an observation checklist and a parental due process checklist are included as well. The inclu-

sion chapter has important information, such as ensuring all children are placed according to their individual needs; inclusion research results; and how parental involvement helps ensure success.

Anyone involved in education who may be confused about the special education process, or with a dream of supporting inclusive practices, should read this book. Overall, it is a valuable addition to the existing literature on inclusion. However, for those very knowledgeable about special education law and services, several chapters can simply be skimmed as a review. As an interesting summary of relevant research, the special education process, and inclusive strategies, it is well worth the price as an additional textbook or as an addition to a professional library.

This book is available in hardback and paperback editions, but could not be found in audiotape, large print, or Braille editions on the publishing website or other mainstream bookseller establishments.

Book Review

Title: *Siblings of Children with Autism: A Guide for Families* (2nd Edition)

Author: Sandra L. Harris & Beth A. Glasberg

Publisher: Woodbine House, 2003

Paper, ISBN: 1-890627-29-1, 180 pp.

Cost: \$16.95 USD

Reviewer: Rhonda S. Black

Siblings of Children with Autism: A Guide for Families provides insights into the cognitive and emotional world of siblings who have a brother or sister with autism. The text discusses issues across the lifespan, starting with early childhood, moving through middle childhood and adolescence, and finally addressing issues for adult siblings. Text boxes and tables are included throughout. One text box, titled “Telling Your

Child About Autism,” gives simple explanations for youngsters in early and middle childhood. Examples such as “you can’t catch autism” and “it is nobody’s fault” fall under what to say in early childhood. “It causes problems with talking, playing, understanding other people’s feelings” and “people with autism can learn, but it takes a lot of work” are examples of what to say to siblings in middle childhood. The authors also discuss sibling bonds which change over time and may not be as strong between children who are widely separated in age or who have spent relatively little time together. This bonding pattern may be common for siblings where one child experiences autism. The authors skillfully remind readers that strong bonds are not always happy ones. Intense sibling bonds “can be warm and loving, but also can be negative and tension filled” (p. 9).

While the authors have impressive research credentials, they manage to leave the language of professional journals behind to provide an accessible guidebook for parents struggling to address often overlooked needs of *siblings* of children with autism. They have created a reader-friendly text without using jargon or lengthy technical explanations. For a topic as perplexing as autism, they excel not only at describing autism spectrum disorders in plain language, but also in explaining how to convey that information to siblings.

The text recommends keeping explanations about autism simple and truthful, easing fears, understanding and dealing with sibling emotions (especially jealousy), keeping children safe from explosive behavior, and not expecting siblings to assume too many caregiving responsibilities. Two chapters are devoted to ways to help children share their feelings and a discussion of barriers to communication. Another chapter explained how to help children play together with recommendations such as giving clear instructions (and teaching siblings how to do the same) modeling play skills, teaching siblings to use behavioral techniques and the Picture Exchange

Communication System (PECS), and selecting appropriate activities siblings can share.

A “Parents Speak” section, using direct quotes from parents to illustrate the chapter’s topic, is offered at the end of all but one chapter. This adds to the accessibility and relevance of the text for an audience of parents. I speculate few parents would feel “alone” after reading these sections. Another section of the book talks about support groups for parents and siblings, and the importance of drawing on both informal and formal support networks.

An especially pertinent table identifies “Professionals Who May Be Able to Help.” Professionals, including psychiatrists, clinical and educational psychologists, special education teachers, behavior analysts, and family therapists are all described and explained according to their educational backgrounds, roles they may play, and services they may provide. This information can be invaluable to families who may be caught in a maze of human services organizations providing different, but related, kinds of assistance. At the end of the book, a section of resources/organizations for parents is provided. The authors convey a message that help is out there, so don’t be afraid to ask.

Case studies offered throughout *Siblings of Children with Autism*, make the text more concrete and personal. For example, a case study early in the book portrays Kevin, who secretly resented his younger brother Mitch. Kevin confessed to a friend that he thought his parents loved Mitch much more than they loved him. Kevin then expressed he knew Mitch had autism but did that mean every little thing Mitch did was great, or that he should be able to get away with anything he wanted? Kevin felt he was treated unfairly, and had to be perfect at “everything” to make up for what Mitch could not do. The next-door-neighbor overheard the boys talking and informed Kevin’s mother who had not realized he felt that way. Some of Kevin’s outbursts and uncooperativeness now made sense to her.

This case example demonstrates one of the most common issues for siblings of children with autism—doubt about one’s importance in the family when parents appear preoccupied with the child with autism. Similar case examples occur throughout the book to illustrate other issues facing siblings of children with autism.

In summary, quotes from parents and siblings, easy-to-read text boxes and bullet lists, and pictures and case studies provided throughout are invaluable in making this a family-friendly text. I thought this book well worth the price.

Book Review

Title: *Incentives for Change: Motivating People with Autism Spectrum Disorders to Learn and Gain Independence*

Author: Demolito, L., & Harris, S. L.

Publisher: Woodbine House, 2004

Paper, ISBN: 1-890627-60-7, 145 pp.

Cost: \$17.95 USD

Reviewer: Landry Fukunaga

Incentives for Change: Motivating People with Autism Spectrum Disorders to Learn and Gain Independence summarizes a few of the practices currently used to create motivational systems for people with autism. This book is written clearly and concisely so it becomes an easy reference guide for parents and educators, especially those just beginning to implement an incentive system into the daily routine of a child with autism. *Incentives for Change* is an introduction to some typical ways of increasing motivation to learn and/or make behavioral changes. The book may act as a stepping point for interested parents and teachers who need some simple techniques for an incentive program that can become more complex as individual needs change.

Perhaps the most valuable aspects of this book are the detailed descriptions of how these techniques were implemented successfully and

how they helped to bring about positive change for the individual and their family. For Max, a young child with autism, and his family, identifying and utilizing an activity he enjoyed as motivation to learn functional communication skills helped to reduce tantrum behaviors both in the home and at school. For example, Max found swinging to be naturally rewarding. Max’s parents were able to get him to initiate social interaction with a functional word that worked well (“pu” for “push”), and Max received the reinforcement of being pushed for a short period of time. As Max became more adept at using his new language skills, his reinforcement schedule became more complex to continually challenge him and help him grow. The authors keep in mind that intervention plans need to constantly evolve to suit the changing individual and they give valuable tips as to how to keep an incentive system both challenging and rewarding as a child matures.

This book is not accessible for people who have vision impairments or for those who have limited reading comprehension, however, it is relatively inexpensive and can be a useful guide for increasing the independence of individuals with autism. I recommend this book to parents and educators as an introduction to motivational systems and reinforcement techniques.

Book Review

Title: *The Disability Rights Movement: From Deinstitutionalization to Self-Determination*

Author: Duane F. Stroman

Publisher: University Press of America, 2003

Cost: Paperback - \$37.00 USD

Reviewer: Mike Clear

The book *The Disability Rights Movement: From Deinstitutionalization to Self-Determination* by Duane F. Stroman sets out to describe the history of disability as a minority group model in the United States through the lens of

what Stroman describes as “multiple perspectives within sociology.” At the outset he provides a basic framework of some sociological concepts, analysis of medical and social models and traces the changing definitions of disability. Stroman frames his discussion as a journey of change from institutionalization to self-determination.

The primary worth of this book is that it contains a wealth of valuable information, about the history of disability in the United States since the latter part of the nineteenth century, particularly since the 1950s. This history is a strong focus on changing issues of definition, rights, services and advocacy. It is a broad survey of change.

The book identifies the “beginning student” as the audience and it is likely to be a useful text for senior high school and undergraduate students or others such as professionals or interested laity. *The Disability Rights Movement: From Deinstitutionalization to Self-Determination* is not, however, well written and although the use of tables to explicate a range of issues does assist, the format is dense and the writing mostly turgid. Sometimes the structuring of headings and sub-headings is not logical or conducive to an easy and accessible read. The broad survey approach lacks a quality of engagement at the personal and political level. The issues of self-determination and the journey of the disability rights movement is a powerful political history, yet reading Stroman’s work I was not connected with this. The profound injustices and the personal and social struggle for change that underwrite the achievements towards greater self-determination is more or less written out of his account. Notwithstanding these criticisms, the book is a useful resource for students interested in the broad social history of disability in the United States.

Book Review

Title: *Deaf People in Hitler’s Europe*

Editor: Donna F. Ryan & Jon S. Schuchman

Publisher: Gallaudet University Press, 2002

Paper, ISBN: 1-57230-643-2

Cloth, ISBN: 1563681269

Cost: Paperback - \$24.95 USD; Hardcover - \$45.95 USD

Reviewer: Beth Omansky

An unexpected bonus of *Deaf People in Hitler’s Europe* is that it records Nazi policies and treatment of all disabled people, not just deaf people, as the title might lead one to believe. This edited reader is divided into four sections: Racial Hygiene; The German Experience; The Jewish Deaf Experience, and Concluding Thoughts. Each section contains an introductory essay by one of the editors followed by writings of various contributors. This book is a fine addition to the small but growing body of evidence about how disabled people were treated in the Holocaust.

The first section provides a thorough historical report about the T-4 program, the result of a symbiotic partnership between legislative, military, and medical branches of the German government. Under the guise of supposedly compassionate “euthanasia,” T-4 “killing centers” were housed in psychiatric hospitals where methods of mass genocide were devised, tested, and perfected on “those not worthy of life” (p. 23). In 1939-1940, 80,000 disabled people were killed in T-4 hospitals.

In the sections about the treatment of deaf people specifically, we learn this history is full of contradictions. A film made in 1932, *Verkannte Menschen (Misjudged People)* by Wilhelm Ballier, championed the rights of deaf Germans. This was the last time during that era deaf people were portrayed in positive ways. Early on in the

rise of Nazism, some deaf people formed their own community through sign language, but these groups, along with formal Deaf organizations were subsumed into the Nazi Association of Deaf People, the REGEDE (the Reich Union of the Deaf of Germany). Many deaf people were forcibly sterilized while others profited socially by supporting the Nazi effort and being ranking members of REGEDE.

The authors provide a mostly balanced view, not shying away from chronicling negative actions of the deaf community, e.g., deaf Germans betraying deaf Jews. However, Heberer (2002) writes what could be interpreted as an apologist explanation as to why some deaf people turned deaf Jews over to the Nazis, explaining they did not have access to much news, and dismissed anti-Nazi information as enemy propaganda.

As the climate of hate worsened, teachers of the deaf reported their students for sterilization or abortion in compliance with the 1933 and 1935 racial hygiene laws, which declared Jews, Gypsies, and disabled people to be “unfit” (Friedlander, 2002, p. 31). As time went on, deaf people were targeted for sterilization, marriage prohibitions, and death.

A salient theme for all to remember, and a particular point of interest to disability studies is that the German medical community was more than compliant in the abominations of what the Nazis sometimes referred to as “applied biology” (p. 34). In fact, doctors were leaders in the Nazi movement in larger percentages than any other profession. Those in the current disability movement who question the merits of genetic screening, the Human Genome Project, etc. might be interested to know the Nazis had genetic counseling centers to help screen for hereditary impairments. The marriage of eugenics with national socialism proved fatal to nearly 12 million people.

The third section of the book poignantly records how deaf Jews were dealt with by the Nazis, and how they were assisted by hearing

Jews in concentration camps. The final section of *Deaf People* calls for more research into the contradictory history of Deaf people in the Holocaust. Despite some overlaps in information from chapter to chapter, this book is a good source of information about disability and the Holocaust. Anyone who is interested in Deaf Studies, eugenics, Holocaust Studies, the treatment of minority groups, in general, or in disability as a category of Otherness will find this a worthwhile addition to their library.

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Book Review

Title: *Forgotten Crimes: The Holocaust and People with Disabilities*

Author: Suzanne E. Evans

Publisher: Ivan R. Dee Publisher, 2004

Cloth, ISBN: 1-56663-565-9, 224 pp.

Cost: \$26.00 USD

Reviewer: Fred Pelka

Forgotten Crimes: The Holocaust and People with Disabilities recounts in brutal detail the

history of the Nazi campaign of extermination against Europeans with disabilities. The volume comes out of the Disability Holocaust Project, established “to shatter the silence that has surrounded the fate of people with disabilities during the Holocaust,” to heighten “public awareness about the current desperate plight of people with disabilities” around the world, and “to relate pre-Holocaust Nazi concepts to pernicious contemporary attitudes and enhance awareness of the existing stigmatization of people with disabilities” (p. 5).

Written by Suzanne E. Evans, a lawyer, journalist, and historian, the book traces how the Nazis were able, in only six years, to murder perhaps three quarters of a million Europeans with disabilities. So widespread were the killings that entire disability communities were virtually swept out of existence. “The deaf community of Germany has yet to recover fully from its almost complete annihilation by the Nazis” (p. 126). Evans also traces how this initial campaign became the model for the subsequent murder of millions of Jews, Roma, gays, and other “undesirables.” The use of gas chambers as weapons of mass extermination, for example, was first tried on adults and children with disabilities. Physicians, nurses, and other “helping professionals” were not only co-opted into serving genocide, but were in fact often the instigators of some of the worst atrocities against people with disabilities, including the use of children for pseudo-scientific experiments. After the war the “overwhelming majority of the participants in the disability killing programs quietly escaped punishment,” (p. 146) while disabled victims of Nazi atrocities have yet to receive formal compensation or even official recognition for their suffering.

Though the book describes events that took place in Europe in the middle of the twentieth century, its discussion of attitudes toward people with disabilities is relevant today, particularly given the resurgence of eugenics and the controversy over physician-assisted suicide. As

Bengt Lindqvist writes in his introduction, “In a world where the deliberate medical killing of a newborn, solely because of the infant’s disability, is a matter of serious discussion as an ‘ethical’ issue among both academics and physicians, the Nazi experience cannot be ignored or forgotten” (p. 11).

Forgotten Crimes would be a valuable aid to any college level disability studies or general holocaust studies curriculum.

Book Review

Title: *The Staff of Oedipus: Transforming Disability in Ancient Greece*

Author: Martha L. Rose

Publisher: University of Michigan Press, 2003

Cloth, ISBN: 0-472-11339-9

Cost: \$42.50 USD

Reviewer: Mark Sherry

Martha Rose analyzes a wide range of Ancient Greek material in *The Staff of Oedipus*, focusing on “physical disability” (but excluding dwarfism and epilepsy). In the first chapter, “The Landscape of Disability”, Rose stresses that although there were terms for specific impairments (such as blindness or deafness), there was no Greek equivalent for the modern overarching term “disability”. People with physical disabilities were not routinely segregated, excluded or marginalized from the community. Chapter Two, “Killing Defective Babies”, challenges the idea that disabled children were regarded as abhorrent and were routinely left to die in Ancient Greece. Rose suggests that there is scant information about such “exposure” of any baby – disabled or not – in Ancient Greece, and that “sweeping conclusions” are unwarranted in the light of this “scant evidence” (p.81).

Chapter Three, “Demosthenes’ Stutter”, discusses speech impairments (including stuttering, communication impairments associated

with developmental disabilities and age-related speech impairments). Rose admits that “we have no direct testimony from anyone with a speech disorder” but nevertheless suggests that each case of speech impairment was separately negotiated by the individual and the community. Chapter Four, “Croesus’ Other Son: Deafness in a Culture of Communication” suggests that deafness was not seen as a sensory impairment, but instead an impairment of reasoning and intelligence. The chapter begins with an etiology of deafness, then speculates on the differences in the social experiences of people with mild, severe and pre-lingual hearing loss. In “Degrees of Sight and Blindness”, Chapter Five, Rose argues that the Greek notions of blindness were very different from contemporary understandings. “One saw, even if only a little, or one did not see. Either condition could be reversed in an instant. No one in the Greek world was immune from blindness” (p.92). A brief conclusion highlights three themes: the notion of “physical disability” was foreign to Ancient Greece; physically disabled people were banned from very few social roles, and communities integrated physically disabled people into a wide range of social, economic and military roles.

My main criticism of this book is that Rose occasionally seems to have engaged in precisely the behavior which she often critiques: imposing modern perspectives on the material she analyzes. The most obvious example of this practice is the way she divides experiences of disability into (modern?) diagnostic categories, such as “speech impairment”. But she also blends historical material with ill-fitting contemporary material, such as a contemporary American narrative about the intersection of race and disability, and a modern advertisement from the Stuttering Foundation of America. Nevertheless, the book does illuminate an unexplored area (disability in Ancient Greece) and it will particularly appeal to those interested in disability within historical and cross-cultural contexts.

Book Review

Title: *Sociopolitical Aspects of Disabilities*

Author: W. V. Bryan

Publisher: Charles H Thomas Publishers, 2002

Paper, ISBN 0-398-07240-X

Cloth, ISBN: 0-398-07239-6

Cost: Paperback - \$41.95 USD; Hardcover - \$63.95 USD

Reviewer: Mark Sherry

This book focuses largely on American experiences of disability. Chapter One, “Foundation of Beliefs and Treatment of Persons with Disabilities”, begins with a brief history of discriminatory attitudes and practices towards disabled people and concludes with a short description of the development of rehabilitation. Chapter Two, “Concepts of Disabilities” discusses two perspectives on disability – one which Bryan calls a “sociopolitical concept” (a mélange of British and American work) and the other which he labels the “functional limitation concept” (which might more appropriately be called a medical model). Bryan is keen to emphasize the value of both approaches, though he does not shy away from stressing the horrors of eugenics and the medical model. Chapter Three, “The Landscape of Disabilities”, discusses the increasing size of the disabled population, and also emphasizes the degree of ethnic and racial diversity within the disability movement. Chapter Four, “The Oppressed”, analyses some of the psychological reasons for prejudice, forms of discrimination, and the impact of discriminatory and paternalistic attitudes on disabled people.

Chapter Five, “Social Environment”, highlights a number of myths that prevent equal employment opportunities for disabled people, and discusses various types of employment opportunities (such as supported employment and sheltered workshops). Bryan suggests that criti-

cism of sheltered workshops for paying low wages and inadequate training is “unfair for many workshops” because they “operate on a limited budget and work with individuals who have limited skills” (p.106). Though this is not a major part of his book, I certainly felt that Bryan’s treatment of this issue was inadequate and his conclusions questionable. Chapter Six, “The Advocates”, identifies individuals and groups who have been important historical figures in the development of the US disability rights movement, such as Dorothea Dix and Ed Roberts, the National Organization on Disability, and the National Federation of the Blind. Chapter Seven, “Disability Rights Movement”, discusses the ideas behind independent living, and identifies important historical protests such as the Section 504 protest, and the Deaf President Now protest at Gallaudet University.

“Political History”, Chapter Eight, contains a description of American vocational, rehabilitation, employment, educational and anti-discrimination legislation. While largely descriptive, this is still one of the better chapters of the book, collating a large amount of useful information. Chapter Nine, “Family”, seems to sit uneasy with the rest of the book, as it moves back to a more psychological examination of family responses to disability as a “crisis”, and rehashes traditional psychological adaptations to loss (shock, anger, disbelief, and so on). Even the positioning of this discussion – well after previous (more sociological) discussions of cultural responses to disability seemed puzzling.

Overall, this book will probably be a useful introductory textbook for undergraduate students. It provides a fairly basic introduction – each chapter contains a chapter outline, a set of learning objectives, and review questions which examine whether students have carefully read the text. It is easy to read and free of jargon, though it tends to be simplistic at times.

Journal Review

Title: *Independent Living and Self-Help in 2003: A Global Snapshot of a Social Change Movement*

Editors: Barbara Duncan & Jennifer Geagan

Publisher: World Institute of Disability (WID), 2004

Available from WID, 510 16th St., Ste. 100, Oakland, CA 94612

Cost: \$30.00 USD

Reviewer: Katharina Heyer

Readers of this journal will not be surprised by the growing attention to global issues in disability studies. This volume is part of this international trend: aptly entitled a “global snapshot” of the state of the art of independent living (IL); it is a collection of essays from countries across the globe. Specifically, countries covered are the US, Canada, China, Japan, India, Mozambique, South Africa, and the countries of the Latin American region—somehow this needs to parallel the earlier clause. The volume also features analytical essays documenting international efforts to spread the independent living philosophy, including problems this will entail. Editors Barbara Duncan of Rehabilitation International (RI) and Jennifer Geagan of the World Institute on Disability (WID) intend the volume also to be a progress report since the International Summit on Independent Living (Washington DC, 1999) organized by the US National Institute for Disability and Rehabilitation Research (NIDRR) with assistance by WID and Rehabilitation International. This summit was considered so successful in solidifying an international eye on independent living movements that just a year later WID launched the highly popular *DisabilityWorld*, an online magazine featuring IL-related news from countries around the globe. Many articles in this collection were previously posted on the *DisabilityWorld* website (www.disabilityworld.org) or in the International Journal of Rehabilitation Research (see [Volume I Issue 4](http://www.indepen-</p></div><div data-bbox=)

dentliving.org), which gives immediate access to the essays for those preferring the paperless version. Translated excerpts are included from a Spanish language volume on international IL issues not otherwise available to monolingual readers.

As the independent living philosophy spreads across the globe, one fundamental issue people grapple with is the question of cultural sensitivity and competence. Culture occupies a central place in this volume as well. How can the (Western) notion of “independence” be translated to make sense to other cultures? This does not only apply to non-Western cultures that have different ideas about independence and family life, but also to cultures within the US that will question the urban-based middle-class values imbedded in the IL-philosophy. In her excellent overview of US IL history, for example, Kathy Martinez outlines some pressing issues for what is now considered the second generation of IL activism: poverty, services development for people from rural communities, and the critical examination of “Anglo bootstrap independence and self-sufficiency” (p. 15) as applied to ethnic communities that value family interdependence and for whom notions of disability pride are so alienating it is “counterintuitive to introduce them” (p. 16). A related issue is the question of personal assistance services (PAS). In the US, PAS is currently based on the assumption that adults with disabilities want to live outside of their parents’ home, and that hiring professionals is preferable to relying on family for personal assistance. Again the question is, “whose values are these?” (p. 53) Based on these issues, Independent Living Centers have begun outreach services to Asian, Black, Native American and rural communities. National Technical Assistance Centers have been developed for Latinos, Asians and Pacific Islanders, and Native Americans.

Similar questions are being asked by those in non-Western countries importing the IL philosophy, and this is where the volume both shines

and disappoints. Some country reports are extensive and detailed, giving a good overview of history and current issues. Examples of these are the essays featuring Canada, Japan, South Africa, and the Latin American region. Here, scholars and activists can easily access information about policies and organizations, as well as the relevant literature. The essay on India is especially valuable in showing how a non-Western country can generate and implement culturally appropriate forms of independent living and self-help. It allows us to follow nine young Indian women for two years as they fashion their own self-help group and independent living community while undergoing a vocational training program in prosthetics.

When it comes to less well-studied countries, however, the volume promises more than it delivers. For example, the chapter on China consists of a brief, technical study of quality of life issues of hospitalized adults with spinal cord injury. It is a case study that needs to be placed in a larger context: as is, it does not tell us anything about the state of independent living in China. Similarly, the chapter on Mozambique is full of general statements on community-based rehabilitation, but tells us nothing about local approaches or organizations, with the exception of a curious mention of a traditional healer housing adults with mental disabilities to administer “spiritual treatment towards recovery” (p. 85). While it is doubtful this is to be interpreted as an example of a culturally appropriate adaptation to the IL principle, curious readers are left in the dark about what it all means. Readers interested in these studies cannot follow up with the authors—there is no information (contact or otherwise) about the contributors, which is a serious oversight in a volume so concerned with international cooperation.

The volume’s primary strength lies in its more comprehensive essays that trace larger analytical themes, such as the development of the IL philosophy in the United States (Ch. 1) and the ways it has informed the international

community (Ch. 7). Another essay in this category features the UK's "Action on Disability and Development", a development organization that supports IL in twelve of the world's poorest countries in Africa and Asia. This essay makes a strong case for the inclusion of disability in the planning and implementation of larger developmental projects, in the same ways that gender issues are already being addressed. At heart lies the recognition that poverty can not be eliminated without addressing the needs of disabled people (p. 59), and this essay gives compelling examples of how this inclusion has worked in practice. The volume concludes with an extensive timeline of major milestones in independent living communities all over the world, along with an international review of IL literature featuring a large number of online articles. Both are excellent resources for further study and discovery.

Book Review

Publisher: *Building an Inclusive Development Community: A Manual on Including People with Disabilities in International Development Programs*

Editor: Karen Heinicke-Motsch & Susan Sygall

Publisher: Mobility International USA, 2004

Available from MIUSA, P.O. Box 10767, Eugene, OR 97440 USA, www.miusa.org

Cost: \$40.00 USD

Alternate Formats: Audiocassette, electronic text files, Braille, and other alternate formats available upon request.

Reviewer: Liat Ben-Moshe

This book is a practical manual for development agencies, and others who create related policy, on how to make sure people with disabilities are included in the planning, delivery and evaluation of these programs and services. The manual is divided into seven (7) chapters:

Management Practices and Human Resource Development; Legal Policy Issues; Governance; Accessibility; Inclusion of Disability in Delivery of Programs/Services; International and Regional Responses, and Development Topics and Disability (including Gender and Disability; Civil Society; Micro Finance; Disaster and Emergency Relief; Refugees and Disability; Domestic Violence; Women with Disabilities and Health Care; Parenting with a Disability; Community Based Rehabilitation; Inclusive Education; Agriculture, and Mental Disabilities and Development). It also includes a basic checklist to survey the level of inclusiveness of organizations, and several appendices and forms.

The book is designed to look like a large textbook, with about 650 pages (page numbers are not marked). It is written in simple language, and is full of examples and tips from around the world, for example, 'best practice' sections appear in many chapters. It supplies a plethora of additional resources, mostly web based, that can lead to more detailed information. Many of the chapters have been previously published elsewhere (like Degener & Quinn's excellent survey of international disability law, that appears in chapter 2), but their compilation under specific sub-chapters is convenient and time saving.

The problem with this publication, if one sees it as a problem, is the lack of ideological positioning, especially in regards to the development discourse itself. When protests against the World Bank, WTO, IMF and even the UN abound, one cannot assume that including disability into these and other development organizations with their existing ideology is unproblematic. For instance, chapter 4.1, about assistive technology, discusses the donation of old wheelchairs by people in the U.S. and their delivery to developing countries by various charities. Are wheelchairs the best assistive device all over the world? And will donation by private citizens and reliance on American charities carry the desirable effects?

In conclusion, once one gets past the benevolent imperial discourse, this is a very helpful practical guide on inclusion, in general. Many of the issues covered in the manual can be expanded as effective inclusive strategies of people with disabilities in most realms of life: doing outreach to attract disabled people into the organization; active focus on the inclusion of women with disabilities and other minorities; calculate and budget for accommodation in advance; emphasize and create accessible transit; and evaluate effectiveness of inclusion at every stage of the project, not just at the end. Therefore, this manual does what it sets out to do in its subtitle (*A Manual on Including People with Disabilities in International Development Programs*) and if taken as a case study, can be further used by various organizations and advocacy groups that are non development-centered, especially in a U.S. setting.

Reviewer Biographies

Rhonda S. Black is an associate professor in the Department of Special Education at the University of Hawai'i at Manoa.

Steven E. Brown is an assistant professor at the Center on Disability Studies, University of Hawai'i at Manoa and an Editor of this journal.

Mike Clear is an Adjunct Senior Fellow and formerly the Director of Critical Social Science Research in the School of Applied Social & Human Sciences at the University of Western Sydney. He is a founding director of the national Disability Studies and Research Institute (DSaRI) in Australia.

Patricia Duffley-Renow, MS, CRC, ATP, is a certified rehabilitation counselor and assistive technology practitioner at the East Tennessee Technology Access Center. She is pursuing a doctoral degree in adult education at the University of Tennessee, Knoxville.

Landry Fukunaga, Center on Disability Studies, University of Hawai'i, has been working with children with autism in the state of Hawai'i for five years, as an in-school Skills Trainer, Independent Instructional Services Coordinator, and parent consultant. She is currently conducting research on emotional expressions and empathy with children with autism at the University of Hawai'i and is pursuing her Doctorate in Psychology.

Katharina Heyer is Assistant Professor of Political Science, Law and Disability Studies, University of Hawai'i.

Cassian B. K. Kimhan, M.A., is a graduate student at the University of Hawai'i at Manoa in clinical psychology. She is also a recent graduate of the Maternal Child Health Leadership Education in Neurodevelopmental and Related Disorders program affiliated with UH.

Liat Ben-Moshe is a Ph.D. student in Sociology, Women's Studies and Disability Studies at Syracuse University, and a member of Beyond Compliance (BCCC), http://soeweb.syr.edu/thechp/beyond_compliance.html. She can be contacted at: lbenmosh@maxwell.syr.edu.

J. Gary Linn, Ph.D. and *Dr. Carol Bompert*, RN, Ed.D. are both faculty in the School of Nursing at Tennessee State University. They share a common interest in women's health issues, especially HIV/AIDS problems of women in developing countries. Dr. Linn can be reached at jlinn87844@aol.com or at 615-297-1354.

Sally Y. Nhomi, D.Phil., Research Specialist and Project Coordinator at the Center on Disability Studies, University of Hawai'i, currently coordinates a research project on "self-determination" for culturally and linguistically diverse youth with emotional and behavioral disorders. She holds a master's in Development Studies from the London School of Oriental and African Studies, and a doctorate in Educational Studies from Oxford. Sally can be reached at nhomi@aol.com.

Beth Omansky, received her Ed.S from the School of Social Work and Applied Human Sciences at The University of Queensland, Brisbane, Australia. She resides in Portland, Oregon and can be contacted at BethOmansky@yahoo.com.

Fred Pelka is the author of the *ABC-CLIO Companion to the Disability Rights Movement* (ABC-CLIO 1997), editor of *The Civil War Letters of Charles F. Johnson, Invalid Corps* (University of Massachusetts Press, 2004), and a 2004 John Simon Guggenheim Memorial Fellow.

Katherine T. Ratliffe, Ph.D., is an Assistant Professor in Educational Psychology, University of Hawai'i. Her areas of interest include the Pacific Islands, multicultural issues in education, family involvement in education, education of children with disabilities, and related services in educational settings. She may be contacted at: ratliffe@hawaii.edu.

Mike Reynolds holds a BA in English with a minor in Disability Studies from the University of Maine Orono. Reynolds runs www.uppity-disability.net and speaks on media issues and grassroots disability organizing across the country. Reynolds wrote and directed *Life and Death in Maine* and is currently working on future releases. Reynolds recently had a commitment ceremony with his spouse, James Doucette. They reside together in Lewiston, Maine.

Judy Riffle is working on an Ed.D. in higher education administration from the University of Southern California and works as a junior specialist/mentor at the University of Hawai'i at Manoa. She primarily works with beginning special education teachers in public schools.

Kelly D. Roberts, Ph.D., is an Assistant Professor at the University of Hawai'i-Manoa, Center on Disability Studies. Her interests are in learning and cognition.....among other things!

Mark Romoser is a *cum laude* graduate of Yale. He rediscovered his identity as a person with au-

tism during the mid-1990s, and has presented his first-person accounts of life with the condition to audiences along the East Coast, in Canada, and in Hawai'i. He currently serves as the Self-Advocacy Coordinator of Hawai'i Centers for Independent Living in Honolulu, and as the chair of the Hawai'i State Developmental Disabilities Council.

Mark Sherry, Ph.D. is the Ability Center of Greater Toledo Endowed Chair in Disability Studies at the University of Toledo.

Announcements

22nd Annual Pacific Rim Conference on Disabilities

March 13th – March 15th, 2006

Honolulu, HI

<http://www.pacrim.hawaii.edu/>

Since the first Pacific Rim (Pac Rim) Conference in 1985, the scope and size of this premier event has grown to include participants from the U.S. Mainland, Alaska, Pacific Islands Nations, Japan, Australia, the Philippines and numerous other countries. Persons with disabilities, family members, researchers, and service providers join policymakers and nationally recognized speakers in the field of disability to share resources for communities to fully include and support persons with disabilities. Sponsored by the Center on Disability Studies at the University of Hawai'i at Manoa and various community partners.

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About the Center On Disability Studies

The mission of the Center on Disability Studies (CDS), at the University of Hawai'i at Manoa, is to support the quality of life, community integration, and self-determination of all persons accomplished through training, service, research, demonstration, evaluation, and dissemination activities in Hawai'i, the Pacific Region, and the mainland United States.

The Center on Disability Studies is the umbrella for some 25 funded projects. It originated as the Hawai'i University Affiliated Program (UAP) funded by the Administration on Developmental Disabilities of the U.S. Department of Health and Human Services. It was established in 1988 as part of a network of over 60 UAP's in the United States. It is now a University Center for Excellence in Disability Education, Research, and Service.

Although core funding for the Center is provided by the Administration on Developmental Disabilities, other federal and state funds are provided by the Maternal and Child Health Bureau of the U.S. Department of Education, various other programs in the U.S. Department of Education, the University of Hawai'i, and the State Planning Council on Developmental Disabilities.

The activities of the Center for Disability Studies extend throughout the state of Hawai'i, the mainland United States, and the Pacific region with funded projects in several initia-

tive areas including intercultural relations and disability, mental health, special health needs, Pacific outreach, employment, and school and community inclusion.

The Center provides a structure and process to support and maintain internal professional development, collegiality, and cooperation, reflecting an organizational commitment to excellence. Center activities reflect a commitment to best practice and interdisciplinary cooperation within an academic, community, and family context. Activities are culturally sensitive and demonstrate honor and respect for individual differences in behavior, attitudes, beliefs, and interpersonal styles.

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The Review of Disability Studies: An International Journal

Submission Guidelines

The Review of Disability Studies is a peer-reviewed journal. The Review is published four times a year and runs approximately 100 pages an issue. Every article published in the Review is evaluated by a peer reviewer. Upon request of an author and if appropriate, two anonymous peer reviewers will evaluate a submission and this will be noted upon publication. Scholarly and professional standards are expected from all authors. Essays, personal experience articles, reports, and other materials are also expected to meet quality standards.

Contributors who are not subscribers are urged to subscribe. Authors will receive one printed copy of the issue in which their work appears.

Submission of material will be considered evidence that you are offering the Review all publishing rights and the copyright.

All written material must be submitted in an email attachment or on an IBM compatible diskette or CD-ROM in MS Word or text format to submissions_rds@cds.hawaii.edu or to the attention of Megan Conway, Review of Disability Studies, Center on Disability Studies, 1776 University Avenue, UA 4-6, Honolulu, HI 96822. If an author does not have access to a computer, two hard copies, double spaced with an explanation is acceptable. For more information, email or write to the address above, or phone: 808-956-5688, fax: 808-956-7878, web: www.rds.hawaii.edu.

Format Requirements

- While there is no page limitation on individual contributions, generally articles run from ten to fifteen single spaced pages or 5,000 to 7,500 words. Each submission must include an abstract of no more than 50 words, a three sentence biographical statement, and three key words. Please also indicate what degrees, professional credentials and affiliations are to be listed after the author's name(s).
- Forum editors are responsible for obtaining and reviewing at least four articles on the forum topic or a total of 50 single spaced pages. It is recognized that some topics may require more pages. Forum articles must follow the guidelines for individual submissions. Each forum editor is also responsible for writing an introduction to the forum topic.
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