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The first journal in the field of disability studies.

Disability Studies Quarterly is a peer reviewed journal of scholarly and other articles and reviews in the field of disability studies. Each symposium article is carefully reviewed by the symposium editor(s) and the DSQ Editor. Often we invite an author to revise the original manuscript and if it is still not acceptable we allow the author to withdraw it. Non-symposium articles are also carefully reviewed by the DSQ Editor. All reviews are carefully reviewed by the DSQ Book, Video, and Film Review Editor and then by the DSQ Editor. Scholarly articles and reviews must meet professional standards. Non-scholarly articles must offer insight, ideas, experiences, or information relevant to disability studies.

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The Disability Studies Quarterly is published for the
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in the humanities, disability rights advocates, and others
concerned with the problems of people with disabilities. The
purpose of the Quarterly is to provide a place where people from
diverse backgrounds can share ideas and to engage in dialogues
that cut across disciplinary backgrounds and substantive
concerns. The Quarterly is committed to developing theoretical
and practical knowledge about disability and to promoting the
full and equal participation of persons with disabilities in
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Editor's Preface

Michael Dorn and Deborah Metzler have put together an excellent symposium on disability geography. It is a new field within the discipline of geography and it is a growing one. The papers in this symposium represent some of the very best research on the cutting edge. We are grateful for their hard work. Perhaps the reader does not understand how much work is involved in bringing together and editing a symposium. If so, we invite all readers to submit a symposium idea for a future issue and then carry it out.

In addition to the symposium articles, Tanya Titchkosky contributes a perceptive article titled "Coming Out Disabled: The Politics of Understanding" which presents the ambiguity of a scholar without a visible disability conducting research and teaching in the field of disability studies. It is something to which many readers of *Disability Studies Quarterly* will viscerally relate.

Trevor R. Parmenter in his "Implementation of Disability Studies within Post Secondary Education: An Australian Perspective" presents the history of recent developments in academia in Australia. He treats disability studies as consisting of special education and rehabilitation counselling, not as a separate, quite different field.

Finally, the editor contributes an article on the distributive impact of US disability policy which says that the policy does not distribute resources very well. Instead, class, race, and gender govern such things as employment and income within the disability community as they do in society as a whole.

Book, Film, and Video Review Editor Elaine Makas again presents an excellent set of reviews. The University of Chicago Press sends information on one of their forthcoming books, *Crippled Justice* by Ruth O'Brien. The title alone should entice readers of the *Quarterly* to examine it. Beth Haller announces the reactivation of the News & Notes section that will have news, announcements, and information about Society members and others

engaged in disability studies research both in the U.S.A. and internationally. And finally there is an announcement about the Fall 2001 issue of *Hypatia: A Journal of Feminist Philosophy*. It is a special issue on feminism and disability studies edited by Eva Fedder Kittay, Anita Silvers, and Susan Wendell.

David Pfeiffer, Editor

**Symposium on Disability Geography: Commonalities
in a World of Differences**

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Introduction

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We are pleased to have been given the opportunity by DSQ editor David Pfeiffer to present some of the wide-ranging and fascinating work currently being undertaken by geographers and researchers in other related disciplines on disability topics. As a means of introducing disability studies scholars to the geographical perspective, we begin with some comparisons to the discipline of history. Geographers approach the study of human phenomena through a spatial or areal lens, using an enriched spatial analytic vocabulary (proximity, locality, access, etc.) and employing maps, in much the same way that historians tend to organize their studies of human phenomena through a lens of time and the temporal imaginary. While most of the studies included here may be classed within the realm of social, cultural, and medical/health geography, we also are happy to present work by urban environmental planners.

Social geography emerged as a subdiscipline of American and British geography during the late 1960s. It has long had close ties with socialist and radical geography, areas of concern that were the product of human geographers' negative reactions to the heavy emphasis of quantitative analysis and regional studies on describing rather than explaining the causes and socio-spatial relationships of social dislocation and social inequity. The

robust body of urban social geographic research on deinstitutionalization and mental illness can be traced back to this period. Health and medical geography have also experienced intense growth in the last 35 years. But only since the mid-1990s have researchers conducting work on disability and chronic illness begun to meet and collaborate (and occasionally confront) each other. Some of these initial encounters were strained, as advocates of a social model approach went head to head with researchers whose work relied more heavily upon the terminology and models of medicine and the behavioral sciences (see the article by Rob Kitchin).

Yet disability geographers, housed within a discipline that habitually spans conceptual boundaries (art vs. science; people vs. landscape; social science vs. physical science), have learned to accept the diverse character of their colleagues' work. Whether we opt to work in collaboration with, or on behalf of, the persons with disabilities, disability geographers (who may or may not have disabilities themselves) share a similar motivation to draw attention to the presence of people with disabilities within our societies and to improve the lives of persons with disabilities. This has been captured in the mission statement for the Disability Specialty Group (DSG), affiliated since 2000 with the parent Association of American Geographers (AAG).

In this issue, seventeen contributors present research based in Thailand, Indonesia, India, Ireland, England, Scotland, Australia, Singapore, Southern Africa, and the United States. While recognizing the diversity of these papers in terms of locality, approach and subject matter, we have grouped them here around two key themes: Voices and the Paradoxes of Policy.

The first section, Voices, is devoted to papers that flesh out geographically-nuanced portrayals of lives with disabilities. All of these authors utilized qualitative research designs to pursue their research questions. The first two papers grow out of dissertation research considering the conflicting priorities of different Southeast Asian voluntary organizations. Based on her work in an in-depth study of a South Indian charitable organization for children with disabilities, Nirmala Erevelles describes an uneasy paradox that exists between marginal classes (particularly children with disabilities and the impoverished single women employed to care for them) within Indian society. As part of his dissertation research Vincent Del Casino volunteered for a year-and-a-half with an organization devoted to HIV/AIDS outreach in Northern Thailand. In the case presented here, Del Casino focuses on the limited agency that persons with HIV/AIDS exercise within such organizations. While subjected to surveillance and authoritative discourse, some are still able to use the organization's non-governmental status to resist discrimination in other areas of their lives.

Neela Thapar and her collaborators, Surinder and Candy Bhardwaj, use the stories of two US men dealing with the onset of

multiple sclerosis to examine the relative contributions of physical and social supports in promoting and preserving quality of life. Ruth Butler and her colleagues share with us some of the findings of their on-going research with d/Deaf teenagers and older adults in the United Kingdom. Susan Levy discusses the contrasting perspectives of those persons with disabilities living outside and within sheltered housing in Dundee, Scotland. Finally, Rob Kitchin reflects on some of the hard lessons he has learned from several years of undertaking and completing participatory action research projects. We feel that this is a timely assessment of an approach that has been long advocated by geographical researchers and persons with disabilities alike.

The second section of essays, *Paradoxes of Policy*, is comprised of papers that demonstrate how policies articulated in abstract terms and at typically distant loci of authority (well intended though they may be) too often fail or fall short in their implementation. In the wake of Sydney, Australia's hosting of the 2000 Paralympic Games, Simon Darcy reviews the planning process and the potential outcomes of the Games for persons with disabilities.

The next three contributions discuss the potential for increasing disability awareness and promoting realistic plans and goals addressing physical access in developing countries. Marcus Power draws upon his recent work concerning war-related physical disabilities and with definitions of disability in Mozambique and Angola to consider the prospect for empowering development policies in Southern Africa. He finds that in South Africa and Mozambique local disability initiatives show the greatest promise. Inge Komardjaja gives us an in-depth look at how people with disabilities are perceived in Indonesia and how the streets and related infrastructure limit the mobility and access of people with mobility impairments. More broadly, Kenneth Parker reviews demonstration projects and awareness campaigns undertaken throughout Asia on behalf of persons with physical disabilities, as well as the elderly, as part of the United Nations' "Asian and Pacific Decade of Disabled Persons" (1993-2002). Parker also discusses the kind of economic arguments that are more successful in countries like Singapore that lack formal civil rights guarantees for persons with disabilities.

In the final contribution to this section, Deb Metzler and Pamela Walker summarize the historical and contemporary social policies for people with mental handicaps that impact their participation in American society, in many cases tying them to formal service and support systems while providing the illusion of inclusion.

We have been so pleased with these submissions that a second symposium on Disabilities and Geography has been scheduled for Winter 2003. Consider this announcement an early Call for Papers and please contact Deb Metzler at <dsmetzel@yahoo.com> about submitting. A more complete Call for Papers will be posted and

distributed next year.

We invite scholars in the allied spatial disciplines (those devoted to planning, landscape interpretation, and spatial analysis) to join the Disability and Geography International Network (DAGIN). Founded six years ago by geographers from Britain, Canada and the United States, DAGIN members have since organized conference sessions and special publications in all three countries. The primary venue for organizing and discussion amongst DAGIN members is the international discussion list GEOGABLE, operated out of the University of Kentucky. Information on joining the GEOGABLE listserve can be found at the following address: <<http://www.georgetown.edu/crossroads/interests/ds-hum/geogable.html>>. Additional questions should be directed to Mike Dorn at <mdorn@zoo.uvm.edu>.

If you happen to be in Los Angeles this spring between March 19 and 23, 2001, we invite you to meet us at the Annual Meeting of the American Association of Geographers. When the final schedule is confirmed, we will post the schedule of presenters and their abstracts via the GEOGABLE listserve.

Mike Dorn and Deb Metzler are also happy to field inquiries regarding the AAG Disability Specialty Group, the Disability and Geography International Network, and disability geography more generally. As co-editors of this issue, we contend that the breadth of perspective within the discipline of geography lends itself to the complex task mapping the changing place of the disability in today's society.

Finally, we would like to thank all the contributors who enthusiastically submitted abstracts that turned into great articles. We were pleased to receive works from old friends and now new friends and we hope that you enjoy reading about disabilities through these various geographical perspectives. Thanks also to David Pfeiffer for being an encouraging and amenable editor-in-chief.

VOICES

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Disability and the Political Economy of Place:
Case Study of a Voluntary Organization in South India

Nirmala Erevelles
University of Alabama

Introduction

To geographers, space is viewed as a universal feature of all social relations - "a medium through which social life is produced and reproduced" (Rose 1993: 19). This is because geographers have described spatial structures as instrumental in mapping out the dialectical relationship between human beings and the social world they inhabit. Place, another geographical concept, is used to define this critical relationship between the spatial and the social. Place represents not only the geographical coordinates of location but also the hierarchical social relations located within specific spatial structures as well as the subjective meanings that are associated with these same structures (Cresswell 1996). It is this concept of place that I use to map out the social and material relationships that linked the professional and non-professional staff at DOST (a voluntary organization located in a large city in South India) with their clients, children with disabilities.

At DOST I found a persistent irony: the hierarchical boundaries traditionally used to distinguish between "client" and "service provider" were blurred. In voluntary organizations like DOST, it is commonly assumed that an organization's staff generally serves as benefactor to their clients who are portrayed as the beneficiaries of the charitable services offered through the organization. However, this ethnographic study of DOST revealed that contrary to this distinction, many of the non-professional staff - single, poor, lower caste women - spoke of lives of destitution that often seemed to outstrip by far the destitution experienced by many of the children with disabilities with whom they worked. This observation that blurred the hierarchical boundaries between benefactor and beneficiary led me to raise the following question: in what ways did these shifting hierarchical boundaries relate to the role "place" played in the construction of social difference at DOST? Responding to this question, I present an analysis of how and why certain bodies marked oppressively by class, caste, gender, and ability are associated with particular spatial orderings within segregated contexts like DOST.

Background of the Study: Mapping the Distance between "Us" and "Them"

Being a voluntary organization that caters to the needs of one of the most disenfranchised segments of Indian society (i.e., children with disabilities), DOST is regarded as marginal to the central concerns of the Indian polity. However, Cresswell (1996: 149-50) points out that the margins, despite seeming to appear socially peripheral in relationship to the center, are, in fact, symbolically central to construction of the center and therefore cannot be categorically dismissed. Therefore, in this section of

the essay that serves as the background for this study, I will map out the critical relationship between the margin (e.g. DOST) and the center (e.g. mainstream Indian society) using the methodological standpoint of political economy.

Broadly speaking, political economy maps out the complex relationship that exists between the economic interests of the state and the political interests of its citizenry. More specifically, I invoke Marxian political economy that conceives of political forces as originating in the dynamics of the capitalist economic process and as supporting a social division of labor that highlights class antagonisms (Caporaso & Levine 1992). Deploying this analysis, I will examine DOST's location within the broader political economic context of the Indian State and describe the implications this location has for those individuals associated with the organization.

The Voluntary Organization DOST

Started in the 1970s, in a context where services for people with mental disabilities were woefully lacking, DOST is a voluntary organization that offers a comprehensive range of services to children with disabilities living in both urban and rural areas in South India. DOST was the brainchild of Sister Benedict, a member of a religious order that is dedicated to providing charitable services to needy individuals in Third World settings. While Sister Benedict knew very little about disability when she first started this organization, her experiences working in her convent's hospital helped her provide the organizational structure and the vision that has sustained DOST through several difficult decades. Most of the difficulties are financial because DOST is primarily dependent on the Indian State and philanthropic organizations for its economic survival.

The annual operating budget for DOST is about 16 lakhs (1 lakh = 100,000 RS.) and DOST receives only one lakh from state agencies to meet its economic needs. This low contribution from the State is further exacerbated in the current political economic context of neoliberalism where the Indian State has refocused its energies to subsidize the structural adjustment policies of the World Bank and the IMF and has subsequently decreased its involvement in the welfare state (Sheth & Sethi 1991). While other populations dependent on social welfare have not fared as badly, persons with severe disabilities have been negatively affected by these cuts. This is because a market economy is geared towards the profitable extraction of labor from a productive and efficient workforce. In this context, the physical challenges that persons with severe disabilities experience, even after rehabilitation, are seen as impediments to the efficient and profitable extraction of labor geared exclusively to the maximum accumulation of profits (Soder 1984, Nibert 1995). It is, perhaps, because of this logic that the Indian State allocates less than 0.3% of its social welfare

budget for services provided to persons with disabilities. As a result, organizations like DOST are encouraged by the State to augment their already scarce financial resources by soliciting philanthropic contributions from private wealthy donors and international aid agencies and by collecting fees from the few clients who can afford to pay for these services.

The majority of the children who receive services at DOST come from economically destitute urban and rural households with a monthly income of less than RS. 600 (about \$20). However, not all the children who attend DOST are poor. Children from some of the city's wealthiest families also attend DOST, an unusual occurrence in a city that is otherwise clearly segregated on the basis of class. Thus, it appears that for the brief periods when all these children are at DOST, the segregation that is characteristic of a class and caste based Indian society is momentarily suspended. This is because, notwithstanding the differences in their social positions in mainstream society, it is the children's collective marginalization as beneficiaries of the voluntary organization on account of their disability that disrupts an otherwise rigid hierarchical social structure.

Since the organization derives an almost negligible income from the meager fees paid by its clients (most of whom are poor), DOST is forced to market itself in competition with other voluntary organizations for the attention of individuals and organizations committed to philanthropic practices. I use the verb to market deliberately to demonstrate that DOST is still subject to the effects of supply and demand - characteristic features of market economies. But while the working of supply and demand in market economies is geared to the realization of profit, in the non-profit sector supply and demand is subject to the dictates of a moral economy where exchange is not motivated by profit, but by an identification with abstract moral values (e.g. philanthropy). This realization, thus, places the onus on DOST to market its activities in such a way so as to demonstrate the moral advantages gained through any philanthropic interest in the organization.

DOST uses a number of marketing strategies to generate philanthropic interest in the organization. Every year Sister Benedict travels abroad to Europe, America, and Australia and distributes videos and other informational packets to elicit financial donations as well as inspire volunteers who are trained professionals to spend some time at DOST. At the local level, Sister Benedict organizes an annual function where the children perform songs, dances, and plays for an audience that includes wealthy donors, state officials, parents, and other supportive community members. In conjunction with this event, DOST also publishes a publicity brochure that is sold to all guests and is imprinted with a number that is then included in a general raffle drawing. Since both the international and local publicity campaigns are crucial for DOST's financial survival, Sister

Benedict and her administrative staff are forced to deploy two competing yet complimentary discourses in order to enhance its marketability. One discourse uses the clinical language of medicine to explain the scientific rationality behind the everyday activities at DOST in an effort to emphasize the critical role the institution plays in the community. The other discourse draws on the ideology of charity to project the aura of need and provide legitimacy to DOST's constant requests for financial support from the community.

These two competing discourses were clearly discernible in the publicity brochure marking the 15th anniversary of the organization. The first 25 pages of this brochure were devoted to reports of DOST's activities, the felicitations of prominent donors, and articles from some parents and professionals extolling DOST's services to the community. For example, one article in the souvenir describes DOST's struggle for survival as enabled by the tireless efforts of its staff members - a unique group of people who possess the laudable characteristics of determination, compassion, dedication, devotion, nurturance, and service mindedness. At the same time, the narrative also describes the beneficiaries of such inspirational qualities - the children and young adults with disabilities - in the following way:

The least of God's children is not the worm or the little crawling insect, for even that has the vital urge to live, to take care of its life and survive within the space created for it in life.... The most extreme cases [of mental defective children] ... are born even without the hereditary instinct to suck. They have to be force-fed.... They may be capable of inarticulate cries but they cannot speak. Nor can they ever be taught.... The tragedy of mental retardation is its near irremediability.

This portrayal of children with mental retardation as afflicted, helpless, pitiable, innocent, and abnormal and therefore totally dependent on the benevolence of its service providers stands in sharp contrast to the competing discourse of clinical objectivity observed in another article written by a professional staff member at DOST:

The popular philosophy in dealing with the mentally retarded [sic] is normalization. Due to [the children's] mental deficiency and sub-average intelligence, they have not been able to learn in normal schools but have been instructed through special education which is highly individualized and moves towards short and long range goals, giving a child multi-sensory experiences.

I argue here that both these scripts of charity and clinical

objectivity intersect strategically to locate children with disabilities and their service providers in the diametrically different positions of beneficiaries and benefactors - locations that are necessarily hierarchical. Ironically, it is through the celebration of this hierarchical relationship that DOST is able to effectively market itself in the arena of social welfare and project itself as most deserving of public philanthropy. To do so, it becomes imperative that DOST support depictions of disabled people as hapless, dependent, and almost inhuman, such that the medical discourses of rehabilitation can be deployed in order to demonstrate the organization's ability to transform their lives. That this strategy is especially successful is apparent when one leafs through the remaining 80 pages of the brochure that contains advertisements from about 123 different private local businesses in the area - numbers indicative of DOST's success in its fund raising attempts.

The Professional Staff

Given its paucity of funds, DOST is also compelled to solicit voluntary assistance from medical personnel, rehabilitation professionals, teachers, and other members of the public who are expected to offer their services for little or no wages. This is especially crucial, since DOST needs trained personnel to staff the various units it supports that include a dormitory unit, a special school, an occupational and physical therapy unit, two sheltered workshops and a manufacturing unit that produces artificial limbs.

The professional staff at DOST included the general practitioner, four medical specialists, three social workers, two occupational therapists (OT), two physical therapists (PT), one speech therapist, and two trained special education teachers who received a modest compensation for their services. However, recognizing that they could have received much better wages if they had worked in the private sector, they were often celebrated for espousing an ethic of service towards children with disabilities.

Additionally, during the six months that I spent at DOST, a dentist, two physiotherapists, and five undergraduate students from England, Australia, and Canada spent six months to one year at DOST offering their highly specialized services for virtually no compensation. This group was the most highly celebrated for their ethic of service and were often touted as role models for the Indian staff with the comment that "We do not do it for our own. We need people from outside to show us what real charity is." Both these groups collectively served to support an ethos of charity and clinical rationality that the institution painstakingly sought to project to the outside world.

The Non-Professional Staff

Finding professional staff to serve in a voluntary capacity

at DOST was difficult. Therefore, Sister Benedict was forced to depend on semi-trained workers to provide some of these services. The non-professional staff at DOST included eight teachers, three PT and OT aides, eight dormitory workers and three janitorial staff, almost all of whom had not finished high school, had very little formal training in their areas of expertise, and who had learned their skills while on the job. All of them were also women, mostly from poor working class families. Many of these women were unmarried. Both the married and the unmarried women had taken jobs at DOST because of extreme financial need.

The teachers and the PT and OT aides earned salaries ranging from RS. 500 (about \$12) to RS. 800 (about \$20) a month. The dormitory workers received room and board and a monthly salary of RS. 300 (about \$8). Since these women needed wages to compensate for the services they provided, their presence produced a distorted version of the ethos of charity - a situation that often led to their devaluation as service providers to children with disabilities.

The above discussion that provides the background of this study highlights some important features of DOST's location within the Indian social context and the implications this location may have for all individuals associated with the organization. Firstly, on account of the political economic decisions of the Indian State, DOST's marginal location in the area of social welfare has been further exacerbated because the population it serves is deemed of little economic value for the rapid transformations required for this burgeoning capitalist economy. This location, in turn, necessitates that the institution project itself as an instrument of both charity and clinical rationality in an attempt to entice prospective donors to the institutions. Such representations, though enabling DOST's financial survival, continue to reinforce the aura of marginality that attaches itself firmly to its clients (children with disabilities) - the very population the DOST seeks to empower.

Moreover, I would like to emphasize here that DOST's location within this moral economy has yet another negative implication for all those associated with the institution. By locating DOST within the moral economy, what gets ignored are the social, political, and economic structures that are responsible for the oppressive, hopeless conditions within which children with severe disabilities live. Thus, the "realness" of these conditions, the feelings of despair that the families own up to, and the financial troubles experienced by voluntary organizations are all rendered "natural" by the discourse of charity that is deployed. Additionally, this discourse of charity allows the state administration and wealthy elite to celebrate private philanthropy and the moral courage of those involved in providing services to society's most neglected population without ever having to feel accountable for fostering this neglect or to feel obliged to get their own hands "dirty" in the actual work of

service provision. And it is to this discussion of the social and economic conditions that are often obscured in the above narrative that I now turn to in the essay.

Methodology

This essay is derived from a larger ethnographic case study conducted when I spent six months at DOST. The case study was a detailed examination of one setting - the voluntary organization - where my broader focus was on the cultural constructions of disability at this organization. This essay, however, as mentioned earlier, is specifically focused on exploring the role "place" plays in the construction of social difference at DOST.

Data Collection

I had volunteered at DOST six years prior to this visit and when I asked Sister Benedict's permission to do my research at DOST she willingly gave it to me with the unspoken expectation that I once again serve as a volunteer while conducting my research. As a result, during the six months that I spent at DOST, I was a participant observer in the PT & OT center, the special school, the dormitories, and the sheltered workshops where I offered my assistance whenever it was required. I kept field notes and maintained a weekly field journal documenting my observations. Then in last two months of my stay, I conducted 32 in-depth unstructured interviews with almost all the staff who worked at DOST. Before interviewing each research participant, I obtained their informed consent to use the information they shared with me in this study, assuring them that their responses would remain anonymous because I would use pseudonyms instead of their real names and disguise all other distinguishing information. Most of my interviews were in English, but there were twelve interviews that were in the local language. After returning to the U.S., I transcribed all the interview tapes. I employed a native speaker of the language to check my translations.

Data Analysis

Once I had transcribed all my tapes, I began the complex process of data analysis. Using Glazer and Strauss' (1967) grounded theory approach to qualitative data, I sorted through my extensive field notes and interviews to identify common elements/themes, which were then grouped together into categories/codes. This initial coding strategy generated more than 40 codes which, on further refining, focussed on three major themes. The themes were as follows: how disability was constructed through the organizational structures at DOST; how the everyday experiences of the staff members at DOST produced several conflicting meanings of voluntary work associated with disabled people; and finally how the staff members' varied understandings of the concept of rehabilitation produced

alternative and multiple meanings of disability.

Re-examining the themes once again, I began to explore possible connections between the three identified themes. Taken together, these themes exposed the hierarchy, exclusion, and exploitation that shaped the lives of both the staff members and the disabled children with whom they worked and that forged a curious relationship between these two groups. In the specific context of this essay, I argue that this relationship was spatial and appeared to be constituted by specific political, and economic structures that had an impact on all individuals associated with DOST.

To further explore this spatial relationship, I utilized the theoretical perspective of geographical historical materialism (Harvey 1996) to describe how and why disability is spatially represented within the voluntary organization DOST. Historical materialism begins with the presupposition that labor is the central organizing force in history because human beings do not just live, but instead produce their lives within specific historical contexts through their relationship to labor. In other words, historical materialism is able to map out the dialectical relationship of individuals to social structures as determined by their locations along the social divisions of labor. Therefore, in a context where unequal social relations are both expressed and constituted via spatial relations, a geographical historical materialism will describe how and why difference is constituted via spatially ordered (often segregated) social distinctions that separate certain populations from larger society (Harvey 1996). It is this theoretical perspective that I deploy in this essay to foreground how the social division of labor observed at DOST is dependent on the ideological category of disability to justify the spatial arrangements implicated in the production of gender, class, and caste oppression.

The Rhetoric of Service v. The Politics of Need: Spatial Contradictions

Because DOST espouses an ethic of service, the organization claims to be structured according to a familial ideology that supports mutual reciprocity, voluntary service, and a consensual hierarchy. Such a position was articulated by Mr. Murugan, a middle-aged Brahmin (upper-caste) male who served as the personal assistant to Sister Benedict, the Chief Administrative Officer of DOST, and who enjoyed a great deal of administrative power. He explains his position as follows:

Unlike other institutions [for profit] this one is an institution that creates a family-like atmosphere.... We can't find any difference [hierarchy] at all. We move with every one. We share with each other. I'm the boss.... Like that we won't talk. In this type of institution such relationship we keep here.

Murugan's position invokes the familial ideology that treats the household as if it is an equitable space and therefore refuses to acknowledge the hierarchical structures that exist and that are based on unequal divisions of labor. And just like in the patriarchal household where women's subordinate position is justified because of their devalued locations based on the sexual division of labor, I observed similar hierarchies at DOST. At DOST, these hierarchies were based on the distinction made between professional services like occupational, physical, and speech therapy that were performed by mostly upper class and upper caste staff members. On the other hand, the actual work of teaching and caring for children, performed by lower caste women was often devalued because such work has traditionally been associated with reproductive labor that is not considered "real" work.

It is for this reason that Murugan's assertion was passionately contested by several members of the non-professional staff who were acutely aware of their devalued location along the social hierarchy at DOST. One of the PT aides (non-professional staff) described the constraints she experienced due to her oppressive location at DOST:

Actually, even if you want to do something for the child, we can't because we are treated as slaves and we are not respected here...Even if we want to express something, we are afraid that the others are watching us. And all, each and every news from here goes to Sister [Benedict]. So we are afraid.

In addition to the dysfunction within the "family" that is described above, the inherent inequalities that attended those staff members who performed some of the most important reproductive labor - the caring for the residents in the dormitory - was also exposed. The general consensus of the professional staff and administrators at DOST was that the dormitory workers, unlike the other staff members, were lazy and reluctant to take on the role of benefactor - another issue that was contested by the workers themselves. I was surprised by such representations because in the course of the interviews one dormitory worker after another dispassionately recited for me the litany of their day's routine.

These dormitory workers were assigned in pairs to care for about eighteen children in each of four dormitory rooms at DOST which served also as the women's living quarters. The regular working day for these women who had to do all the care-giving tasks for the children represented a monotonous routine that extended from early morning to midnight and which continued to make demands even on their personal time. Despite the fact that the day's work for these women officially ended at around 7 p.m.,

it was often the case that their free time was interrupted to take care of a sick child or to clean up after children who were incontinent. For doing this work, each woman received free room and board and a monthly salary of about RS. 300 (\$8). Given that this job took up the 24-hour day, seven days each week, the salary and benefits they received did not really compensate for their labor. Why was it then, that these women still continued to do this work under circumstances that demanded that they leave their homes and families and commit their lives to the care-giving of children who were not even their own, in return for minimal wages that could barely allow them economic survival?

In addition to the sheer invisibility of their work, the historical "naturalization" of women's roles as care-givers renders the voluntarism associated with this work as a precondition for being a "good" woman and which required that these women transform the actual mechanics of performing such labor into a moralistic abstraction by viewing it as "labor of love." However, for most these women this transformation was not possible. It is for this reason that Sister Benedict, in the manner of the householder castigating the disinterested housewife, complains:

But again, I'm up against a wall because I don't know how to do that [motivate them]. ...If a motivation can be put in there...and help them to see that they are service givers, helpers to somebody who requires aid.... There will be less fighting. And they wouldn't care two hoots because they would feel they were needed.

However, it is not the lack of motivation that prevents these women from taking up their "noble" position as benefactors, but the oppressive social, economic, and political structures that constantly displace the mythical romanticism of the familial ideologies. Many of these women who served as dormitory workers and untrained teachers came from contexts where both patriarchy and capitalism colluded to deny them access to education and other resources that, in turn, prevented their access to other work alternatives. Often for many of them, DOST served as an institution that offered a safe haven from the brutal world they lived in. In this context, they embraced the discourse of the "ethic of service" to obscure their dependence on the organization while at the same time struggling to live up to its ideals.

Take the example of Marika, a 28-year-old teacher who had been abandoned at birth by her parents and had been brought up in an orphanage that was run by Catholic nuns. She was able to finish high school. However, in a society where young women move from the protection of the parental home to the auspices of the husband's household, Marika found that, as a poor single woman without any means of livelihood and without any familial

affiliations to form a support network, she needed to construct such a network for herself. In her search for both financial and social support, Marika found out about DOST. Even though she knew little about teaching children with disabilities, Marika was eager to take up this job because it seemed to provide for her a place of solace from the misery in her own life.

Three years after she joined DOST, Sister Benedict provided a dowry and other wedding funds for her marriage and it appeared that Marika had actually done well as per her social circumstances. However, even though she did not share this with me in the interview, it was common knowledge that her husband sometimes physically abused her. One day she had come to school with a bloodied forehead, where her husband had beaten her with a brick. This indicated that her troubles were not over, and it was here then that her own work with children with disabilities managed to give her life a new meaning. As she explains:

I did not come to do this work because of my sufferings alone. I feel it is my calling. That is what I felt when I first saw these children. I did not come to do this work because of the work conditions.... My salary is very low.... [But] I feel that God is showing me a way here. For the rest of us, there is a lot we can achieve. But these children cannot. In order to help these children become like us, become normal - to show them the way, I want to teach.

By articulating an "ethic of service" directed towards the children with disabilities in her classroom, Marika is able to distance herself from the suffering in her own life. Far removed from the misery in her home, DOST has become a place where she does indeed find solace, where she can visibly see the accomplishments of her most challenging students as a result of her efforts, and where she receives reinforcement for doing work that has a high moral value in a society that otherwise does not value her at all.

In another example, Palani, one of the dormitory workers in a similar situation as Marika, learned that marriage was the only other avenue to pursue in order to get away from the oppressive conditions of her life. However, Palani is astute enough to realize that marriage cannot provide an appropriate solution to her life's problems. Palani explains:

I want to reach a certain position before I settle down. Married life is not very easy. At present, most men seem to...feel that we should be under their control. If we reach a certain position in our life and then get married, then the adjustment process would be so much different. And there would be a lot more understanding. But if we were a little low and he is in a higher position, then it is slightly different. That is why I want to get a good position and

then think in terms of marriage.

Given the vulnerable circumstances of her own location, in both the social and the economic sphere, Palani is aware of the inevitability of patriarchal control over her life unless she is able to achieve social and economic independence for herself. Therefore, she realizes that it is important to find work that will give her both social status and economic stability so that she can resist the constraints that patriarchal structures place on her life. However, like many of her co-workers, Palani's lack of education handicaps her and restricts her options of finding respectable waged work outside her family home.

For women from her social class background, one possibility was working as a servant in an upper middle class household. This dead-end option would offer her little beyond the bare minimum in terms of economic survival while placing her in a very vulnerable social position. So, instead, Palani enrolled in a short six-month course sponsored by the government on child care. Upon completion of the course, she was employed as a teacher for a balwadi (rural day care/kindergarten) in a small rural town. However, once again patriarchal restrictions intervened.

Palani, being a young single woman living alone in a strange town, and thereby outside the domain of patriarchal protection particularly in relation to her sexuality, was not allowed to work there for very long. Instead, her family persuaded her to return home and suggested that she take up the residential position of dormitory worker at DOST. Like many parents, hers have entrusted Sister Benedict as Chief Administrative Officer at DOST with the responsibility to monitor these women not only in their work related activities, but also in their private lives.

This was such a common practice that even Sharada, a 40-year old dormitory worker and a parent of a child with a disability, describes the level of institutional control that intruded into her private life:

N: What do you do after the children go to bed?

S: After they go to sleep, we are a little free. Then we sit outside and talk. We just have time pass. Sit outside and if you like anyone, then you talk to that person.

N: Do you go out sometime?

S: No. No. No outside going!!! If we have to go out anywhere we have to get permission before leaving. Only if we have any shopping to do near by, we go and ask [Sister Benedict]. Otherwise we cannot go anywhere. It's like when we are at home, whatever our age, we have to tell our mother and father where we are going. If they say you cannot go anywhere, you will not go. Similarly we have to do the same thing here. We have to tell them. We are mothers to these children and

still we have to do this.

Intrusive as this control may be, its justification, as Sharada herself reflects, is based on the patriarchal ideology that upholds the control of women's sexuality within the familial context, a control that is seldom applied to men.

What was consistently reiterated in the different stories of these dormitory workers is the fact that if not for the material conditions of poverty that surrounded their lives, they would not have chosen to work at DOST. Despite the long working hours, the low wages, the devaluation of their labor, and the patriarchal control exerted over all aspects of their lives, most of these women had little choice but to continue to remain at DOST. Moreover, given the long work hours and the real impossibility of saving any money, there were hardly any opportunities for these workers to acquire skills in more lucrative professions in mainstream society. Thus, these women had little choice but to wait their time out at DOST. The women were, therefore, caught in their own webs of destitution and super-exploitation that exclude them from participating as "productive" workers within mainstream society in a manner very similar to the children with disabilities whom they serve.

Yet at the same time, the situations of these women stand in sharp contrast to the situations of the children with disabilities served at DOST. Many of the children with disabilities, even though they came from very poor families, had access to relatively comfortable living arrangements, round-the-clock availability of medical attention, three basic meals a day, creative educational experiences, physical, occupational, and speech therapy and individualized personal care. Neither their non-disabled family members nor the non-professional staff at DOST had access to these amenities and services because of the conditions of poverty in which they lived. Thus, in a curious way due to their disability, these children enjoyed certain material advantages over their siblings, their parents, their peer groups, and particularly in this context, their caregivers who shared a similar social and economic background. What benefactors and beneficiaries shared a common was their socio-political-economic alienation from mainstream society.

Conclusion: Organizing a World of Imbalance

If, as geographers argue, place is representative of the hierarchical social relations located within specific spatial structures, then it is crucial to examine what role "place" plays in the construction of social difference at DOST. More specifically, using geographical historical materialism, I conclude this paper by examining how the spatial location of DOST related the social divisions of labor (spatial hierarchies) and what discursive implications these locations had for all those associated with the voluntary organization.

DOST being located within the moral economy required that its social division of labor assigned to its service providers/clients the two distinct and hierarchical categories of benefactor/beneficiary. However, the ethnographic data analyzed in this case study indicated that the spatial distances between benefactor/beneficiary and disabled/non-disabled were, in fact, non-existent and/or imaginary. In other words, the data suggested that in a manner similar to the children with disabilities, this group of women, though physically and mentally able, were economically, socially, and politically disabled and as a result of such destitution were collectively rendered unproductive in a struggling economy.

The ethnographic data suggests that this class of people who are generally associated with these organizations (either as clients or as service providers) have personal histories that have constructed them as extremely marginal subjects. The lack of education, restricted access to economic resources, and institutionalized exclusionary practices of racism, sexism, and casteism, render them only marginally useful to the capitalist enterprise since the market has very little use for their labor power. It is here then that institutions organized around the ideological category of disability become the most benign tools that are utilized as effective means of separating the "favorables" from the "unfavorables."

Under the rhetoric of welfare, and in this particular case, "rehabilitation," it appears to be the most useful way of constructing a division of labor that is broader than the divisions that have historically been described in sociological theory. Such institutions can now become the newest forms of institutionalizing difference under the guise of social welfare. In this context of social welfare, disability becomes the organizing and grounding principle in the spatial organization of difference along the axes of race, class, gender, caste, and sexuality to produce subjects who are bound to live separately from those who are considered productive in the mainstream society.

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Enabling Geographies? Non-Governmental
Organizations and the Empowerment of
People Living with HIV and AIDS

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Some people accept me, but some people still don't. Sometimes people abhor (chang) me. And [sometimes] they display an attitude of discrimination (Ton, a PLWHA living in Chiang Mai Province, Thailand, cited in Del Casino 2000: 256).

Disability is a form of social difference whose marginality is confirmed both by the oppression which disabled people experience and by its invisibility within the concerns of social sciences, including human geography (Gleeson 1997: 199).

Introduction

While early investigations of HIV and AIDS by geographers

focused on the spatial distribution and diffusion of these phenomena from a spatial science perspective (e.g., Gould 1993; Lam and Lui 1994; Pyle and Gross 1997; Shannon and Pyle 1989), in recent years geographers have become more concerned with the socio-spatial configurations of HIV and AIDS (Brown 1995, 1997; Craddock 2000). In particular, geographers have examined the day-to-day experiences of people living with HIV and AIDS (PLWHA) in relation to social activism, health care needs, and social welfare services (e.g., Brown 1995; Chiotti and Joseph 1995; Del Casino 2001; Takahashi 1998). The interest in the socio-spatial dimensions of living with HIV and AIDS also coincides with the growing interest in the geographies of disability (e.g., Gleeson 1999). In some cases, these two areas of study have been interrogated in concert (Takahashi 1998; Dear et al. 1997). As a result, geographers have examined how disabilities, such as AIDS, are not only physically disabling, but socially disabling as well.

Constructed through discourses of difference, disabilities such as AIDS are mediated through their relation to local and global socio-cultural and political economic processes (e.g., capitalism, biomedicine, patriarchy, etc.). In addition, the socio-spatial constructions of disability are mediated through organizations (e.g., hospitals, schools, churches, families, activist organizations, etc.) (Del Casino 2000), whose spatialities and constructions of disability also differ in relation to broader socio-cultural and political-economic processes (Foucault 1973). In some cases, organizations reify disabilities by forging social and spatial boundaries between disabled peoples and their 'others.' On the other hand, some organizations actively work to challenge the ways in which disabled people are marginalized in society. PLWHA, like other disabled people, must negotiate a myriad of organizations from the time when they first learn they are HIV positive to the moment before their death when more often than not they are bedridden. Therefore, understanding the ways in which disabilities are constructed and negotiated through organizations is an important question not only for geographers, but also for other social scientists working in the area of disability studies.

In this essay, I focus on one organizational form, non-governmental organizations (NGOs) and their work with PLWHA in the Upper North of Thailand. In so doing, I want to explore the ways in which NGOs work with, and for, PLWHA to challenge the disabling effects of HIV and AIDS that are often manifest in a variety of organizations (e.g., the public health care system, the community, and the family). In the following section, I offer a brief theorization of organizations in order to provide a starting point from which we can examine organizations (see Del Casino et al. 2000 for a detailed discussion of methodological frameworks for the study of organizations in geography). Second,

I provide context for the study of non-governmental activities in relation to the growing AIDS crisis in Thailand. Finally, I offer a brief explication of the theoretical elements through one ethnographic example from fieldwork conducted in Chiang Mai, Thailand, during which time I collected in-depth data on one key NGO, AIDS Organization, and its work in several rural districts.

Organizations as Objects of Analysis

What do we mean when we deploy the term 'organization'? First, organizations are fields of inquiry which are messy, unbounded, networks of socio-spatial relations. As such, they are not simply empirical objects fixed in space by the bricks and mortar that constitute their walls (Klausner 1993). Instead, organizations are constructed through the discursive practices of social actors who choose to define the boundaries of one organization in relation to another: they are constructed out of their engagements with others, be that a target population or other organizations (Natter and Jones 1997). A non-governmental organization in Thailand, for example, claims its identity as 'non-governmental' because it is believed that the organization is not embedded in a State-centered development agenda which works on the side of the urban-based industrial sector and against community-centered approaches that empower PLWHA, and others, to organize their own outreach (Costa 2001; Del Casino 2000).

Second, since the boundaries of an organization are fluid, the day-to-day practices of organizational actors cannot be examined outside the layers of context and flows of socio-spatial relations that mediate their work (Appadurai 1990).

Organizational actors are subject to the same discourses of gender and class or to the flows of capital to which other actors are related. At the same time, the fluidity of boundaries exposes tears that exist in the socio-spatial configurations of power, allowing social actors to play those tears to their benefit. What this suggests is that the process of constructing spaces as spaces of power is never complete. This is not to say that those in power do not have the ability to close down or shut off access to the tears - through the process of temporarily fixing organizational boundaries through the deployment of hegemony (Natter and Jones 1997) - but that tears can be exploited. Boundaries between organizations are blurred and often ambiguous. Thus, for many PLWHA it is often difficult, and perhaps unimportant, to distinguish between *ongkaan rat* (government organizations) and *ongkaan ekachon* (private organizations).

Third, organizational relations are antagonistic, signaling the failure of organizations to secure 'difference' (Laclau and Mouffe 1985). Since the strategies of creating social identities through organizational politics can only ever be a partial process, social categories remain contested and open. This is true because, as Laclau and Mouffe (1985: 125) argue, "...the

presence of the 'Other' prevents me from being totally myself. The relation [between organizations and individuals] arises not from full totalities, but from the impossibility of their constitution." It is argued here, therefore, that through antagonistic socio-spatial relations, tears appear through which resistances to dominant discursive practices are coalesced. One could say that antagonistic social relations metaphorically 'rip open' the sutures that are designed to fix and assign meanings to particular organizational spaces and the actors that travel through those spaces. Antagonisms existing at the boundaries of organizations afford social actors the opportunity to expose tears (i.e., opening up moments of access to needed services) and push the margins of organizational structures.

Finally, the extent, and size, of the tears in organizational boundaries varies from organization to organization and in relation to the practices of organizational actors. As government officials in Thailand, public health care workers must negotiate not only authoritative practices that are constructed through biomedical discourses (Foucault 1973) but government policies as well (Del Casino 2000, Chapter Four). In some cases, public health care workers invoke discourses of authority in order to regulate the health care of client populations (e.g., in order to control the movement of AIDS-related funds in the locale). In similar ways, Thai local administrative officials, who are the link between communities and government resources, may be more interested in maintaining patrimonial hierarchies between themselves and their constituencies than in opening up the locale's decision-making mechanisms to community groups (Hirsch 1990). Thus, when new structures of health care outreach, such as support groups for PLWHA, are suggested and implemented by PLWHA, NGOs, and concerned public health care workers, the extent to which those organizations are able to create new networks of socio-spatial relations for PLWHA depends on local relations of power and authority.

Organizational Politics and the Geographies of AIDS

The spread of HIV and subsequent increase in the number of AIDS cases globally has brought to the fore the need to address both prevention and care issues. In most cases, governments are unable, or unwilling, to provide adequate prevention outreach or health care services for PLWHA. As a result, non-governmental organizations (NGOs) have grown in importance as a key part of the service economy for PLWHA in many contexts. In Thailand, where there are an estimated one million HIV positive people, NGOs provide a number of critical preventative, health care, and social services for PLWHA, their families, as well as the broader communities in which PLWHA live. This is most clear in the Upper North of the country (Fig. 1) where it is estimated that one third of total HIV cases currently reside and a substantial amount of

AIDS-related funding has been targeted by both the international community and the Thai government (Del Casino 2000, Chapters Three and Four).

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Since the early 1990s, the number of NGOs working on AIDS-related issues in the Upper North has also grown. By the late 1990s, there were over fifty organizations operating in the region. AIDS Organization, which began its work in the early 1990s, has grown along with the amount of available funding in the region for AIDS-related activities. When it was founded there were only three full-time staff. By 1999, the total staff had grown to sixteen full- and part-time workers. AIDS Organization's main charges have been to provide PLWHA with opportunities to gain access to needed social and health care services - including alternatives to biomedical treatments for HIV disease and AIDS-related illnesses - and to assist PLWHA in organizing their own support groups. In the case of the latter, the goal of organizing PLWHA support groups coincides with AIDS Organization's broader goal to provide rural poor with opportunities to participate in the decision-making structures of local government organizations, including health stations, community hospitals, and or bor tor (tambon (sub-district) administrative organizations). AIDS Organization's goals also coincide with the broader goals of AIDS-related NGO movement in Thailand, which is to challenge the negative constructions of PLWHA as 'disabled' (for further discussion of the social construction of PLWHA and HIV/AIDS in Thailand see Del Casino 2000, Chapter Three; and Lyttleton 2000). AIDS Organization thus works to enable PLWHA to take charge of their own health care regimen and to open up opportunities for them to participate in the socio-spatial organization of Thai society as active citizens, not simply as passive recipients of health care and social welfare benefits (Reeler 1996).

AIDS Organization, like many other organizations in the Upper North of Thailand, also works through a framework of PLWHA empowerment to increase the social and spatial mobility of PLWHA. One of the mechanisms that AIDS Organization has used to that end has been the PLWHA support group. PLWHA supports groups in the Upper North, of which there are now more than 200, have been initiated by PLWHA themselves, by NGOs, and by the public health sector as a means through which to increase PLWHA access to needed services (psycho-social and medical). In all cases, they are considered their own entities, termed in Thai ongkaan chumchon (community based organization). The extent to which PLWHA are empowered to facilitate their own outreach efforts, however, depends on the interests of other organizations that work with, and through, support groups. In some cases, public health care administrators have tried to maintain strong control of PLWHA support group activities.

As Hirsch (1990: 162) has argued government officials sometimes help organize ongkaan chumchon in order to gain "access to the village population" and to extend "the pyramidal hierarchy [of power and authority] down to the village level." In so doing, public health care officials may be more interested in expanding their own base of power than in providing PLWHA with access to decision-making structures of the public health care sector (i.e., health care officials do not always support transparency). In other cases, PLWHA have organized themselves without outside assistance and thus have more autonomy over their group's agendas and daily practices. NGOs, which often operate through a discourse of local autonomy, see support groups as vehicles through which community members are empowered to participate in the historically closed spaces of public administrative life. Ironically, being a PLWHA, which can be socially and physically disabling, can also provide a point from which individuals who have historically sat outside local power structures may now participate in the political decision-making mechanisms of the State.

PLWHA support groups are also potential vehicles through which PLWHA can participate in their own health care regimens, thereby enhancing their own economic and social well being. Since PLWHA support groups sit at both the margin and center of governmental and non-governmental organizational outreach, they are also subject to the flows of various discursive practices emanating from a number of sites. As such, PLWHA have an opportunity to engage what it means to be a 'person living with HIV and AIDS.' As social actors involved in their own outreach (i.e., consumers) and not passive recipients (i.e., patients), PLWHA who are organized have the opportunity to transform the social and spatial boundaries that exist between the disabled and the enabled. They also have the opportunity to blur the metaphorical and material lines that exist between the 'healthy' and the 'ill.'

The process of enabling PLWHA and challenging rigid discourses of disability, however, is never complete. In the next section, I discuss the ways in which AIDS Organization's outreach impacts the ability of PLWHA to have access to and participate in the construction of needed services. I do this through an examination of one PLWHA's role as a member of her local PLWHA support group, a group initiated with the help of AIDS Organization in 1997.

Enabling Geographies

I first met Aun, a PLWHA living in Chiang Mai, in 1997. She was, and continues to be, the president of her local support group. As a member of the PLWHA support group, Aun has learned to not only negotiate the complex organizational structures of health care and social welfare in Chiang Mai province, she has also become an activist in her community. She speaks with local

youth and participates in round table discussions with NGO representatives, health officials, and other PLWHA on the care of PLWHA in her tambon (sub-district). In the case of the former, Aun explains her role:

I go to advise [youth] not to be associated with this issue [HIV/AIDS]... I tell them 'you should not pai thiaw' (go out partying)... I tell them how I can not work hard.... I will have to leave my child with my younger sibling [after I die]. Sometimes my child would like sweets and she asks me to buy them for her, but I don't have the money for such things... I have to find money. My ability to make a living continues to decrease.

Aun provides information on living with HIV and AIDS to people in her tambon. Through her educational outreach and advocacy she illustrates that PLWHA are not 'helpless victims,' but are productive members of society who have information and experiences to share with other in the community. Her work as an HIV/AIDS educator also addresses other segments of the tambon population - such as parents and teachers.

In the beginning there was a problem of discrimination at the local nursery school... There was a training session on HIV/AIDS for the teachers. Really it wasn't the teachers that discriminated, but the parents of the other children were afraid that their children would contract [HIV] from my child. But now there isn't a problem.

Through the training, teachers have been able to more effectively educate youth and parents about basic HIV epidemiology, in the process reducing fear and stigma against PLWHA and their children. Aun has also participated in AIDS awareness projects that used elementary-aged children as educators. In one case, the PLWHA group, along with the tambon administrative council, the health station, and mor muang (village healers), held an AIDS day rally in conjunction with students from one of the local schools. The march raised over 8,000 baht (about US \$230) for AIDS-related activities in the tambon.

Aside from her roles as Committee representative and community educator, Aun also has a formal position as a volunteer for a different NGO (Community Action), one that provides her with a small stipend to conduct outreach and collect data on the AIDS situation in her tambon. Aun's job is to visit other PLWHA as well as the guardians of AIDS orphans on a monthly basis and provide them with both moral support and information on outreach programs available to them.

There are several facets to her outreach. Her visits offer people an opportunity to improve their kamlangjai (spirit)

through friendship (one literally "gives" (hai) kamlangjai) and thus improve their overall health. The social aspect of the visit, which is accomplished through the sharing of stories (and laughter) and showing others that someone else understands the situation, is a critical part of the outreach program. It is also a chance to broaden the informal membership of the community of PLWHA and those impacted by HIV and AIDS. Through her outreach, Aun tells others about their rights as patients or guardians to basic government services, such as access to social welfare and health care programs; and she discusses other issues, such as the NGO funding that may be available to families in need.

As a PLWHA volunteer in her community and as the president of her tambon PLWHA group, Aun extends the boundaries of health care by making connections between herself, the more fixed spaces of health care (i.e., sites in the public health care system), other PLWHA, and those impacted by HIV and AIDS. She acts as an intermediary between individuals and organizations and her visits provide an opportunity to make connections with other people. She can also chart the progress of AIDS-related programs in the tambon. She literally shares her experiences of engaging her community and the public health care and social welfare sectors thereby illustrating to other PLWHA how to negotiate the various organizational structures designed to assist PLWHA. Moreover, various organizations call on Aun to provide information on the status of PLWHA in her tambon.¹

There is a gap, however, between some of the information she collects and actions based on that information. In one case, Aun visited an older woman (70+ years old) who cares for her ten-year old granddaughter and has no income or experience participating in the mechanisms of the public health care infrastructure. The older woman knew nothing about funds that could provide some support for her grandchild's education, and Aun did not present the older woman's problems at any meetings. Aun did tell the grandmother about the funds available for her grandchild's education at the health station, but she did not alert the health stations about the woman's problems. Rather, she left the choice of accessing the funds to the woman. Aun thus may not always know how to use the data she has collected from other PLWHA to alter the patterns of health care or social welfare in her own tambon. Or, the issue may be one of local power dynamics. Because of the power relationships between state and NGO representatives and most PLWHA, Aun might not feel that she has the authority to speak directly to health station officials regarding other PLWHA.

In Baan Nan in particular, the health station is often seen by PLWHA as adversarial (see Del Casino 2000, Chapter Six for a further explanation). Perhaps this is because the health station worker is more motivated to accumulate social and political capital so that he appears as the authority on health-related issues in the tambon than he is to work with PLWHA (see Hirsch 1990 for a further discussion of local tambon politics). In Baan

Nan, PLWHA thus find it more beneficial to engage health station personnel through the PLWHA support group, rather than on a one-on-one basis (see Del Casino 2000, Chapter Six; and Del Casino 2001).

On the other hand, the knowledge and experience Aun gains through her participation in the activities of NGOs, PLWHA support groups, and government-sponsored programs does work to her and her family's benefit. She does not simply consider health and health care as her own problem, but she is very much concerned with the health of her child. She has strong aspirations for her daughter and hopes that she will do well in school - "Studying to a high level" - and get a good job. For this to happen, however, Aun must find a way to save money toward her daughter's education. Because her daughter comes first, Aun is motivated to work a variety of part-time jobs (i.e., paid agricultural work and part-time work cutting herbs for the local mor muang group). Aun is also motivated to utilize the spaces of health care and social welfare when they are beneficial to herself and her family. The PLWHA support group, and their activities, can provide new opportunities for PLWHA such as Aun.

Conclusions

Aun's position as a PLWHA activist (perhaps a word she would not use herself) in her community is possible, in part, because of the existence of competing and overlapping governmental and non-governmental organizational geographies, which have opened up opportunities for Aun to challenge the boundaries of AIDS as a disabling illness. In her case, NGOs, in conjunction with PLWHA efforts, have partially exposed tears in the boundaries of other organizations (e.g., schools, communities, public health departments) and in the culture of fear and social violence that often limits the ability of disabled peoples to participate in the socio-spatial mechanisms of power in their own communities. This is not to say that in all cases PLWHA have been able to gain access to the decision-making powers of the State, or that PLWHA have been successful in eliminating discrimination. Rather, it is to suggest that we cannot think of any organization as fixed in discourse or practice, but instead must understand organizations as containing both emancipatory potential as well as the potential to enforce social and political mechanisms of authority.

Notes

1. It is difficult to say what happened with the money. It was placed in the tambon account for AIDS-related activities. There was a problem, however, with the distribution of the funds to PLWHA (see Del Casino 2000, Chapter Six for more details).

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Multiple Sclerosis in its Context:

Individual Narratives

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The meaning of a disease depends greatly on the context in which it is embedded. For multiple sclerosis (MS), significance of its context becomes critical because it is a chronic and unpredictable disease and the consequences of its disability manifest very differently in a variety of contexts. In some individuals one disability's consequence may be dominant, but in others several disabilities' consequences could occur together. In fact, it can be argued that MS is a cluster of interrelated disabilities. For example an individual may simultaneously present impairment of motor control, shaking of limbs, shaking of eyeballs, partial loss of eyesight, and even certain cognitive disorders and each one could lead to a disability. Thus the same "disease" behaves very differently in different contexts.

This situation is quite unlike the relative uniformity of symptoms of many other diseases, especially acute infectious diseases. Disabilities of MS arise partly from the endogenous effects of the disease, but also from the societal externalities in the context of which the person with MS lives. The significance of society's role in how it "goes on disabling people with impairment" is increasingly being realized (E-mail from Ann McCutcheon, February 15, 2001).

Here, we examine the narratives of two individuals with MS to illustrate how the meaning of their geographic activity space is dependent upon their context, including their MS condition and their broader social setting. Activity space here refers to sites frequently visited by the individual for work, shopping, health, recreation, and social relationships. The narratives of persons with the same disease show a remarkably different meaning of their activity space because of their different contexts.

This paper first examines some interdisciplinary literature related to context and disability. It then briefly describes the method of this study. Third, using selected narratives, we describe the context of two case studies of individuals with MS followed by a short discussion.

Context and Disability

The prevailing disability paradigm emphasizes context in which individuals fulfill their daily roles rather than the

clinical aspects of disability itself (Haley et al. 1994). Interactions of persons within the context is a major tenet of the disablement framework. The ICDH-2, the International Classification of Functioning and Disability (WHO 1999) which is undergoing revisions, conceives functioning and disability as a dynamic interaction between health conditions and contextual factors which include both personal and environmental factors. In the same vein the National Institute of Disability and Rehabilitation Research (NIDRR) Long Range Plan (1999) also encourages researchers to explore new ways of studying disability in context taking into account the physical, policy, social environments and the dynamic nature of disability over the lifespan and across environments.

Although the ICDH-2 distinguishes between the terms context and environment, in earlier literature the terms have been used interchangeably. In this paper we adopt the WHO definitions (WHO 1999:21-22) that define contextual factors as the complete background of individual's life and living and include environmental and personal factors. Environmental factors are external to the individual and include physical, social and attitudinal dimensions such as home and work environments, formal and informal social structures, services, and laws of the society. Personal factors refer to individual characteristics such as age, gender, race and education.

Geography, rehabilitation and environmental psychology, though separate disciplines, share common goals of understanding the impact of disability and its management. Within geography the importance of studying disease, health and place in the context of the environment - social, cultural, behavioral, economic - has been long recognized (Kearns 1993; Mayer and Meade 1994). Renewed emphasis on the significance of context in human and medical geography has resulted from the impact of postmodernism, social theory and feminist perspectives. Kearns (1993) talks about a socio-ecological model of health that involves an interactive set of relationships between a population and their social, cultural, and physical environment. Dyck (1992; 1995a; 1995b) and Moss (1997) provide examples of contextualized understanding of disability.

Informed by the occupational therapy perspective, Dyck (1992b) examines the case of a Chinese immigrant woman with rheumatoid arthritis to show how the individual's current environment, interwoven with her cultural beliefs and values, shapes the daily management of her illness. In her later work on unemployed women with MS Dyck (1995) focuses on how home and neighborhood spaces are renegotiated with a disability. Using Giddens' structuration theory she describes how routine activities, carried out in spatial-temporal settings, reveal ways in which the "society and the individual recursively constitute each other" (1995:3). Likewise, Moss (1997), in her case studies of elderly women with rheumatoid arthritis, shows how older women

with chronic illness negotiate their home environments, both physically and socially. In mapping these micro geographies both Dyck and Moss position their work in the context of gender, age, race, culture, and disability to understand everyday lives and health experiences.

Rehabilitation professionals are now recognizing the critical importance of context for clinical assessment and outcomes research. Haley et al. (1994) depict the importance of context in assessment of physical disablement using the example of the performance of self care and mobility tasks by children with severe functional delays in home and school settings. Dunn (1994) provides a useful Ecology of Human Performance framework for considering the effect of context. This framework provides a structure of context as a key variable for assessment and intervention planning based on the interaction of the person and environment interdependent relationship.

More recently, environmental psychologists (Clitheroe et al. 1998) focus on the behavior of individuals in responses to 'prompts.' They are concerned with ways in which physical and social features of the environment influence people's transactions with their everyday surroundings. Their model is useful in conceptualizing disability and disease in this study as a prompt or trigger that interacts with a host of contextual factors which in turn determines the spatial outcomes (Figure 1). The narratives in this paper illustrate the context and the spatial outcomes as perceived and interpreted by the individuals.

CONTEXTUAL FACTORS

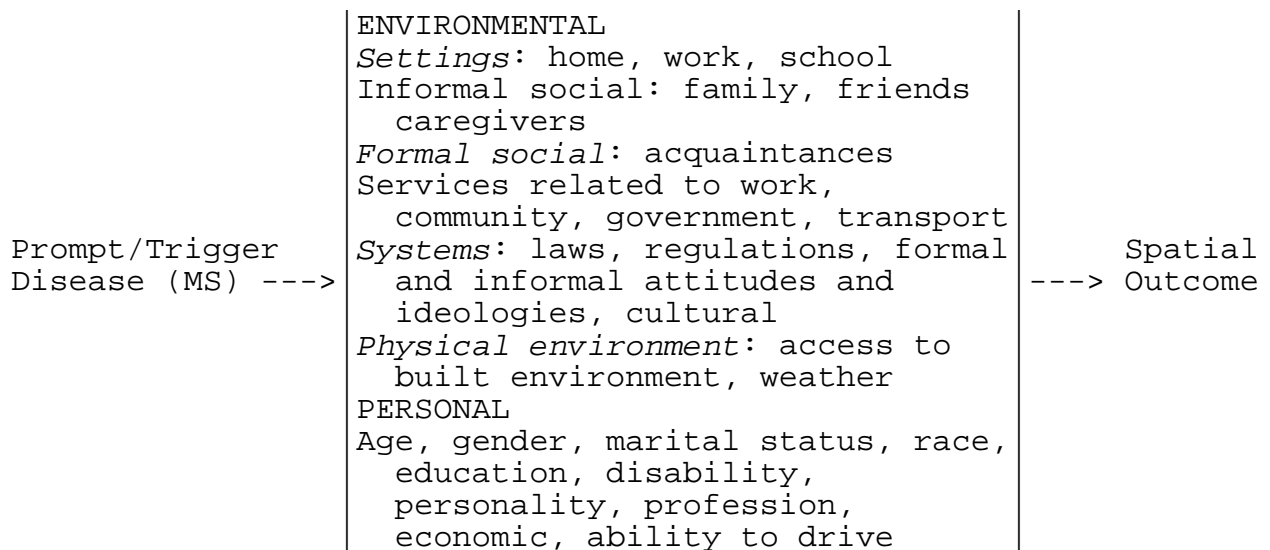


Figure 1

Methods

This paper is part of a larger study on the activity space of persons with MS in Akron and Canton-Massillon metropolitan areas of Northeast Ohio, a high risk MS area (Thapar 1999). The two main cases reported in this paper are selected from a stratified random sample of 53 in-depth interviews that focused on issues on spatial negotiation, the nature of activity spaces and the impact of MS on activity spaces. With the consent of the participants the interviews were audio taped and transcribed verbatim. The interviews were carried out from November 1997 through March 1998. This long time period was primarily due to the fact that interviews had to be scheduled at the convenience of each participant. Most interviews lasted for well over two hours and some had to be rescheduled. Due to the amount of time required, and the specific needs of the participants for medication, diet, rest and comfort, interviews were generally carried out in the home environment including the two cases in this paper. The first two authors conducted several interviews together, including the ones reported in this article.

The following two selected case studies illustrate with narratives the context and varied spatial outcomes for two individuals living with MS. These selected narratives illustrate the significance of context in which a disease strikes. The spatial outcomes can not be attributed to disease alone, but to the entire context of a person which is a combination of a host of factors such as the social and economic conditions, support systems, age, gender, education, marital status and many more. Progression of the disease in both cases resulted in negative health outcomes and diminution of the activity space.

Case 1

Mr. C is a 55 year old, white, married, self-employed farmer. He was diagnosed with chronic progressive MS, the more severe type of MS, when he was 45. His disability level is now high¹ requiring 3 hours of daily personal care and making it necessary for him to use a battery-powered wheelchair for mobility. Earlier, Mr. C had led an active life as owner of a service station for 20 years, and later as a farmer, until he was struck with MS. Mr. C was a volunteer basketball coach and counselor at youth camps for 10 years. The progressive chronic nature of MS had a drastic impact on his life. He could not play his favorite sport of basketball nor could he effectively play a youth leadership role in coaching girls basketball as a volunteer.

I coached girls' basketball for ten years. You see the trophies up there. These things were taken away.

A recent incident triggered his decision to retire from farming where he was unable to help a cow as he helplessly watched the mother deliver her still-born calf.

I spot the cow, she's laying down having the calf.... And everybody else is gone and I see this cow is stretched out like she is dead or she has a problem. So this is what the MS that I have, I can live with it. I couldn't live with that. She [his wife] has a phone for me here. The phone wasn't here.... The phone book wasn't here (voice breaks). That particular day I have nothing. I can't get to the cow, I can't do nothing to the cow. I can't call for help. That's life or death. For me that's life coming down on the earth... I cried. I said, 'Dear Lord, I can't help her.' But there was me with MS on that particular day. Because I had MS I couldn't help that calf live and that hurts, that hurt bad.

Deeply hurt by this incident, he is now transferring his farm to a young man who has been working in his employ. Although his wife drives him everywhere, and thus he has not reduced his activity space significantly related to shopping and leisure, Mr. C's major concern is with the perceived loss of his role through the loss of related activity, whether as girls basketball coach or as the male head of household. Since that activity helped define his role, the loss was substantial. Even in this loss, however, there is a sense of discovering the previously undervalued significance of his wife, his primary caregiver.

We got a van. She [his wife] put a hoist in it. My wife drives. That is sad. 19 years old, when I graduated from high school, I bought a service station.... For 20 years I was there. I worked on cars.... Now I can't drive a car. ...The first couple of years I drove it, but I can't drive now. She won't let me drive it and I do agree with her that it is dangerous for me to drive. I don't have the reflexes. I can't get my foot on the right pedal. It's not safe for me to drive.

My wife is the greatest. I have often wondered that if she had MS, would I be good to her as she is to me. I couldn't have reached the heavens and pulled a better lady. And, I am a good husband, but I could not be that good.

He is unable to visit friends as their homes are inaccessible, but instead they visit him. Thus his activity space has been transformed, but his social relationships have endured.

Friends don't have ramps for me to get up. They come here, and there's somebody here all the time.

Blows to pride can be as important as physical ability to access a facility in the shrinkage of activity space. Mr. C hesitates to participate in community activities because of a

fall in a restaurant.

I was in a restaurant with my cane and I fell flat on my face. The friend of mine come over to help me, asked if everything was alright. I said, 'Everything but my pride.' That was the last time that I was in a restaurant for a long time.

He participates in activities that he can perform in restricted space with limited abilities without embarrassment. He sometimes watches his grandchildren and helps a little with vacuuming, but does not do any other household chores. Outside of home he mentioned only three locations that he visited in the last year - a restaurant, ball game and the neurologist.

With the Americans with Disabilities Act (ADA) he has also considered changing his employment, but feels left out from its impact.

Disability act is everybody's fair for a job, but that has not included me. When the government did that, it cannot be a bad thing. I have not taken advantage of it. I have taken a seminar at Kent State University to find out what I am best suited for, but they don't know what I am suited for.

Though he does not dwell on the financial impact of MS but he mentions that he applied for Social Security and did not get it. He therefore had to sell some of his land. Being self employed he also has to buy his own medical coverage.

Although his activity space in geometric terms is small, intensity of spatial relationships at his home has greatly increased due to strong support from his wife, family, and friends. This is reflected in the way he shows his compassion, expresses gratefulness, and the degree of equanimity with which he copes with his progressively deteriorating physical condition. Underneath it all, the roles he has lost and the psychological impact of MS on restricting his activity space is evident. We wonder whether the role of space should be stressed as an active agent or as a mediator.

Case 2

Mr. P is a 38 year old, Native American who was diagnosed with remitting exacerbating (RE) MS at the age of 33. He has 11th grade education and 2 years of technical college, but would like to get some computer training to make a living. Currently unemployed, he is separated from his wife and 3 children. Having a moderate level of disability,² he uses a cane for walking and sometimes a wheelchair. Climbing stairs is hard for him, and his general mobility has been severely curtailed because he can no longer drive. He lives alone in a rented apartment on the first floor. He depends on one friend and sometimes his sister for

caregiving and mobility. He has Medicaid and Supplemental Social Security Disability (SSDI) Income. Unlike Mr C, he feels deserted by his wife. Unhappy by the plans his father and stepmother were making "to put me in a home because I needed skilled nursing [care]," he elicited his sister's help. She moved him from Tennessee to Ohio resulting, however, in a restricted activity space and limited social relationships. He maintains that due to MS disabilities he lost his job and his wife separated from him. Since he is only 38 years old, however, he is determined one day to go back to work, and maintains a positive attitude.

I wasn't going to stay put down in a wheelchair in a hospital for too long. The nurses thought I was most stubborn. I might fall, I might drag my legs, hold on with one arm, throw the other arm up on it and kind of push my body with it. I was bound and determined to get my legs going back in order, didn't want none of their help, for letting me try and do it.

At home he does his own cooking, cleaning and laundry. His sister helped him when he was in a wheelchair. He also helps his friend at the garage and babysitting. His friend in turn watches over his well-being.

I help out a friend. My friend tinkers with cars. I can't work on them myself but I help him figure out what's going on, and stuff like that, gives me something to do. I try to go over everyday.

If he doesn't see me everyday, he's over here beating on the door wondering what's happened. Few times I had him come over and pick me up, put me in wheelchair, and wheel me down the road. ...We treat each other like brothers. When he and his wife take off, I sit there with his two kids, I don't get to see my kids too often so I enjoy somebody else's kids, their dog.

Thus, Mr. P has developed a symbiotic relationship with his friend and this friend's family. Mr. P longs to reclaim some roles and relationships he has lost because he is separated from his wife and lives away from his children. The loss of relationships was not wholly his choice. It seemed partly to have been imposed upon him by the disease and partly by the actions of his close relatives. Thus there is some support for the view that society plays an active role in disabling individuals with impairments.

He does not like being away from home (Tennessee) and misses his children and social contacts.

I wished I could have stayed in Tennessee. If it wouldn't have been for my dad and my adopted mother going to put me

in a home.

He has also encountered health insurance problems in Ohio.

Out of my pension I pay for part of my medication, all of a sudden Medicaid doesn't pay for them no more. They are starting to not pay for some prescriptions but they pay for other stuff. And I got so many allergic reactions, that the other stuff that they want you on, I can't take. And they don't look at none of that. They just look at what they wanna pay for what they don't wanna pay for. This state [Ohio] they are messing people on health care pretty good.

Also due to the unpredictably of MS he fears losing his independence.

That's one of the worst things. Being scared, wondering, like the doctor says, you don't know, when something's gonna... when your system goes bad, if its going to stay like that or if its gonna to go away. I've always done everything for myself and when I can't do for myself it bothers me a lot. I hope I don't get to the point where I'm in a bad shape. Even in a wheelchair, if my legs go, stay that way, I can suffice with that. If I can get stuff to, so that I can do my own cooking, and be able to do my own dishes, get in an out on my own, and getting one of those ... stick things, where I can get up into cupboard, where I can get something like a cup on my own, instead of asking for somebody or wait until somebody comes around and say, hey could you do this for me. I hate that.

MS has certainly restricted Mr. P's activity space, but his move to Ohio from Tennessee probably contributed to it as well, since he had to start developing a new social network. Whereas Mr. P's MS condition did contribute to his move, it was precipitated by his father's plans to place him in a nursing home. Thus context made a major impact on the outcome.

Although, there is a ramp to enter his apartment, there is little space inside for the wheelchair. Narrow doors hinder access to the bathroom and all other spaces while lack of grab bars prevents him from using many spaces efficiently. Outside the home he mainly visits the convenience store nearby and a few other stores. Twice a month he visits a doctor and counselor depending on a ride. He sees a neurologist 4-6 times a year and is undergoing chemotherapy. His banking can be done from home and a postal worker helps him with mailing needs. He daily visits his friend who lives nearby. He wishes to participate in recreation, support group meetings and outdoor activities but is dependent on other people for rides. The weather too restricts his activities.

The most I get out is when I go to the doctor, or when I go to the grocery store in a couple of weeks. I don't get out. I got stuck once here in the pharmacy. I made a mistake. I thought I could walk it. Trying to make it back, my legs just gave up. I had to sit there for a while. So I don't attempt to go too far.

He is considering other employment. As already stated, he has 11th grade education and 2 years of technical college, but would like to get some computer training to make a living.

There is one man in Alliance. He's got MS and he don't use his hands or legs whatsoever. And he's not on social security now. He makes a living from his home doing something on computers. His is completely voice controlled. I don't know exactly what. I figured if you can set me up with something like that, if he can do it, I can do it. Since then I haven't had anybody that would get me up to Canton right now. I can't set an appointment till I know I've got somebody that will take me. That makes it hard right now.

This narrative points out not only to the debilitation due to MS, but the contextual factors related to race, economic and emotional deprivation, and educational handicap that together result in a much reduced activity space. Mr. P.'s activity space is restricted to health related needs and a few nearby social activities. But it is not access to specific places that Mr. P. is really talking about. His concern is with the kind of future he is going to have. The critical factors leading to his restricted activity space are limited family support, inadequate finances and debilitation due to progression of MS. He also strongly implies that various societal components such as the intricacies of the Social Security system, lack of adequate local transportation system, and the actions of some of his own family members are together keeping him in a state of disability due to his MS impairments.

Discussion

Disease and disability are experienced by individuals in their highly personalized contexts. The spatial outcomes are determined by the interaction of MS with the individual's contextual factors - personal, family support, social, psychological, economic and environmental. The two narratives describe the unique context for each individual. In each of the two cases these form different combinations resulting in different social-spatial outcomes.

These two cases also show how contextual examination provides a greater understanding and can help target interventions at the critical factors. Because of the

unpredictability of MS, individual context becomes all the more critical. The two cases describe the unique context for each individual's life. The activity space has shrunk in both cases, but not entirely due to MS. The meaning of that reduced activity space, however, is very different.

In the first case all the important relationships, especially of the immediate family and friends, have converged upon Mr. C's home. In the second case, Mr. P lives in a socially, spatially and spiritually fragmented world, trying to rebuild his life. In both cases there has been a loss of key personal roles. But in the second case the loss of several key roles and relationships is compounded by a sense of spatial and spiritual displacement. Mr. P. first 'lost' his home and family, and is now lost in the new place (Ohio). He has, however, attempted to replace some lost relationships and roles through symbiotic interaction with the family of his only friend.

With family support, pension, and farmland to fall back upon, and without the need to worry for future employment, Mr. C. is able to maintain a relatively cheerful personal disposition even with mobility constraints due to MS. Manifestation of MS in the context of a caring family, and a successful earlier life experience of Mr. C., seemed to make the giving and receiving of care an acceptable experience. His physically reduced activity space was compensated to a great extent by family and friends willing to drive for him and to visit him in his home. His home became the center of his social activity space, though inability to participate in some activities (that could not be carried out at home) did weigh on his mind.

On the other hand, having been uprooted from his original home in Tennessee, having lost the very outdoor lifestyle of a Native American, and unable to access new technology for a possible job opportunity, Mr. P.'s life reflects uncertainty, even despair. The fact that he is only 38 years old is important in his context because potentially he has decades of productive life ahead of him.

In both cases there were references to distance as a barrier, but the meaning and significance of geographic space was expressed primarily in terms of the ability or inability to participate in social activities and social relations. Weather, mainly the impact of heat and humidity, is one aspect of the environment repeatedly mentioned by several persons with MS we interviewed. The personal outcomes of the MS patients are, however, determined by myriad of interaction with their contextual factors - personality, family support, social, psychological, economic, cultural and environmental. These two cases also suggest that contextual examination can provide greater understanding of the meaning of disease and activity space.

The two cases form different combinations of contextual factors resulting in different social-spatial outcomes. The

changing nature of context and disability is well displayed by the case of Mr. C. He has made accommodations at his own level and through supportive care of his family. Successful careers and active community involvement through volunteering provided Mr. C with positive past experiences of a fulfilling activity space. At his age, he is not looking to a career for self-fulfillment.

Mr. P's quality of life, on the contrary, could have been much different if he had not been torn away from his family and from his preferred lifestyle in Tennessee. His activity space physically shrank, but more importantly became, for some time, deprived of fulfilling social and economic relationships, until he began to develop new strategies for social networks. These cases lead us to conclude that one cannot expect similar activity space outcome for different individuals simply because of the same disease such as Multiple Sclerosis because the meaning of the 'same' disease is very different from one context to the other.

Conclusions

Our study highlights the significance of context in the activity space of two individuals with multiple sclerosis. Each individual's activities relate to a myriad of contextual factors. The personal factor of age, for example, makes learning new skills unimportant for one, but critical for the other. Family support makes a major difference in how the two persons experience their life: a nurturing, caring world for one; and a fragmented world for the other. In one case the house itself has become the nexus of many social activities. The other person has to seek substitutions for lost roles in a willing friend's household. In one case the home provides a secure psychological environment, in the other the very sense of home has been lost. In one, successful earlier career, and financial security can provide a secure retirement. In the other economic uncertainty looms large. The same disease has a widely different meaning in the lives of two individuals living in the same physical environment of Northeastern Ohio.

The significance that each case attaches to geographic space seems not to be as evident, however, as geographers might expect from their disciplinary perspective. Instead, what appeared more prominent was the meaning and significance they attached to activities and relationships with space as a taken for granted entity. The two cases that we examined illustrate major differences in outcome. The meaning of activity space as revealed by the two case studies seems not to be found in distances covered or space traversed due to limitations imposed by MS, but by participation in meaningful activities in space. For both persons activity space was not defined primarily by spatial parameters, but rather by the richness of the social-spatial content and its meaning in terms of human interaction. The meaning of physical space was most important at the immediate

micro level in terms of negotiating barriers in one's house or apartment.

Notes

1. The level of disability was determined by using the Environmental Status Scale (ESS) by Fog and Mellerup (IFMSS 1985) that provides an assessment based on seven items of work, financial status, home, personal assistance, transportation, community services and social activities. The scale emphasizes performance rather than ability and highly correlates with disease severity.

2. See note 1.

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Language barriers: Exploring the
Worlds of the d/Deaf¹

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I am always sorry when any language is lost, because languages are the pedigree of nations. (Samuel Johnson, as quoted in Boswell 1785)

Despite d/Deaf studies' ability to demonstrate how a 'different [sensory] experience of the world can forge a completely different approach to life, which is expressed through a separate and unique language and culture' (Corker 1994: 150), there has been a notable absence of research with d/Deaf people amongst the growing literature on geographies of (dis)ability.

The significance and value of Deaf culture to the Deaf community is made clear by Paddy Ladd, a UK Deaf consciousness promoter (quoted in Campbell and Oliver 1996: 120), when he explains:

Basically deaf people whose first language is BSL [British Sign Language] should be seen as a linguistic minority. It helps if you think of us as parallel to, say, an Asian community. Deaf people have been joyfully getting together since time began, and our schools go back to the 1790s and our clubs to the 1820s. Our language is much older. Deaf people marry each other 90 per cent of the time, 10 per cent have deaf children. Our customs and traditions have been passed down the ages and these, together with our values and beliefs, constitute our culture.

As Ladd makes clear sign language is at the core of Deaf culture. In the UK approximately 70,000 d/Deaf people consider BSL to be their preferred, first language (Baxter 1999). It is the only one through which they feel able to express themselves and attain fluent, two way communication. It is not simply a mimed form of English (Baxter 1999). Rather, it is a language in its own right, with its own symbols and structures. However, as this paper illustrates, the lack of recognition of it as such can mean social, political and economic marginalisation for those who depend upon it.

The research reported here is part of an ongoing project funded by the United Kingdom's Economic and Social Research Council (ESRC) Youth, Citizenship and Social Change programme. Its aims are, firstly, to shed light on some of the processes that result in the social, economic and political marginalisation and exclusion of young people from various minority social groups including the d/Deaf. Secondly, it explores the choices and risks these youths take in order to overcome such processes. The research is being conducted in two UK cities; one predominantly white and working class, the other more cosmopolitan.

Biographical interviews with d/Deaf youths and retrospective

interviews with older d/Deaf people are still being conducted. The material reported here from interviews with a wide range of professionals who work with d/Deaf youths, are not intended to speak for their clients, but rather should be taken at face value. They are reflections of rarely heard, professionals' concerns about the exclusionary policies and broader social processes that they and the youths they work with currently have to face. The professionals are drawn from a range of occupations in both the public and private sectors, covering the fields of education, social work, housing, health and crime.

The paper falls into three main sections. Firstly, the different political philosophies on the integration of d/Deaf people and their relationships with the use of sign language are outlined. The importance of communication systems that allow everyone to interact with ease is stressed. In this context the paper then moves on to consider the nature and implications of inadequate sign language related service provisions. This second section falls into three parts considering the lack of interpreters: the conflicting roles of social workers for the d/Deaf; the implications for home and family life; and the divisions which exist in the Deaf community due to differing political stances. Finally, the paper concludes by asserting the importance of increased d/Deaf awareness and sign language tuition for hearing and d/Deaf people alike.

Sign language and policies of integration

Approaches to the education of d/Deaf people have generally fallen into two broad categories, those of oralism (lip reading and spoken English) and manualism (sign language). From the late 19th century to as recently as the 1970s oralism dominated schooling policies and practices in the Western world (Baynton 1997, Gregory et al. 1995). In the US in 1918, for example, 80% of d/Deaf people were taught without the use of sign language (Baynton 1997).

Policies of oralism fall in to line with right wing thinking on integration (Corker 1994, Northway 1997). In accordance with the medical model of disability the 'different' and 'inferior' are expected to fit into what is considered a 'superior,' hearing, speaking world (Oliver 1990, Barnes 1991). Speech and/or lip reading is seen as preferable to signing as it is the norm, part of a more socially acceptable, able-bodied, pattern of behaviour to which all should aspire (Butler and Bowlby 1997). Assisting students to speak and communicate orally is seen as aiding their participation in society and hence to be of benefit to them.

In contrast, however, advocates of the social model of disability have stressed the importance of the broad economic structures of society in creating disability (Oliver 1990, Barnes 1991, Butler and Bowlby 1997). Such writings have raised awareness that right wing, normalisation philosophies place

little if any emphasis on society's need to adapt to the d/Deaf individual's needs or the value of Deaf culture, including sign language.

More left wing ideologies talk of human rights and equal opportunities (Corker 1994). Deaf culture, including its languages,² should be respected like those of any ethnic group. An individual's preferred language and methods of coping with daily tasks should be respected and work harmoniously alongside other alternative strategies. The recognition of the cultural value of sign language in this way has been reflected by the return of manualism to teaching policies in the last thirty years (Baynton 1997).

An increased ability to communicate offers much potential. However, with the lack of recognition from the British Government of BSL as a language (Disability Now 2000a, 2001) and the limited use of the language outside the Deaf community, the right to choose to sign does not necessarily result in integration, but can rather in many instances lead to segregation. As one university's Disability Support Officer put it:

I'd say yes segregation fundamentally is wrong, however if the kids that you've got involved in the education are using a different language to everybody else in the school then any kind of integration is going to be segregated anyway if that makes sense.

For any form of communication to be effective it must operate efficiently for both the informant and the recipient. If a speaker or signer has a limited vocabulary, or if someone cannot understand, or even access, the fluent signs or words they express, the interaction of the two has little value. Information must be available in a range of forms that all can comprehend regardless of sensory impairment, a 'total information environment' (Hurst 1996: 135). In relation to education of d/Deaf youths Corker (1994: 150) argues:

The location of the environment is immaterial compared with the language environment, the breadth of knowledge of teaching staff and the peer group, and the fluency of communication.

Her sentiments could be applied to any space a d/Deaf individual may enter. It makes clear the need for understanding of Deaf culture including its language by the hearing population with whom the d/Deaf are expected to integrate. Total education policies of bilingualism (oralism and manualism) are now seen as the way forward by many professionals, not just for d/Deaf children, but their peers as well (Gregory et al 1995).

With an international market place in mind, much emphasis has been placed on the teaching of foreign languages to children

from an early age. The potential value of teaching sign language, in a similar manner, was explained by one Communication Support Worker who said:

I remember the example of [a mainstream school] where they have a total communication unit there - I mean there's little totlets, 5, 6, 7 years, running round signing. [...] I saw kids in the playground signing at each other - you couldn't tell which was deaf, which was hearing, because they'd learnt to sign with the other kids.

This type of situation is, however, still rare. It is more common for sign language speakers to be in a segregated minority in their places of education, work and leisure.

The lack of general awareness about d/Deaf issues, and in particular the lack of sign language users in every day public spaces create the biggest barriers to d/Deaf youths integration into society. Restricted numbers of professionals who can sign limits their ability to communicate with and develop improved understandings of the Deaf community. It also has serious implications for the assistance youths receive from public and private sector, service providers.

A lack of interpreters

The professionals interviewed reported a lack of qualified interpreters for formal settings such as training workshops or business appointments. Where interpreters are required they usually have to be booked at least two weeks in advance, and often are cancelled at the last moment if the interpreter is called to an emergency. There can be particular problems where advanced levels of sign are required to deal with technical or legal language. As one university's Disability Support Officer explained:

Interpreters are rare and interpreters who can interpret for mechanical engineering and computing and graphic design and business studies. I mean that isn't me being flippant, those are the areas that we've got d/Deaf students in at the moment and one interpreter came to me and said 'look I can't do this mechanical engineering any more, it's going right over my head, I really don't understand it, you need to get someone in who's got mechanical engineering experience and is an interpreter' - well there just isn't [such] a beast you know.

The limited numbers of signers and the cost of them, as well as the undesirability of having to have a third party with you at all times, creates further problems in more informal, social settings. For example, however successful their early schooling, many young people drop out of college or university because while

they have signing support from interpreters in lectures they are socially isolated. Few fellow students sign and communicate easily with them in social contexts. One city's Director of Deaf Education Services explained that many individuals will consider moving or travelling large distances to specialist colleges to avoid such situations. This can lead to self-perpetuation of segregation of the d/Deaf from their hearing peers.

Even for students in specialist colleges, there are inevitably times when interpreters are needed to assist them. Often this can be a role filled by a social worker. Apart from the general stigmatism that can be attached to having a social worker there are further problems relating specifically to social workers for the d/Deaf.

The conflicting roles of social workers for the d/Deaf

As Paratt (1995) found, social workers for the d/Deaf often have to be jack-of-all-trades. This means their work is sometimes seen as low status within the profession. The lack of social workers who can sign adequately means it is hard to fill job vacancies. The working class city that this research was conducted in is currently without a social worker for the d/Deaf for this very reason. What is more, where once the Local Authorities used to pay for and provide time out for BSL courses, staff now have to fund their own language training (Paratt 1995). All of this can mean a high turn over of personnel, at times reducing the consistency of service provided.

Another finding of this research supported by Paratt's (1995) study is that other local authority providers (e.g. housing or health departments) often refuse to pay for interpreters (to save budgets) and try to make the social workers for the d/Deaf interpret for the young people. The social workers are caught in a trap: they do not want to act in this role as this is not their job and blurs the boundaries of their responsibilities, but if they do not the young people have no voice and cannot follow the proceedings of meetings.

A further factor is that, where a social worker does stay in post, they often follow d/Deaf young people from birth to adulthood. This is positive in that they can develop relationships, continuity and confidence with them. But it can have negative consequences because the social workers have to fulfill roles as both agents of control (e.g. child protection) and support (e.g. transition planning). Inevitably sometimes these roles clash (Paratt 1995). For hearing young people these twin roles would actually be provided by different social workers. As one member of a County Deaf Team put it.

Once we start getting involved we usually are the only consistent thing in a deaf person's life and they have to come back to us to make sure they get the rest of everything else they can. And it shouldn't be that way, they shouldn't

have to rely on Social Services because they're deaf - you know, it's nothing else, and the rest of society don't have to rely on Social Services to get what they need - from - but deaf people do. And it's really, really difficult to try and break that cycle, to make sure that the agencies out there are doing what they should be doing for deaf people, like they do for everybody else, so that deaf people don't consistently have to keep coming back to us and saying: 'What about this, what about that?'

The need for people other than their social worker to interpret for the d/Deaf youths at times is clear. This is true not least in the home.

Home and the family

Social workers for the d/Deaf argue that educating hearing parents about Deaf culture and in particular teaching them to sign is one of the most effective ways of providing support and countering marginalisation for young d/Deaf people.

... A lot of parents in the past didn't learn to sign with their children, therefore they couldn't communicate with their children - but the schools could. So they'd go home and they'd no communication, so they had behaviour problems and they [the parents] couldn't understand why. And they didn't realise that this child has a personality, he has a nature, he can show you it, but he needs to be able to sign to you for you to understand him. (Communication Support Officer)

Members of ethnic minorities whose families first spoken language is not English can have further problems due to the lack of interpreters who can either translate for such families or indeed teach them to sign themselves. In general, service provisions for d/Deaf members of ethnic minorities have been found to be lacking, resulting in relatively low take up rates of services in these communities (Taylor 1999).

Asian deaf youths often have no way of developing a sense of Asian identity. Unable to communicate with their parents they can find it difficult to attend the Mosque and understand religious teachings or other cultural events. As a result professionals believe they often have no sense of their 'Asian' identity and a negative understanding of their d/Deaf identity.

One Learning Support Co-ordinator explained the difficulties she had faced in attempting to run a signing course for Asian Mothers of d/Deaf youths.

... At least half of them didn't have any English at all and the other half just had a smatter of English. I had no Urdu, Punjabi, and no knowledge of Asian cultures whatsoever....

She went on to explain how the cultural intolerance of eye contact or physical contact between such a group of women meant that she had to reconsider her usual teaching methods.

The sense of isolation and frustration in the home for d/Deaf youths with hearing parents who do not sign can be extreme (Gregory et al. 1995). The realisation, often during the late teens that they are d/Deaf and that this is not 'normal' can be difficult to deal with. This process of self-recognition, coming out, has been noted of disabled people more broadly (Shakespeare et al. 1996). Often in mainstream schools with no or few other d/Deaf youths they have no knowledge or ready access to, what may be expected to be, the supportive space of the Deaf community and its culture. However, even for d/Deaf young people with d/Deaf parents the Deaf community is not always the supportive group of people that it may be perceived or expected to be.

Divisions in the 'Deaf community'

Wooley (1994) describes finding a welcoming and supportive Deaf community upon experiencing hearing loss, but many of the professionals we spoke with raised concerns about what they saw as the marked political divisions in the d/Deaf population as a whole (see also Weale 1999). One explained that:

[T]here are some people who have been so rejected by the Deaf community that they subconsciously are rejecting sign language so much so that they say they can't learn it which does seem a bit crazy to me because when I learnt sign language as a result of losing my hearing it was like going home, it was like oh God, thank God for that you know now I'm home, now I'm comfortable. People are different I know but I think the stresses that there are around are such that - the impression that exists is such that you can completely reject your own culture and the people that are in it because of the way you're viewed. (University's Disability Support Officer)

In line with the social model of disability, this comment draws attention to the impact negative social constructions of d/Deafness can have upon d/Deaf people. The lack of d/Deaf awareness in society and the images of inferiority, weakness and incapability that are linked to the majority of disabled people (Oliver 1990, Barnes 1991), mean that d/Deaf youths have to make certain choices about the methods they will use to cope with the marginalisation they experience. It is the various political beliefs related to these choices that create many of the divisions within the Deaf community and most notably between deaf and Deaf people.

Social pressures can either be complied with or fought against (Butler 1998). At one extreme deaf youths may internalise

social constructs, have low opinions of themselves as deaf, and attempt to 'pass' as 'normal.' They may have cochlea implants, choose oralist schooling and form relationships with hearing partners in line with the right wing normalisation philosophies outlined above.³

The more left wing extreme is to reject negative social constructs, take pride in a Deaf identity, Deaf culture and sign language, as Ladd's quote made clear. Drawing attention and understanding to their culture, including their language, is a key aim of many Deaf people and those who work with them. Making their voices heard, however, can be difficult, both politically and practically. The police and other service providers are not immune to a lack of d/Deaf awareness in Britain (Disability Now 2000b). When protesting their cases d/Deaf young people sometimes end up in trouble at school or with the police because vigorous signing or shouting in frustration is misunderstood as aggressive or threatening behaviour. As a member of a County Deaf Team explained:

Yeah, if a deaf person is actually finding communicating with another person very difficult, and say they raise their voice or they're shouting 'cos they're trying to make themselves understood, or - of course, that's misinterpreted.... [I]f the deaf young people are aggressive, or appear to be aggressive and then they're handcuffed, how are you gonna communicate, you know - it's a real problem.

The impact of the current lack of understanding of d/Deaf culture and sign language is again made clear.

Conclusion: The way forward

If d/Deaf people are ever to be fully integrated into British society rather than normalised or tolerated as a marginalised 'ethnic' group, there has to be increased understanding and awareness of Deaf culture and not least its language. Only then will d/Deaf people themselves be able to have a positive self-image and be free to choose the first language that suits them as individuals best without political pressures from the Deaf community or beyond

The Disability Discrimination Act (1995) has opened up new legislative routes to access to different spaces and provision of services within them. The media, including the magazine programmes, See Hear (BBC2) and VEE-TV (Channel 4), and the Independent Television Commission's promise of increased levels of subtitles and signing on programmes (Disability Now 1999) are, arguably, slowly raising public awareness, but there is still a long way to go.

For full integration to become a reality there needs to be an increased number of signers in all walks of life, not least

amongst social workers and other service providers. There needs to be a greater support and awareness training for families from all ethnic backgrounds. There needs to be total education policies in schools teaching BSL alongside other languages in the curriculum. Perhaps of most significance, however, there firstly needs to be recognition of BSL as a language by the British parliament. This is something that the Disability Rights Commission⁴ has recently called for in line with the Council of Europe's Charter for Regional or Minority Languages (Disability Now 2001).

This paper started by noting the sorrow caused by the loss of a language. It is time we considered how much greater the sorrow when a language widely used fails to be acknowledged as part of a nation's rich tapestry of cultures.

Notes

1. Throughout this paper the terms 'deaf' and 'Deaf' are used to distinguish between the two dominant constructions of deafness that influence deaf peoples' lives. The lower case is used to construe a category of disability, people with medically defined hearing impairments. The upper case is used more politically to construe membership of a linguistic minority who find themselves disabled by social structures and institutions (see Lane 1997). We note that many d/Deaf people do not consider themselves to be 'disabled.'

2. The plural 'languages' is used in acknowledgement of the differences between BSL and other forms, such as American Sign Language (ASL) and Australian Sign Language (AUSlan).

3. We acknowledge and respect that some deaf people believe a spoken language to be their preferred first language.

4. This is an advisory body to the Secretary of State in Britain set up as part of the Disability Discrimination Act 1995.

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Out of Place in Sheltered Housing?
 Insider and Outsider Perspectives

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Geographers have over the last two decades used spatial metaphors to illustrate the ways that social differences (based on gender, race, ethnicity, sexuality, age and class) are experienced and represented within and between spaces and places, and how they influence the spatial interactions of individuals. These social differences have been shown to impact on the way spaces are read and experienced as inclusionary or exclusionary.

Within disability studies the social model of disability has shifted attention from individual pathologies of disability to the social construction of disability and geographers have added a spatial dimension to this understanding. Recent literature (Chouinard 1997; Dyck, 1995, 1996; Gleeson, 1999; Imrie, 1996) demonstrates how disability is produced by, and in, different spaces and societies, reflecting the ways that the value judgements of a dominant group are assimilated and reproduced as society's norms and values.

This paper uses sheltered housing, a form of segregated, special needs housing, in Britain to illustrate the role of place in the socio-spatial construction of disability. A 1948 British government document attributed the name 'sheltered housing' to housing schemes designed for older people located in sites 'sheltered from the wind' (Ministry of Health's 1948 Housing Manual). Today the clustering of 30 to 50 flats or houses built around a communal lounge and supported by an on-site linked warden service are the hallmark features of sheltered housing designed to facilitate independent living for older people. These unique features of sheltered housing define it as a spatial phenomenon characterised by real boundaries delineating and distinguishing sheltered space from wider society.

Research Design

Drawing on the experiential data of people with disabilities¹ the paper explores the role of place (in relation to sheltered housing) in the negotiation of the identities of wheelchair users and their experiences of social inclusion and/or exclusion. Evidence is drawn from 50 semi-structured, in-depth interviews with wheelchair users, aged 18-64 years, living in different types of housing in the city of Dundee.

Dundee, is an old industrial city on the East Coast of Scotland that is currently redefining itself socially, culturally and economically in the new global economy. Dundee's city council has been forward thinking in its planning and provision of special needs housing and in particular sheltered housing. The city's excellent track record on sheltered housing (Public Health Alliance, 1993) has been achieved through the city council consistently meeting and exceeding national guidelines set for this type of housing (City of Dundee District Council, 1993). As the City Council and housing associations strive to provide suitable housing for Dundee's wheelchair users the city's surplus sheltered housing stock has been utilised to accommodate people

with disabilities under the age of 65. The current practice of randomly scattering wheelchair users in their early twenties through their fifties in sheltered housing schemes across Dundee is impacting on individual experiences of disability.

This paper is structured around the two heterogeneous groups that emerged from the analysis of the data: insiders, those living in sheltered housing, and outsiders, those living in housing integrated within mainstream housing. The creation of this dualism deconstructs the concept of people with disabilities as a singular entity and reconstructs them as two heterogeneous groups. This binary division is used to illustrate the spatial contingency of experience; that is, where people live influences how they view the world, how accessible the world is to them and how included they are in society.²

Findings

The experiences, perceptions and readings of the landscape of sheltered housing held by insiders and outsiders were mixed. Insiders experienced sheltered housing as both enabling and disabling. Their readings of the spaces of such housing were based on real experiences and the extent to which sheltered housing could and was meeting their housing needs. In contrast, outsiders perceived sheltered housing as characterized by social disabling barriers such as stigma, dependency and exclusion. Their perceptions were viewed through the lens of, and appeared to be prejudiced by, prevailing social and cultural discourses. Table 1 summarizes the enabling and disabling features of sheltered housing as perceived and experienced by insiders and outsiders. This paper elaborates on three of these features: warden alarm system, communal lounge and stigma.

Table 1: Enabling and Disabling Features of Sheltered Housing as Perceived and Experienced by Insiders and Outsiders

ENABLING FEATURES EXPERIENCED	DISABLING FEATURES EXPERIENCED
Physical proximity of warden Security Independence	Socially constructed space for older people Social exclusion Physical barriers
PERCEIVED/ANTICIPATED	PERCEIVED/ANTICIPATED
Communal lounge Social interaction Companionship Community	Segregation Stigma Surveillance Dependence

Insiders

A warden alarm system and a communal lounge are the two prominent features distinguishing sheltered housing from mainstream housing. Each feature is explored below and in so doing the concept of sheltered housing is problematised as being both an enabling and disabling environment for insiders.

On-site Warden Alarm System

All insiders were connected to their on-site warden through an alarm system that they could activate by pulling on one of the many ceiling to floor cords in the rooms of their home. They could also activate the alarm by a pendant worn around the neck. Insiders were reassured that should they need help, they had the technology to call their warden and that he/she was close by. The alarm was rarely used by insiders, but it was perceived as an asset, an 'insurance policy', enabling them to live independently.

Technology is essentially aspatial, it has the capacity to eliminate space and time. It was not, however, the spatial and temporal aspects of the warden alarm that were functional for insiders, but the physical proximity of their warden who responded to their call for help. Insiders knew that help was close by should they need it. The technology of the alarm was utilised as a device for summoning help, but it was the warden, offering place-based help, that was critical for engendering within insiders a sense of security and independence.

However, a caveat is called for here, for the provision of a warden alarm system appeared to be encouraging dependency on it to generate help in an emergency, and in the process, inadvertently discouraging people from interacting with their neighbours and developing positive neighbourly relations. This suggests that the combination of the warden and alarm could be threatening traditional neighbouring patterns of reliance on neighbours for help in times of need (see Cope, 1999).

Susan: Do you find that people are generally helpful around here and that you have people to rely on if need be?

Laura³: No. Nobody.

Susan: Does that concern you?

Laura: Well I've got the alarm.

It is difficult to deduce whether the limited neighbouring that insiders were experiencing is related to their warden alarm system or is simply a manifestation of modern neighbouring patterns. Any negative impact that may be attributed to the warden alarm system was, however, perceived by insiders to be outweighed by the accrued benefits the system conferred to them. Thus, whilst the alarm system was maybe encouraging dependency on

the technology (Cope, 1999), it was also encouraging and engendering a greater sense of freedom to live away from the parental home or a residential home. There may be an alternative explanation as to why there was limited social interaction occurring between insiders and their neighbours that is related to other unique features of sheltered housing: the communal lounge and the concentration of older people within an enclosed space.

Communal Lounge

The communal lounge was designed to act as a focal point within sheltered housing for neighbours to participate in mutual social activities. Work by Hudson, et al. (1996) and the Anchor Trust (1986, 1994) indicates that older people are benefiting from this facility whereas this study found people with disabilities felt unwelcome and excluded from participating in communal activities in sheltered housing.

Helen: No-one told me when I came here that this is a colony of elderly people, which means the grey hair, white hair people. There are only really two people that I can talk to here. So I visit Jill on Monday and I see Elaine now and again. This was a major mistake coming here. ... A year at the complex comprises of a fund raising bingo, a Christmas party, a concert which is old folks singing and I'm not very enthusiastic about.

The quotation above is indicative of insiders' explicit wish for their communal lounge to function as an inclusive space, that is a space that can accommodate differences between tenants. Helen intimates that some of the problems that people with disabilities are facing in sheltered housing stem from it being socially constructed as an exclusive space for older people. This is illustrated by insiders' experiences of an internal majority and homogeneous group (with regard to age), within sheltered housing schemes, feeling empowered to erect boundaries delineating the inclusion and exclusion of people to their social activities. Consequently people with disabilities were feeling 'out of place' in the social spaces that housing providers had deemed as suitable for them.

The social barriers outlined above were implicated in the continued marginalisation, disempowerment and exclusion insiders experienced in relation to their housing. These social barriers were found to be creating greater difficulties and were perceived to be more (dis)abling than the physical barriers they encountered in relation to the general design of sheltered housing schemes.⁴ However, insiders felt that housing practitioners, in the allocation process, defined housing needs as synonymous with physical and medical needs, in other words, with the 'bricks and mortar' of accessible housing. Many

suggested that the allocation process was inflexible and was unable to account for the physical and social housing needs of people with disabilities.

The use of the example of sheltered housing is illustrative of the importance of place in the process of social exclusion experienced by people with disabilities and the complex social relations associated with the constitution of both identities and spaces. The older people within schemes, coupled with the involvement of housing practitioners in the allocation process were influential factors impacting on insiders' sense of self, their experience of sheltered housing and disability.

Outsiders

The following section reverses the lens focused on sheltered housing and examines the landscape of such housing as viewed by outsiders, people with disabilities living in housing integrated within mainstream housing.

Stigma

'Places are avoided or viewed with apprehension where a stereotype of a despised group combines with and reinforces a negative stereotype of place' (Sibley, 1998:120). Outsiders viewed sheltered housing as stigmatising, providing for the needy and weak in society, and reinforcing negative images of people with disabilities. Whereas they perceived integrated housing to be equated with being a part of able-bodied life.

Kevin: I feel safer that way, [integrated into mainstream housing] because I don't like these rows of houses where you've got all disabled people. Coz it goes back to the stigma. I find it is very, very important for me to meet others, non-disabled people. ... I've got something in common with disabled people, but that's where it stops. I like to get away from it. ... Everyone deserves to be treated as an individual.

For Kevin, and other outsiders, place matters in the construction of his identity. He did not identify with other people with disabilities, and he thus anticipated feeling 'out of place' in sheltered housing. Furthermore, he believed that he could not be 'an individual' in such housing, as he predicted that outsiders and support staff would perceive him first and foremost as a disabled person rather than moving beyond that weighted imagery to see a 'normal' person who used a wheelchair.

Through exploring outsiders' perceptions and experiences of sheltered housing, it is apparent that sheltered housing, as a social space, is containing and reproducing an ableist discourse. Outsiders identified with, or aspired to identify with, culturally defined concepts of the normal body through living in

integrated housing. In so doing the benefits accrued to insiders from living in sheltered housing were overlooked by outsiders who perceived independence from the 'shackles' of a culturally defined disabled identity as impossible inside segregated housing schemes.

The spatial contingency of identity formation that is evident in the experiences of both outsiders and insiders reveals the power of place to produce and reproduce boundaries to the social exclusion and inclusion of different social groups. Imaginary and tangible boundaries, perceptions and experiences of places do not always and need not be consonant, but they influence how landscapes are read and interpreted and who is included or excluded, consciously or unconsciously, from our own living spaces.

Carol: ... for me sheltered housing has the stigma attached to it. "Oh we're no goin' near that scheme, that's got, its all disabled people."

Re-evaluating Sheltered Housing

The working practices of housing practitioners appear to be embedded within an ableist discourse that is grounded in the medical model of disability and embodies a fear of difference. Sheltered housing presently serves to maintain perceived social boundaries between the normal and the abnormal, 'between same and Other' (Wilton, 1998, see Sibley, 1995) by providing a space where people with disabilities are hidden, where they are outside the public gaze.

Sara: They provide you with all the adaptations you need, but keep you out of sight, always in the corner of schemes, always separate. I've always believed in integration not segregation.

Sheltered housing was perceived by outsiders to be (re)producing negative disabled imagery and as a social space was seen as being implicated in the stigmatising of a certain group of people and certain places. It is thus understandable that outsiders considered the spatial segregation of people with disabilities, through their housing, as inhibiting moves towards greater social inclusion for all within British society. By resisting sheltered housing as an enabling living environment outsiders were challenging the status quo and present policies and practices. Throughout the UK there 'is a sense that sheltered housing has become "fossilised" within an outmoded framework. This has spawned a host of reports that call for dramatic change in the design of schemes' (Fisk, 1999:35).

One salient feature to emerge from this study that could inform the future design of sheltered housing is that such

housing needs to build on the success of diminishing the physical distance between disabled housing and mainstream housing. Not all sheltered housing schemes are spatially segregated or physically different from mainstream housing. Rows of tenement flats in Dundee have been renovated and transformed inconspicuously into sheltered housing. The unique features of sheltered housing that are valued by insiders exist without the stigma perceived by outsiders. This form of housing could be crucial in meeting the holistic housing needs of people with disabilities in the future.

Beverley: This is just a normal street, you can't tell it's sheltered. But I have the cords, the warden's good, I mean if I'm really bad, he phones, "Are you needing anything, will I come along and make you a cup of tea?"

Conclusions

The experiences of people with disabilities living in sheltered housing and their perceptions of the concept of such housing are ambivalent. Insiders did not problematise the spatial separation of sheltered housing from mainstream housing nor its associated negative imagery. As Helen indicated, her experience of feeling socially isolated in sheltered housing taught her to prioritise the social and demographic characteristics of future neighbours. She felt that on becoming an insider the physical appearance and associated cultural perceptions of buildings were not as important as the social make-up of the people inside the buildings. Helen's philosophy illustrates an acceptance and tolerance of difference and, in addition, the underlying concept that sheltered housing is favoured by insiders, but not in its present form.

In contrast, outsiders could not conceive of themselves living in sheltered housing. The very mention of it conjured up ideas and images of stigma, dependency and surveillance. Outsiders identified with or sought to identify with the able-bodied majority and living in integrated housing helped them assimilate that assumed identity and feel 'normal.' Outsiders constructed imaginary boundaries between themselves and the spaces insiders occupied.

This study demonstrates that people and places, and perceptions of people and places, are critical in influencing the ways people negotiate their identities, the type of housing they want to live in and how socially included they feel. The experiences of insiders and outsiders illustrates the ways that social differences, and specifically disability, are produced both socially and spatially. Recognition by policy makers and society at large of the socio-spatial nature of disability could herald an important step on the road to questioning and changing present ableist values and future housing for people with disabilities.

Notes

1. All references to people with disabilities in the paper refer to people aged 18-64 years.

2. Despite working within a postmodernist framework that seeks to deconstruct binary divisions, the insider/outsider dualism is adhered to. Even when one works within a postmodernist framework dichotomies persist and can be useful as a means of reconstructing data into a comprehensible form. In this way the dualism has been utilised to highlight, rather than obscure, the fluidity and spatiality of the experiences of people with disabilities.

3. All the names of the interviewees are pseudonyms with the exception of Susan who was the interviewer and is the author of this paper.

4. Overall insiders encountered few problems with the design of their own home, but were faced with steps at the entrance to neighbours' homes and in some instances into their communal lounge.

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Using Participatory Action Research
Approaches in Geographical Studies
of Disability: Some Reflections

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Introducing current debates in disability research

In short, the challenge is to pursue a geography with disabled people which seeks the goals of material justice and political emancipation that are shared by contemporary movements. (Gleeson 1996: 395)

There have been several recent debates both within disability studies and geography about how disability issues should be researched and who should conduct such research. This debate has primarily centred on ideology and ethics, but has also focused on methodology per se.

The debate in disability studies has centred on the arguments of a group of mainly British sociologists, Barnes (1992), Oliver (1992, 1999), Stone and Priestley (1996), and Zarb (1992) (also see collections edited by Rioux and Bach 1994 and Barnes and Mercer 1997). These scholars argued that traditional research on disability issues is flawed and problematic in a number of respects. Most crucially, they suggested that disability research is not representative of disabled peoples' experiences and knowledges. This, they contended, was because a vast majority of research is conducted by non-disabled researchers. They argued that it is only disabled people who can know what it is like to be disabled and so only disabled people who can truly interpret and present data from other disabled people. Moreover, they noted that research concerning disability is invariably researcher-orientated based around the desires and agendas of the (non-disabled) researcher and able-bodied funding agencies rather than subject(s) of the research (disabled people).

Indeed, Oliver (1992) argued that traditional research methodologies represent a 'rape model of research' which is alienating and disempowers and disenfranchises disabled research participants by placing their knowledge into the hands of the

researcher to interpret and make recommendations on their behalf. Researchers are compounding the oppression of disabled respondents through exploitation for academic gain. Drawing on work within feminism in particular, they argued that power-relations within the research process needs to be destabilized and the research agenda wrestled free from academic researchers still using traditional research methodologies. As such, they called for the adoption of research strategies that are both emancipatory (seeking 'positive' societal change) and empowering (seeking 'positive' individual change through participation).

In geography, the debate between the Reg Golledge (1993, 1995, 1996) on the one hand and his opponents, Ruth Butler (1995), Brendan Gleeson (1996), Rob Imrie (1996) and Hester Parr (1997), focused on conceptions of disability, understandings of space, ideology and methodology. Essentially, Golledge argued for the development of a geography of and for disabled people conceptualising disability as a function of impairment and conducting studies of (subjects of research) and on behalf of disabled people (beneficiaries of research). Within his position geographic research was cast as an objective, scientific pursuit, where space was conceived as an absolute entity with a fixed Euclidean geometry.

His detractors questioned the basis of such a geography, and instead advocated the search for a geography with disabled people which conceptualised disability as a function of social construction. Within their position geographic research was cast as a situated, political and ethical endeavour and space was conceived of as a social production. In other words, the two proposed approaches to geographical studies of disability were in direct opposition to one another: politically-neutral versus politically-charged; medical model versus social model; space as mere backdrop to life versus space as an active shaper of people's lives.

The upshot of the debate within geography is that despite Golledge's continued resistance to emancipatory and political approaches there is a broad agreement amongst geographers studying disability of the utility and need for such approaches (see Dyck 2000; Chouinard 1997, 2000; Gleeson 2000; Kitchin 1999a; Wilton 2000). How to successfully implement such an approach though is still being explored. The interviews and the three empirical projects reported here sought to determine whether the ideas developed (but largely unimplemented) by Barnes, Oliver, Stone and Priestley, and Zarb, might be a fruitful approach to developing emancipatory and empowering geographies of disability.

Methodology

The initial research project consisted of two phases. In the first phase, disabled people's opinions on disability research were solicited through in-depth interviews with 35 disabled

people with a variety of physical, sensory and mental impairments. The majority (26) of them were working in the disability field for a variety of organisations. The remainder were either attending a training course or day centre at the Irish Wheelchair Association, Clontarf. Seventeen of the interviewees either lived in the Belfast Urban Area or within 15 miles of Belfast city centre and the other 18 either in Dublin or County Kildare.

Interviewees in Belfast were sampled using a snowballing method with initial contacts supplied by Disability Action. Interviewees in Dublin were arranged by the Irish Wheelchair Association and in County Kildare using a snowball sample. All the data were collected between March and November 1998 by the author. Interviews lasted from twenty five minutes to over three hours. Twenty four of the respondents were interviewed separately, either in their home or place of work, two were interviewed as a pair, and the remaining nine in two focus groups of six and three (these were the training centre and day centre attendees). Interviews were taped except in one case where notes were made by both interviewer and interviewee. Respondents were interviewed using an interview guide approach (see Kitchin and Tate 1999). The issues covered in the course of the interview included: whether respondents had taken part in research and their experiences; their general opinions concerning research; whether they thought research had served/was serving disabled people well; how research on disability should be conducted; who should conduct research on disability; and finally what they would like to be researched.

The second stage consisted of implementing two participatory action research (PAR) projects (one in Belfast, Northern Ireland, and one in Dublin, Ireland). This second phase has subsequently been followed by another on-going PAR project in Newbridge, Ireland. Simply stated, PAR aims to re-negotiate the position of 'the researched' to one of co-researchers involving participants in every stage of the research process from the design stage to the writing of the research results. As such, PAR is an attempt to address the problems of representiveness and unequal power arrangements between researcher and researched within social research. The philosophy behind PAR then is to try and facilitate a moral geography of social action through the facilitation of studies with and by research subjects. Here, the role of the academic becomes enabler or facilitator: the academic takes a supportive position and seeks to inform and impart knowledge and skills to the research subjects who co-direct the project.

Findings from the Interviews

The interviews revealed a number of interesting themes about how disabled people themselves view research concerned with disability issues (see Kitchin 2000 for a full account). The majority of interviewees were of the opinion that research

concerning disability issues is important and needed. This is not to say that interviewees accepted research non-critically. Some warned that research needs to be carefully selected, presented in a way that is unambiguous, has clear connections between theory and the lives of disabled people, and needs to be acted upon. In their opinion, most research seemed to be ineffective at changing social relations 'on the ground,' failing to transfer from academic realm to the 'real world.'

When asked whether they felt that disability research as practised was serving/had served disabled people well the interviewees were divided. Some felt that research had/was serving disabled people well and was helping to dismantle disabling barriers and others thought research was helping to reproduce particular problems.

Many of the problems noted by the British sociologists as detailed above were articulated. For example, some interviewees worried that much research was not representative of their views because it was conducted by people who did not know what it was like to be disabled. Their opinions were based not only on their perceptions of research, but also their experiences of taking part in studies. Many of these experiences were negative and some interviewees felt they had been exploited - their knowledge and experiences 'mined' by the researcher(s) who were then never heard of again and whose research had made no or little perceivable impact on their daily living.

All but three of the interviewees were of the opinion that disability research should involve disabled people beyond the subject source. Rather than research being conducted solely by disabled people, however, it was argued that the way forward was a collaboration of disabled people and (non-disabled) academics through consultation and partnerships. The role of non-disabled researchers was seen as important for a variety of reasons. For some interviewees, the disabled status of the researcher was simply not an issue as long as the researcher was approaching the research from a 'disabled-friendly' position. Others recognised that disability issues extend beyond disabled people to include carers, family members and service providers. To many of the interviewees in this study, alienating researchers who are non-disabled allies is counter-productive and does not aid the disability movement's cause. Some were concerned that the removal or discrediting of non-disabled researchers from disability studies would leave the fledgling field in the hands of a small number of disabled academics who are already seen as having their own agenda.

Interviewees suggested two potential approaches to combat some of the issues described above. The first was a consultant approach. Here, the academic would retain control of the research process and the questions being asked, but the participants get the opportunity to correct misinterpretations and influence the direction of the research. The second, more popular approach, was

a partnership approach where instead of merely advising the researchers disabled people were full partners in the project. In every case, respondents expressed enthusiasm at the prospect of PAR projects being undertaken in their local area, but when offered the opportunity to take part in this research without fail the interviewees (including strong advocates of inclusion) declined, bar three (these were the three most prominent and politically active interviewees who were keen to explore any avenue that would aid the cause of the disability movement).

The PAR Projects

Each of the PAR projects focused on a different aspect of disability. The first project investigated disabled people's access to family planning clinics, sex education and sexual health in Northern Ireland (see Anderson and Kitchin, in press, for full results). The chosen method of data generation was a short questionnaire that was mailed to all family planning clinics in the Province in August 1998.

The survey consisted of two sections. In the first section the clinic staff were asked to assess the overall accessibility of the clinic and conduct an access audit of their building. In the second section the clinic staff were asked about information access and specific services. The questionnaire was anonymous to encourage responses without fear of undue publicity. The aim was to assess the accessibility of the clinics, not to make scapegoats of particular clinics.

The second project investigated disabled children's access to schools in County Kildare, Ireland in light of the Irish Education Act 1998 (see Kitchin and Mulcahy 2000 for full results). The chosen method of data generation was a questionnaire survey that was mailed to all first level (age 5-11) and second level (age 12-18) schools in county. The survey comprised of six short sections: (1) school details, (2) a census of numbers of pupils, including those with different disabilities, (3) school policy, (4) access and provision, (5) plans for the future, (6) further comments. To complement the survey data, a random selection of 10 school principals, who indicated that they would be willing to discuss further issues raised in the survey, were interviewed. Interviews were conducted over the telephone and were recorded and transcribed in full.

The third project was an access mapping of Newbridge, County Kildare conducted with Newbridge Access Group. The project is divided into three parts. The first part was to map levels of access in the town (see Kitchin 1999b; Kitchin and Law 2001, see <http://www.may.ie/staff/rkitchin/newbridge.htm> for access maps). The second was a public exhibition of the maps and photographs developed from the first part displayed in several places. The third part is to produce an accompanying guide including a list of the most pressing problems and a guide to good practice. The project as a whole will be used to lobby the local council and

businesses in Newbridge to tackle existing problems and to adopt more disabled-friendly planning approaches in the future. One result so far has been that the Newbridge Access Group have spoken with a number of key people.

Experiences of using PAR

It is fair to say that none of the three projects ran smoothly. The two initial projects were hampered by four principal factors. The first was each project only consisted of a partnership between myself and one other person. As discussed earlier, whilst enthusiastic, the disabled people interviewed were very reluctant to commit themselves to a project. This was due to a number of factors such as the time involved, a lack of confidence, and, as explained below a lack of familiarity with myself. Both the individuals who did take part worked full-time: Paul at the Family Planning Association in Belfast; and Frank as a disability activist (secretary of both the European Union's Disability Forum, and Disabled People's International).¹

Second, both projects were initially set-up to be run with the assistance of Disability Action in Belfast and the Irish Wheelchair Association in Dublin. By the time funding had been secured, contacts in both establishments had left and both groups claimed to know nothing about the project.

Third, there were a set of personal factors that made setting-up the projects difficult. I moved to Northern Ireland as the initial funding bid was being formulated. Whilst I certainly made a lot of contacts through the interviews I conducted, I was previously unknown to all the interviewees. Therefore there was little basis upon which interviewees could decide whether to commit time to working on a joint project. PAR projects it seems are only really suitable in cases where all members are already well known to each other and who know they can work together. As it happens, both initial projects were highly personable and a working trust developed very quickly. Moreover, I moved to Dublin mid-way through the project running in Northern Ireland, making it difficult to sustain. On moving, I once again encountered the problem of forming a new network of contacts.

Fourth, the project funding was minimal and did not permit either project to hire any personal or professional assistance, although it did pay some transport costs.

The third PAR project was formed through existing contacts. However, the project has suffered from other problems. The Newbridge Access Group is undoubtedly very dedicated to access issues, but there have been a series of hiccups that have delayed the project. Significantly, the group meets only periodically, every one to two months and not all members attend these meetings. Indeed, the meetings have clashed with my own commitments forcing me to miss attending. This inevitably delays the project further. Moreover the project has not received any significant funding and the group is run on a voluntary basis.

The Irish Council for People with Disabilities paid for the base maps and for two days work by a cartographic assistant. As such, there is a labour shortage that is hampering progress. This said the project has so far been very rewarding to work on.

All three projects then slipped from being full PAR projects to a semi-PAR status. The disabled people were involved in setting-up the projects and did share the task of data collection, but analysis and writing-up has largely been left to myself. Almost inevitably, given my familiarity with various literatures and professional research experience, the projects have reflected and been shaped by my opinions. As a consequence, whilst the projects alluded towards equal partnership, they have to varying degrees been directed by myself.

Despite these difficulties, I would argue however, that a 'third-space' (Routledge 1996) between researcher and researched, academic and activist, was occupied and that the projects have had partially successful outcomes with articles in internationally refereed journals. The extent to which the research will change the 'practical' conditions of disabled people has yet to be assessed. At the least, it is hoped that the findings will influence health board officials in Northern Ireland, the Department of Education in Ireland, and the local councilors in Newbridge, and the policies they draw up and implement.

Conclusion

Whilst not denying that there has been, and will no doubt continue to be, high-quality, rigorous, scholarly, and critical studies of and for disabled people, the route of critical studies with disabled people needs to be more fully explored. It is clear from the analysis of the interview transcripts and my experiences of undertaking PAR projects that disabled people advocate the development and use of emancipatory and empowering research projects aimed at improving their lives in both practical and political ways. The paradox is, however, that despite the rhetoric most disabled people are unable or unwilling to actually contribute to full PAR projects.

It is my suggestion therefore that a different strategy be adopted, but one that still seeks to be emancipatory and empowering. This strategy would be one of consultation. Here, disabled people would help to formulate and monitor the research project, providing constructive criticism at all stages, but the actual processes of data generation, data analysis and writing-up be undertaken by a professional researcher. The academic then would largely retain control of the research process, but a panel of disabled people would get the opportunity to shape the research agenda and correct misinterpretations of the data.

Notes

1. Permission has been obtained to use people's real names.

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The Games for Everyone? Planning for
 Disability and Access at the Sydney
 2000 Paralympic & Olympic Games¹

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Introduction

This paper examines how the Sydney 2000 Paralympic and Olympic Games (the Games) planning processes sought to incorporate disability and access related issues. Firstly, background information and a rationale for paper will be presented. The paper will then examine the planning processes of the Sydney Organising Committee for the Olympic Games (SOCOG), the Sydney Paralympic Organising Committee (SPOC), the Olympic Coordination Authority (OCA) and the Olympic Roads and Traffic Authority (ORTA). This will be followed by an investigation of the issues associated with the Sydney 2000 Games from a disability perspective. These include the operational issues associated with the test event evaluation of access to venues, transport, accessibility of the urban domain, ticketing, and wider social impacts. Lastly, the paper will discuss the likelihood of any lasting legacies that the 2000 Games may have for Sydney's community of people with disabilities.

Background and Rationale

Disability and access are not issues just to be associated with the Paralympics. These issues should be central to the organizational culture of the Host City's Games planning generally. The Sydney 2000 Games includes not just the Olympics, but the Cultural Olympiad and the Paralympics aggregating into a three month festival from the beginning of August till the end of October. While the Olympics included demonstration events of wheelchair racing, some 4000 athletes with disabilities and 2000 officials participated in the Paralympics (SPOC 1999).

The majority of people with disabilities involvement with the Games occurred as spectators, workers and volunteers. Both the participants and visitors to Sydney want to visit other areas of Australia, given that Australia is a long haul tourism destination. The issues that faced Games organisers to be inclusive of people with disabilities were those same issues that face people with disabilities living in Sydney everyday. However, because of the nature of the Games and the concentration of Games activities in certain areas of Sydney, the everyday lives of people with disabilities living in these areas were disproportionately affected.

Games planners not only have a common sense responsibility to incorporate access and disability issues into the planning process, but it is a requirement of Australian human rights legislation. Under the Commonwealth Disability Discrimination Act, 1992 (DDA), and associated state anti-discrimination legislation, it is illegal in Australia to discriminate against a

person on the grounds of disability.

Accessibility of the Urban Domain

Sydney is a sprawling urban metropolis of some 4 million people (Australian Bureau of Statistics (ABS) 2000). There are a range of well documented physical, social and attitudinal barriers that people with disabilities face in Sydney (PDCNSW 1999). The Sydney 2000 Games occurred in some 14 separate precincts covering roughly 70km from East to West as well as soccer matches in four other inter state locations (SOCOG 2000a). The main Games precinct where most of the venues were built was at Homebush Bay.

Homebush is a suburb in the geographic and demographic centre of Sydney. The Sydney Games agenda included a massive urban renewal project for the Homebush Bay precinct that was the industrial heartland of Sydney. With the exodus of heavy industry Homebush Bay was left as one of the most contaminated sites in the Southern Hemisphere (OCA 1998b). The Sydney Olympic Bid for the Games sought not only to develop the bulk of the Games venues in this precinct and to undertake a major urban renewal project, but to do so using by using the very best environmental practice to decontaminate the site (Cashman and Hughes 1999).

Public transport is essential for community participation and citizenship. Sydney historically has not had a public transport culture with the private motor vehicle being a major influence on public policy discourse. Few areas of Sydney are well served by public transport, the exceptions being the Eastern suburbs and suburbs on the New South Wales City Rail network. These general public transport issues are compounded by a public transport system that has not been inclusive of people with disabilities (Downie 1994).

People with disabilities viewed the Games as an opportunity to improve both the accessible infrastructure and the transport coordination of Sydney. Sydney was planned and constructed in an ad hoc fashion (Spearitt and Demarco 1988) since European invasion in 1770 and subsequent settlement 1788. As such, Sydney is a mix of accessible and inaccessible areas. Apart from the Games precincts, the focus of public events took place in six largely accessible "Live Sites" (SOCOG 2000a) in the Sydney Central Business District. Many areas underwent major streetscape refurbishment as part of the Sydney City Council (SCC) Living Cities program (SCC 1994) aimed at revitalizing the street life of the Sydney CBD. However, SCC had been at the centre of a number of controversies with the community of people with disabilities about the accessibility of the urban domain.

The SCC's attitude and behavior led to the Physical Disability Council of New South Wales and People with Disabilities Inc. (two peak disability organizations in New South Wales) taking three separate DDA complaints against the SCC (Horin 1999b). These have had to do with street "improvements"

that did not meet the Australian standards for access and mobility (Standards Australia 1993; 1998). These included: kerb cuts that prevented wheelchair users from accessing and egressing from the footpaths; kerb heights that subsequently hindered access to the newly introduced low floor accessible buses; installation of street scape furniture (benches, phone booths etc.) that did not comply with Australian Standards for access and mobility (Standards Australia AS1248 Series); installation of streetscape furniture that impeded people with vision impairments access of the city streets; and removal of an accessible overpass connecting a car parking station to a government building housing a range of services for people with disabilities (Horin 1999b) As such, the accessibility of the urban domain remains problematic for people with mobility and vision impairments.

Inclusion in the Games Planning Process

There were four organizations charged with the planning of the Games. Table 1 presents their name, acronym & role:

Table 1: Games Planning Agencies

ORGANISATION	ACRONYM	ROLE
Sydney Organising Committee for the Olympic Games	SOCOG	Staging of the Olympic and Paralympic Games, and the Cultural Olympiad
Sydney Paralympic Organising Committee	SPOC	SPOC is charged with the staging of the Paralympic Games SOCOG and SPOC entered into an Operational Partnership whereby the Paralympic programs (sporting competition, volunteers, venue management, medical, security, accommodation, arts festivals, marketing programs etc.) will be delivered by SOCOG (SPOC 1999:6)
Olympic Coordination Authority	OCA	Development of venues Operation of sites during Games Development and maintenance of facilities for future co-ordination across agencies (OCA 1999a) http://www.oca.nsw.gov.au/

Olympic Roads and
Transport Authority

ORTA

Planning and co-ordinating
transport services during the
Olympics and Paralympics
Travel demand management
maintenance of existing
services during Games

Some 30 other NSW
Government Dept.

See the following website for
more information about the
organisations, their roles
and general access provision:

<http://www.gamesinfo.com.au/ac/index.html>

The organisation that was charged with the greatest degree of access planning was OCA. This is because OCA oversaw the planning, design, construction and operation of all Games venues. It is the OCA planning processes that this section will concentrate on prior to reviewing other access and disability issues that arose. The OCA approached access and disability issues by developing Access Guidelines (OCA 1998a), used an inclusive planning process through the establishment of the Olympic Access Advisory Committee and other consultative mechanisms, and developed guidelines for project management to include an access culture. As well as venues, the process involved the issues of the urban domain and transport (with ORTA).

Access Guidelines

OCA together with Australian Council for Rehabilitation of the Disabled (ACROD) and the Olympic Access Advisory Committee developed a set of Access Guidelines that were adopted by OCA in 1996 (OCA 1996; 1998a). They incorporate current access requirements stipulated in the Building Code of Australia (BCA) and the referenced Australian Standards for access, mobility and other relevant standards (Standards Australia AS1428 parts 1-4; AS4299 etc.). Further, they were proactive in seeking to incorporate the spirit and intent of the DDA.

The DDA is Commonwealth legislation that prohibits discrimination on the grounds of disability. As such, the guidelines went beyond the application of the technical requirements of the BCA and the Australian Standards by seeking to provide 'best practice' at all stages. One of the pressing issues of the built environment has been the need for harmonizing of the DDA and the BCA to bring a higher degree of certainty to the stakeholders involved (ABCB 1999). The OCA (1996; 1998a) guidelines sought to do this from the outset.

The Guidelines covered all Games facilities, venues and operations, and require an access strategy to be prepared for each venue and an access audit to be carried out. Further, these requirements were extended to include cultural festival venues

and to undertake audits for any other necessary services that would be considered part of the Games precincts. The Guidelines sought to incorporate access from all dimensions of disability in all of the roles that the Games offer - athletes, performers, spectators, officials, media, volunteers and staff. They are based on the principles of providing people with disabilities with an accessible environment that they can function in independently and with equity and dignity (OCA 1998a). As the Guidelines state,

Access is not only about buildings. A truly accessible environment is one in which a person with a disability can freely express their independence, and one in which any impediment to integration is removed. It involves "seamless" blending of numerous key components such as communication, transport, employment, education, external pathways, community awareness, housing and buildings. Special access provisions should not be necessary if the environment is built to adequately reflect the diversity and needs of the community (OCA 1998:3).

The Guidelines were issued to all professionals involved in OCA developments.

The Process of Inclusion and Access Advisory Committee

The Olympic Access Advisory Committee (OAAC) was a committee set up in 1996 by OCA to provide input from the disability community into the access planning of the building and operations of the facilities and services for the Games. Of the 25 person committee there are 9 separate consumer bodies represented on the committee for people with mobility, vision, hearing and intellectual impairments, and ageing (10 positions in all). Of the 25 person committee 14 positions were held by people with disabilities.

Importantly, the philosophy of establishing the committee was to include people with disabilities within the key planning process rather than to just undertake a consultation process. This began with each project's presentation of a facility brief, the development of an Access Strategy (includes a specialist access consultant), where the OAAC reviews/modifies the Access Strategy. The Access Strategy then had to be approved by OCA's Director General before the final design was then checked for compliance with the Access Strategy. Finally the design was implemented with OAAC monitoring during construction and operations. This was an important inclusion and has been an omission by many planning authorities in the past and an identified weakness of access planning (Fletcher 1998).

The ongoing monitoring through development stages (planning, design, construction and operations) was mandatory. Integral to the process was an active and two-way consultation with the

Olympic Access Advisory Committee and other people with disabilities (Fletcher 1998). This process puts in place a series of checks and balances that are sadly lacking in mainstream environmental planning in New South Wales (NSW). For example, the best plans can be compromised during construction by 'snap decisions' by supervisory or construction staff (e.g. continuous pathway impeded). Similarly, people with disabilities are too familiar with the "the locked toilet syndrome" during operations stages. This is where accessible toilets are provided, but when people with disabilities attempt to use them they find the toilets are locked. The authorities in charge keep the toilets locked to prevent vandalism or other inappropriate uses.

An essential component of the process was the employment of specialist access/disability consultants. The process of selecting an access consultant has been problematic in the past. While consultants with architectural and planning backgrounds have called themselves access consultants there has been no system for assessing knowledge of access and disability related issues. Part of this problem can be firstly traced to the lack of access and disability inclusion in University curriculum for these professions in Australia (Darcy 1999; SRDRN 1999), and hence, the subsequent lack of inclusion of people with disabilities in consultation process of projects organized by these professions.

Consultations with people with disabilities are essential to understand how space is used and not just how to technically adhere to access requirements. Examples abound of access planning completed by "qualified professionals" where the result was unusable for people with disabilities. In 1997 OCA called for expressions of interest for a register of access consultants for Olympic projects. This was the first attempt to develop a resource of "suitably qualified" organizations to provide access advice. This process still lacked a systematic form of evaluation and that is being addressed by two other initiatives (NAWG 1999; Access Institute of NSW 2000).

OCA has continued the process of consultation beyond the official Olympic Access Advisory Committee. From July to November 1999 OCA undertook wider consultation with disability groups and individuals with a series of workshops, tours and information sessions with groups and individuals representing physical, vision, intellectual, hearing, and senior groups.

Games Disability Issues

Test Event Evaluation of Access to Venues

Whenever a major program of public infrastructure provision is undertaken there are always parts they could have been done better in hindsight. However, the test is always in the use of these venues and whether there was a process in place to address these issues. Valuable testing and feedback to OCA, ORTA and the

venue managers was provided through a series of major test events (OCA 1999b). This included recruiting people with disabilities to road test the events (provide tickets ==> receive information ==> transport to ==> spatial use of the event site ==> provision of goods/services ==> the event itself ==> transport from etc.) and provide feedback to through a questionnaire and phone service. The Australian Quadriplegic Association (Hughes 1999) have also assessed their member's experiences of one test event. The major findings of the evaluations and solutions are presented in Table 2.

Table 2: Summary of Issues and Proposed Solutions from Test Events 1999-2000

ISSUES	SOLUTIONS
1. Poor understanding of access requirements of different disability groups and how to provide appropriate assistance	Training for identified staff over and above common disability awareness
2. Poor understanding of how to make best use of venue from access perspective, e.g. pathways of travel, location of handrails, TTYs etc.	Venue `walkthroughs' with venue manager and people with disabilities
3. Modifications required in some venues	Modifications, where possible, to be undertaken as part of `overlay' work.
Where	not possible operational assistance to be provided
4. Shade and shelter	Principles of equity to apply, i.e. ensure shade and shelter, where provided, is accessible to people with disabilities. Consideration to be given to shade and shelter at transport nodes
5.1 Distances and linkages between shuttle drop off points (and parking) and venue entrances venues	Public communication strategy to recognise that this will be a problem for some people and at some
	Operational strategies to be developed

5.2 Distances within venues	Intra-site transport to be considered if possible and appropriate Parking and drop off points to be considered if possible (Paralympics only)
6. Poor condition of drop off points, e.g. surface unsuitable for wheelchairs, people with vision impairments	Fix as per Access Guidelines Contingency planning for wet weather etc.
7. Lack of locational, directional or inaccessible signage	Fix as per Access Guidelines Staff training to ensure knowledge of all amenities etc.
8. Potential problem of crowd management and queuing	Consideration to be given to separate entrances etc. if appropriate Contingency planning
9. People with very particular requirements e.g. 'long' wheelchairs, can not climb stairs etc.	As much information as possible sought from ticketing Contingency planning and operational assistance, e.g. keep some seats on aisles free Fix as per Access Guidelines
10. Some temporary facilities inaccessible, e.g. ramps too steep	Fix as per Access Guidelines
11. Lack of information about transport, venues etc.	Access booklet
12. Trouble accessing information about transport, venues etc.	Access booklet

Sources: Questionnaire; Hughes 1999

Many of these issues related to the large size of the Games precincts. In the earlier stages of development this was compounded by a lack of available shade, shelter, seating, drinking fountains and toilets to enable people to rest or shelter from the elements. Some of these issues, like shade, required time for the trees to grow. Others have been addressed by OCA with modifications to the common domain (open space areas linking the venues) operations plans incorporating greater level of tree planting in some areas, and an increased level of seating, shading and drinking fountains. As more venues were completed the need for directional and location signage became

essential. This has been an ongoing exercise of improvement with each test event together with staff training for each of the venues and the common domain. The remaining issues can be grouped into two areas.

Firstly, operational issues surrounding the venues and their use by people with disabilities. As the venues and common domain were used a range of issues arose about the accessibility and use of these areas. Further, it became apparent that venue managers were not aware of how to make best use of their facilities, and staff were unfamiliar with the best ways to offer assistance to people with disabilities.

OCA and SOCOG addressed these issues through operational audits of venues to assist managers in best understanding the use of their venue from a disability perspective. Accredited access auditors from the aforementioned register of access consultants carried these out. This has been complemented with staff training of customer service for people with disabilities. This training involved an instructional video that was used for all staff and volunteers at Games venues (TAFE 2000). While it was recognized that video based disability awareness training is not as effective as training involving direct contact with people with disabilities (Daruwalla 1999) this was considered the only training format feasible for the 50,000 staff and volunteers involved in the Games.

Secondly, there were issues with information provision, access about the site and how best to get to the site via public transport. These information issues were seen as central to educating the general public, and people with disabilities in particular, about transport and access issues during the Games period. A publication about spectator information for the Games (SOCOG 2000b) and a separate Access Guide for the Games (OCA 2000) were completed to address these issues.

Transport to the Games

Homebush has an excellent Easy Access railway station for handling large numbers of the general public and has excellent access provisions. However, the Sydney City Rail Network system has only 5 percent of stations as Easy Access wheelchair accessible stations (City Rail 2000). This is compounded by the system of ingress and egress from trains that consistently leaves people with mobility disabilities stranded on stations waiting for ramps or for staff to escort them through the labyrinth of access tunnels (PDCNSW 2000; No author 21/11/1999). People with vision impairments are faced with a myriad of access problems ranging from inaccessible ticketing machines, lack of tactile indicators and absence of voice information systems.

The NSW State Transit Authority (STA) has increasingly purchased accessible low floor buses since a complaint was lodged under the DDA to the HREOC in 1995 (HREOC 2000). To this point in time the number of accessible buses has meant fully accessible

services are restricted to a few select routes. This is further compounded because private operators have been resisting the implementation of low floor accessible buses (Todd 1999) and it was a consortium of these operators, through Bus 2000, who won the contract to service a number of these Games routes. This meant restricted services on the Games bus routes for people with disabilities. For example, all Games ticket holders got free public transport to the Games and on these routes buses were available every 5 minutes. However, accessible buses were available every two hours. There were also uncertainties about the departure and return times of these services (Hughes 1999; Darcy and Woodruff 2000).

An inaccessible public transport system means that people with disabilities were reliant upon either private transport, rented vehicles or the Sydney taxi service. The Sydney accessible taxi system has been known for a range of problems that have been well documented (Folino 1998). This includes taxis being consistently late for bookings (1-3 hours is not uncommon!), not enough vehicles, drivers of vehicles who choose not to pick up passengers with disabilities, and lack of availability at night (Folino 1998). OCA and ORTA rightly identified all these transport issues as a major challenge to ensure that the needs of people with disabilities were identified and appropriately addressed. They have specifically targeted the issues of staff training, increasing the number and consistency of accessible transport routes.

Ticketing

Contrary to the approach taken by OCA, SOCOG was plagued by a number of controversies during the Games planning. From a disability perspective ticketing was a major controversy of planning the Games. For example, The Official Olympic Games Ticket Book had a section of frequently asked questions, where it asks,

I am confined to a wheelchair. Will I miss out on the Games?
No. Provision is being made for disabled spectators to attend any session of the Olympics. (SOCOG 1999:7)

The language used does not reflect the way people with disabilities want to be represented and reinforces stereotypes that the disability community have been fighting against (Hume 1995).

The process of allocating seats for people with disabilities left more unanswered questions than answered questions. Each line of the application form had a box to be ticked if accessible tickets were required. However, no details of the dimensions of access were noted. SOCOG had a number of DDA complaints brought against them for a range of ticketing and information issues.

A summary of these complaints include (also see HREOC 2000):

the lack of provision of the ticket book in alternate formats (Horin 1999a); wheelchair users were restricted to ordering a block of 3 tickets, 1 wheelchair ticket and two other tickets, a restriction not placed on other members of the community; a website that was inaccessible to people with vision impairments (Jackson 2000a and 2000b); and attendant/carer ticket refund based on it was discriminatory against people with high support needs who required assistance to attend the Games (Gregory 2000).

Volunteers

The Games period required the involvement of 50,000 volunteers. Disability organizations identified the tremendous strain that was placed on their volunteer resources because of the Games drive for volunteers. SOCOG was offering volunteers a range of extrinsic incentives to join the volunteer program that disability organizations could not hope to match. As Darcy (2001) states,

Olympic volunteers received free uniforms, transport to and from venues, meals, tickets to either a dress rehearsal of the opening ceremony or a morning athletics session, Olympic pins and entry into a raffle for prizes including trips to IOC headquarters in Lausanne, Switzerland and Holden cars. There was also a tickertape parade held in their honour. However, very few organisations working with volunteers have the resources to provide such recognition and rewards to their volunteers beyond perhaps the reimbursement of their expenses.

This drain on the volunteer workforce was of particular concern to disability organizations where current government cutbacks had further eroded these organizations ability to provide basic services to their members (Cumming 1999; Horin 1999c). Many of these and other cutbacks in government funding had been linked to increased expenditure by the New South Wales State Government on the Games. As Fallon (1999) noted, some disability organizations saw the Games period as a time for protest in much the same way that indigenous groups did.

Wider Social Impact

An Olympic and Paralympic Disability Advocacy Service (OPDAS) for people with disabilities was established for the Sydney Games period. OPDAS was established to assist any people with disabilities or their associates who may have problems or complaints with any services, facilities or events during the Games Period. This extends beyond the Games to generic disability services that may be disrupted during the period. OPDAS role included advocacy and legal support provision. The latter role was coordinated with NSW Disability Discrimination Legal Centre and included letter writing, attendance of meetings, and

assistance with lodging complaints under the DDA or NSW Anti-Discrimination Act.

OPDAS (2000) pre-Games planning report identified a range of social impacts that people with disabilities asked for their assistance in addressing. These included: severe access, activity restrictions and surveillance of residents of a residential facility accommodating people with high support needs located in the grounds of the Olympic media village; disruption to respite arrangements due to the extended school holiday period related to the Olympics; anticipated social isolation and lack of support services for people with disabilities during the Olympic period due, in part, to major increases in traffic congestion and transport restrictions in areas surrounding major Games precincts; anticipated increased homelessness among people with disabilities due to boarding house closures and government decisions regarding the removal of homeless people from Sydney streets during the Games (Jamal 1999; Hill 2000); extensive confusion and anxiety about the potential non-availability, disruption, and reduction of support services during the Olympics due to staff leave arrangements, service closures, traffic congestion etc.; lack of availability of accessible cabs due to block bookings by organisations (e.g. by major hotels) to provide Olympic shuttle services for able-bodied people; significant taxi fare increases (10%) during the Olympic period; and price increases for food, drinks and services at Olympic venues and live sites (e.g. Darling Harbour, Martin Place).

Conclusions

To achieve a well-run Games there needed to be a change in operational attitude towards disability and access issues. The Games offered the disability community a range of challenges and opportunities that would otherwise not have eventuated in Sydney in such a short time frame. Access issues were addressed by OCA and there was an inclusive process for this to occur. This saw the beginning of a shift to an access culture within these organizations and with those who worked closely with them (planners, designers, architects, project managers etc.). This saw a range of material developed about access (guidelines, checklists, best practice etc.) and has produced a series of largely accessible Games precincts. Yet, at the same time SOCOG's approach to ticketing and information issues was deliberately exclusionary.

The logistics of staging the Games tested the operational planning of all agencies involved. This will be critical during the Games where vast numbers of spectators will be transported to and from venues each day. There is also concern about the ability to transport, accommodate and entertain athletes and visitors with disabilities outside of the Games precincts (Kennedy 1998; Rudzki 1999). Once athletes and spectators have feasted upon the orgy of sport and culture at the largely accessible venues then

they may wish visit other areas of Sydney and Australia. It is these recreational and tourism experiences that people expect to participate in that may be the most problematic (Darcy 1998). This requires a greater commitment to accessible public transport and the accessibility of the urban domain.

The other possible legacy is increased profile of people with disabilities through the images and messages of Paralympics. However, whether this increased profile has any lasting impact on the general public and politicians can only be assessed a reasonable period after the Games have finished. It will be an interesting time.

Notes

1. This paper was prepared prior to the Sydney 2000 Games taking place. A further paper is in preparation evaluating the post Games experience from a disability perspective.

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Geographies of Disability and Development
in Southern Africa

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Introduction: Disabling Geographies of Development

The complex relationships between space and disability have received increasing attention in recent years as it is become necessary to explore how social and spatial processes can be used to disable rather than enable people with physical disabilities. Brendan Gleeson talks about the 'long disciplinary silence' in Geography and writes that geographers were 'absent without leave' from the broader intellectual campaign around disability issues:

A failure to embrace disability as a core concern can only impoverish the discipline, both theoretically and empirically. (Gleeson 1999: 1)

Debates about how space informs experiences of disability have expanded considerably in the 1990s, but largely urban, Anglophone, western societies remain the predominant focus of attention. Much of this work does however highlight the heterogeneity of physical conditions and social experiences that are commonly lumped together under the disability rubric. Some researchers have criticised approaches that have avoided or understated these differences, but there is arguably also a political need for inclusive theorisations that illustrate the range of social forces that bear down upon 'impaired bodies' and explore the possibility of collective responses. Gleeson (1999, 2001) has referred to the need to bring about 'enabling

environments and inclusive social spaces'. Instead, many development organisations arguably construct elaborate 'landscapes of dependency'. Geographies of Disability begins by expressing the author's hope that eventually no geographer will be able to claim that disability is irrelevant to their work. As geographers interested in development, it is absolutely crucial to play our part in bringing an end to these disciplinary silences through an illustration of the discipline and power of development and dependency and by exploring the possibility of alternatives.

Most of my past research has been focused on the Southern Africa region, in particular on Mozambique. Previous work has explored the role of media communications technologies in the making of cultural spaces of identification and partly sought to highlight the social and cultural exclusion of certain communities from the construction of national belonging. In several parts of the Southern Africa region today, the interests of war veterans have received increasing amounts of publicity, raising some important and neglected questions about conflict, national defence and disability. Although much of my recent research has been concerned with war-related physical disabilities and with definitions of disability in Mozambique and Angola, recent political struggles and debates in Botswana, South Africa and Zimbabwe also have a direct relevance.

Two central objectives in this research were, firstly, to contribute to recent debates about the role of geography in disability studies and secondly to contribute to a further understanding of the shifting and complex landscapes of disability in Southern Africa. There are a number of common themes and experiences shared by disability movements within and between Southern African countries and regional and international co-operation remains an important objective for the future, particularly in the shape of SAFOD, the Southern African Federation of the Disabled. This research tries to explore the 'commonality of disability' in Southern Africa where, on almost every indicator of participation in 'mainstream life', disabled people come out extremely badly; for example in employment statistics, income levels, suitable housing, access to public transport, buildings, information (newspapers, radio and television) and leisure facilities. Being disabled clearly has negative implications and this kind of marginalisation is precisely what many development organisations now seek to 'manage'.

My research seeks to understand the ways in which we produce the 'private room' of disability in the most public spaces and representational discourses of development and seeks to explore how disabled subjectivities are constituted in a struggle with the able-bodied public's perceptions and investments in maintaining disability as alterity (Mitchell and Snyder 1999: 30).

Defining Disability

It is necessary at this juncture to define what is meant here by the term 'disability.' I use the term disability to designate cognitive and physical conditions that deviate from normative ideas of physical ability and physiological function. The terms disability and disabled denote more than a medical condition or an essentialised 'deformity' or difference and are preferable to the terms 'impairment' and 'handicapped' which suggest inherent biological limitations and individual abnormalities. Following Mitchell and Snyder (1999: 3) this research adopts a definition of disability that "denotes the social, historical, political and mythological co-ordinates that define disabled people as excessive to traditional social circuits of interaction and as the objects of institutionalised discourses."

There are a range of estimates and some disagreement on the exact numbers of people with disabilities world-wide and there are all kinds of problems involved with the use of global level statistics and the 'politics of labelling' that these guesstimates can give rise to. Most health professionals estimate that there are about 450 million disabled people in the world, around 3-13% of the population of each country.

Although there is much that is indeterminate about these statistics they do indicate that there are 'root causes of physical impairment' in many parts of Southern Africa which include land mines, malnutrition, iodine and Vitamin A deficiencies, polio, Hansons disease and childbirth complications. The World Health Organisation (WHO) estimates that as little as 1-2% of the total number of disabled people actually have access to rehabilitation services and as a response the WHO has championed the idea of Community Based Rehabilitation (CBR) with the aim of making rehabilitation services available to communities in cost-effective ways.

Managing Disability in Development

It is important however to question the remaining vestiges of what Sung Lee (1997) calls the 'postcolonial paternalism' of the WHO and to contest the centrality of western medical knowledge. In recently reformulating its international standard languages (in ICDH-2), the WHO reportedly came perilously close to returning to the 'medical model', with all its older imperial connotations (Hirst 2000, WHO 2000). There are now a plethora of CBR training programmes and manuals, professional trainers, CBR workers, managers and evaluators. Nonetheless a variety of western trained professionals, employed by particular aid and development organisations, have published widely on experiences of CBR implementation, though it has not always been sensitively implemented and appropriate to local practices and perceptions. For Emma Stone (1999: 9) "what is happening is simply an updated,

less obviously imperialistic, version of what missionaries were doing in the 1890's".

Despite the multiple references to rehabilitation discourses as 'imperialist' in some way, things have clearly changed since the 1890s. Today there are important international networks, e-mail distribution lists and newsletters (e.g. Disability Awareness in Action) and umbrella organisations like Disabled Peoples' International (DPI) which have been crucial in mobilising people with disabilities across the world and have been an important avenue for the international exchange of ideas about issues like CBR and income-generation.

The UN often talks of disability issues as a 'silent crisis' affecting societies of the Southern Africa with UNICEF, UNESCO, the ILO and the WHO as the major agencies involved in developing responses. According to the UN "it is imperative that planners remain sensitive to the disability dimension early and throughout the development process" (UNDP 2000). Again however there is the notion of a singular disability dimension that needs to be appended to an untransformed process. The UN has now produced a Manual on Inclusive Planning and a 'society for all' is promised in this global crusade on behalf of 'disadvantaged persons', otherwise known as the UN World Programme of Action (allied to the African Decade of People with Disabilities, 1999-2009). Many development agencies silence disabled people, however, in their representations, in their disabling politics and in their desire for impairment-specific and technological solutions.

In the majority of cultures physical difference is understood in terms of physical incapacity, special needs accommodations and statistical deviance. Disabled bodies defy correction and normalisation however and so this urge to medicalise disability concerns needs to be widely contested. Historically, disability has been the province of numerous professional and academic disciplines that concentrate on the management, repair and maintenance of physical and cognitive capacity. In Southern Africa this means that disability is often problematically used as evidence of 'damaged populations'. What partly defines disability in Southern Africa however is the 'voicelessness' and institutional neglect of disabled people who are often forced to take positions on the outermost margins of their societies.

How have people with disabilities in Southern Africa become the objects of institutionalised discourses of development and how can this objectification be challenged? In the 1960s many western disability movements struggled to separate the issue of disability from questions of health and illness and to contest the medicalisation of their experiences. This led to a famous and often discussed shift from the 'medical model' to a 'social model'. In the countries of Southern Africa, this shift is underway, but far from complete.

In the West, the term people/persons with physical

disabilities is now adopted in a variety of official and institutional settings and its supporters argue it is preferable to referring to 'disabled people' in that it emphasises 'personhood' over the fact of disability. This is said to be a humanising practice that supports the general quest for cultural respect and equal rights. Advocates of the term 'disabled people' question the 'rhetorical humanism' of this project that they argue lacks political power, particularly in the light of continuing oppression. Replacing one label with another "seems to be an exercise in changing fashions" (Finkelstein 1993: 2) though such 'fashionable' exercises are very common in development circles.

In this paper the term 'people with disability' will be used although it is important to remember that both Angola and Mozambique have Portuguese as their official language and that the translation of key terms like these is not unproblematic. People with disability is used here primarily as a consequence of discussions with ADEMO (the major national disability movement in Mozambique) which has recently campaigned for the use of the term *peessoa portadora de deficiencia* (people with disability) in preference to *deficiente* (disabled).

Key Organizations Informing Geographies of Development in Southern Africa

The World Bank

In Southern Africa people with disabilities are often the object of a range of institutionalised discourses of development. The World Bank's position is that disability issues are central to their mission, but they talk of disability-reduced productivity within the workforce and view disability very much within a kind of 'cost-benefit' analysis. The Bank website (with over 150 sub-sites) lists the 'growing portfolio' of projects they have funded (last updated in mid-1999). Bank officials are themselves still implementing changes to the accessibility of their buildings.

At the Peoples Health Conference 2000 in Bangladesh, the Bank's Health policies were described as 'anti-Third World' and inconsistent on their own terms. Delegates from 3000 NGO's from 95 countries called instead for "justice, not charity". Charles Mutasa from Zimbabwe argued that disease specific interventions, such as World Bank spending on TB or Leprosy, will not be enough as long as the 'trap' of indebtedness remains.

Is the Bank's expanding remit too much for the organisation to handle? The organisation seems to be trying to become the leading global think tank on every issue. A leaked Bank memo for the North Africa office in January 2001 argued that the Bank is overstretched with no focus, driven by the President's favourite subjects and even fads (Bretton Woods Project 2001). This agenda seems to be cumulative rather than selective or even reflective.

Can this self-styled 'knowledge Bank' ever think beyond the economistic and universal frames of reference that have dominated for so long? As a creator of poverty in Africa, where does the Bank's moral authority and expertise come from? (BWP 2001). The recent strategic review and reformulation process has signalled that the Bank intends to escalate investment in health and link its policies to global programmes. What about thinking through the global implications of its own policies?

Save the Children Fund (SCF)

On a different scale, Disability has been part of the work of Save the Children Fund since it was first founded in 1919, even though in the early years European medical models of disability initially predominated (Jones 1999). SCF's Policy on Disability seeks the active participation of children with disabilities in their respective communities (SCF/UK 1998). SCF aims to integrate disability into its programmes and advocacy work and a regional Disability Advisor was appointed in 1988, whilst to date the SCF has supported 10 programmes - in Mozambique, Zimbabwe, South Africa, Swaziland and Lesotho.

According to the SCF, the disability rights movement in Southern Africa has its roots in Zimbabwe and as a result SCF has often tried to organise its disability programmes around Zimbabwean initiatives or with Zimbabwean influence (Miles 1996). Based in Bulawayo, Zimbabwe, the Southern African Federation of the Disabled (SAFOD) has been one of the most active and dynamic regional bodies of the DPI and SCF has increasingly tried to work with disabled peoples organizations like SAFOD consequently coming to prioritise disabled people's access to education and employment rather than to medical rehabilitation. Nonetheless tensions have arisen between the SCF and Southern African DPOs in that the former have always concentrated on children, the latter on adults. Additionally, the SCF still subscribes to the contested idea of CBR, with a small 'r' for rehabilitation but also focusing on the development and 'capacity-building' of DPOs.

Across the region however SCF remain one of only a handful of agencies that have supported comprehensive and inclusionary strategies which go beyond traditional activities. There has generally been only meagre support for Disability related activities and relatively few donors had mainstreaming strategies or even a set of Disability policies until the mid-1990's, as has also been the case in parts of West Africa (Metts and Metts 2000).

Disabled Peoples' International (DPI)

With Zimbabwean Joshua Malinga, a key figure in the struggle for disability rights in Southern Africa, the DPI has focused on economic and social inclusion and talked of empowerment, pioneering agendas for development agencies and making it easier for them to adapt to changing priorities and concerns. Most

importantly the DPI has a Women's Committee that has forged links with a number of disability movements across Southern Africa and played an important role in advocating a rights-based approach at Beijing and Beijing+5. This is a passage from the DPI committee's evaluation of the UN in Beijing:

We expressed deep concern, that such [UN] instruments and mandates have yet to create a significant impact on improving the lives of people with disabilities, especially women and girls with disabilities, who remain the most invisible of all disadvantaged groups. (DPI Women's Committee, 2000)

A poem from Botswana, cited at the beginning of Margaret Snyder's work begins: "Guarantee me an opportunity, not a charity ticket" (Snyder 1995). She argues that gendered issues make coping with disability a much tougher task for women, through unequal access to income-generation opportunities, through male bias in planning and in the way that providing care for people with disabilities is constructed as an exclusively female concern. Until relatively recent there had been little consideration of the ways in which gender might structure the experience of disability and disabled identities (Oliver 1990).

There are important links between the assumed passivity of disabled people and the assumed passivity of women and thus the struggle against social stigma is more complex for women. Women have to negotiate the idea of the nuclear family as the centre of social provision and a range of complex and contradictory sets of social relations. Tensions and contradictions between the discourses of care and rehabilitation abound but have particular implications for women.

There is hope however that at least some states in the region are beginning to comprehend the interconnections between gender and disability. The post-apartheid government in South Africa recently published a comprehensive White paper on Disability in 1997 putting forward an Integrated National Disability Strategy (Office of the Deputy President Thabo Mbeki 1997). This is based firmly on the social model advocating a rights-based approach and referring to both people with disabilities and disabled people. Despite the numerous references to the social model throughout this important White paper, some authors still argue however that the social model should not be transferred beyond the West and that this would be more like imperialism than empowerment (Stone 1999: 4). Komardjaja (2000) has also argued that a lot of caution is needed when exploring the wider relevance of disability debates grounded in particular cultural values and geographical spaces.

Initiatives in South Africa

Estimates suggest that the number of people with

disabilities in South Africa is somewhere between 5% and 12% of the population. Government departments and State organisations now have a responsibility to ensure that the same fundamental rights and responsibilities are accessible to all South Africans.

The Office on the Status of Disabled Persons has been established in the office of the President. The need for a national strategy was first recognised in the RDP (Reconstruction and Development Programme). The text is very much based around UN programmes, rules and guidelines, but involves significant input from the DPSA (Disabled People South Africa), recognised by the DPI as the national assembly of disabled persons in South Africa. Interestingly the strategy refers to the 'medical model' adopted by the Apartheid government and talks of disability as simultaneously both a human rights and a development issue.

A National Environmental Accessibility Programme is also underway which works alongside a National Co-ordinating Committee on Disability (NCCD). There is an important focus on rural areas and on education and employment with constitutionally recognised rights that are monitored by national political institutions.

Initiatives in Mozambique

Across the border in Mozambique a very different (but not unrelated) set of struggles is being waged by ADEMO (Associação dos Deficientes de Mozambique) and ADEMIMO (Associação dos Deficientes Militares e Paramilitares de Mozambique). ADEMO has always maintained an open and inclusive policy of membership whereas ADEMIMO is an organisation established for and on behalf of former FRELIMO (Front for Liberation of Mozambique/Frente de Libertação de Mozambique) combatants.

The opening paragraph of ADEMO's constitution refers to their desire to contest the legacies of colonial paternalism bequeathed by missionaries and the Portuguese colonial state. Both organisations, despite early conflicts over contrasting notions of membership, have recently begun to work more closely together and both now belong to FAMOD (Forum of Mozambican Disability Groups), an umbrella organisation for disabled peoples organisations founded in May 1999 to facilitate co-operation and collective action. FAMOD and its members are well aware however that the mere existence of legislation is far from enough and that longer term strategies to guarantee the effective implementation of that legislation will also be necessary.

There are an estimated 1-1.5 million people with disabilities in Mozambique. ADEMO has 63,000 members across the country and is growing at a rapid rate with representations in all 10 provinces and even in many districts. In the provinces, ADEMO runs a number of initiatives, such as the 'New-Horizons' theatre groups which focus on the rights of disabled children. Sporting activities are also an important part of the agenda, bringing different disability movements together for regular basketball competitions for example. There is also a community

school in Maputo, run by ADEMO, which provides courses to about 500 children a year.

Mapping out the competing cultural understandings of physical disability in Africa is not a simple process (Devlieger 1995, 1999) but research can help to contest negative cultural myths and stereotypes. When members of ADEMIMO organised a land invasion in Matola in June 2000 to protest at the governments neglect of former soldiers, one Mozambican paper referred to the invaders as os mutilados (the mutilated) assuming that the protestors constituted a kind of redundant, homogenous group of disaffected combatants.

ADEMO's work also raises questions about the supposed economic prosperity of post-war Mozambique campaigning for example against the charges imposed by customs and excise for the importation of 'compensation material'. By law this ought to be free but in practice it is for some kinds of material but not the kind required by organisations like ADEMO and its members. In a country where the majority of wheelchairs (not made of local materials) are imported from abroad these problems have become increasingly acute.

Most importantly, ADEMO publicly represents the "many and rich experiences, capacities and talents of disabled people in implementing small and medium-sized employment generation projects" (ADEMO 1999: 3). With this in mind ADEMO has embarked on a two-year pilot project that aims to study the life and visions of people with disabilities and uses participatory methodologies, funded by SCF-UK through a grant from the Princess Diana Memorial Fund.

ADEMO has had problems working with aid agencies in the past though where NGO support for particular initiatives (e.g. women's sewing projects) has often been inconsistent or withdrawn at short notice. ADEMO has been a key part of recent Disability legislation and acts as a pressure group on state agencies like the Ministerio da Coordenatio para Accio Social (MICAS). MICAS seeks to contribute to ADEMO's struggle by highlighting the gross underrepresentation of people with physical disabilities within the Mozambican media. This is an area that ADEMO and FAMOD are beginning to focus their attention upon in a country where radio is a particularly important medium of communication.

Transport and urban planning (particularly in the aftermath of major flooding) are also key themes for all the major Disability organisations in Mozambique. ADEMO brings together groups of disabled people and encourages a common identity, representing an historic leap in defining disability in positive terms.

Effectiveness of Local and Regional Responses in Southern Africa

In contrast to the underwhelming reaction by development agencies to the need to further consider disability issues in development planning and practice, organisations like the DPSA in

South Africa and ADEMO in Mozambique are busy confronting these challenges head on. Each country has its own very specific history, culture and economy but both have recently passed progressive forms of disability legislation and both have active disability movements which are engaged in a variety of urban and rural communities. In regional terms organisations like SAFOD can and have attempted to consider the collective nature of these experiences with development and underdevelopment and to explore the possibility of collective responses.

Conclusions:
Disempowerment, Disability and Development

Mike Oliver argues that "the question of doing emancipatory research is a false one, rather the issue is the role of research in emancipation" (1990: 25). Emancipation has different meanings in different parts of Southern Africa and at different times and so it is unlikely that one set of 'emancipatory' research methods are relevant to all countries in the region at any given moment. Vic Finkelstein (1999) argues similarly that methodological debates have often been reduced to issues of control by disabled people in order to characterise a research project as 'emancipatory'.

Although there are cultural differences of class and gender that can present barriers to the researcher (Priestley 1999), excessive emphasis is often placed on the positionality of the researcher and the limits upon research to the exclusion of discussion about the role of research in emancipatory struggles. Life histories are an important methodology that can be used in African contexts with the caveat that by narrativizing an impairment, one tends to sentimentalise it, and link it to the bourgeois sensibility of individualism and the drama of an individual story (Davis 1995). Important commonalities are thus denied. Solutions to disability oppression are often impairment specific and frequently technological. This kind of disability focus is disabling in that it silences what are undoubtedly shared meanings (Ingstad and Whyte 1995).

The growth of specialist professions as gate-keepers to medical, social and welfare services reinforces the view that disability is a medical problem and leads to the administrative construction of disability as a separate policy category. Discourses of personal tragedy (Oliver 1990) individualise disability rather than identifying a collective form of oppression that is socially produced (Priestly 1999). Sentimentality and patronage are important with disabled people portrayed as powerless and the victims of violence (Priestley 1999).

This paper illustrates that the construction of disability as a separate development policy domain is problematic and argues that to develop enabling alternatives development agencies need

to radically rethink their entire notion of development taking their lead directly from the disability movements who endure its contradictions and shortcomings on a daily basis. Disability issues can not be hidden away in a private room or policy document and must not be allowed to appear as an obscure sub-site of key institutional web sites like that of the World Bank.

Perhaps the very success or failure of every form of 'development' should be measured by the extent to which it is inclusive of disability. In turn Southern African DPOs like ADEMO are showing that effective self-organisation within a cohesive social movement is a necessary prerequisite for the liberation of disabled people in Southern Africa. Additionally important regional/international contexts also have an important bearing on the scope and terms of that liberation.

There remains nonetheless an "urgent need for development organisations and funders to take disability on board as an equal opportunities issue (as with gender and ethnicity)" (Stone 1999: 10). Disability is much more than just a singular issue to take on board however whilst the co-option of disability movements by development organisations is not unproblematic. My own interpretation of the links between disability and development is that to recognise development as disabling is to begin to open up a variety of quite profound questions about the margins of 'development' and its impulse to objectify the 'marginal'. To add disability to a development agenda as if it was some kind of cumulative list of needs means that the underlying ableist assumptions of development remain unchallenged.

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List of acronyms:

Associatio dos Deficientes de Mozambique (ADEMO)
Associatio dos Deficientes Militares e Paramilitares de Mozambique (ADEMIMO)
Community Based Rehabilitation (CBR)
World Health Organisation (WHO)

Southern African Federation of the Disabled (SAFOD)
Disabled People's International (DPI)
Disabled People South Africa (DPSA)
Disabled People's Organisations (DPO's)
International Labour Organisation (ILO)
Federation of Mozambican Disability Associations (FAMOD)
National Co-ordinating Committee on Disability (NCCD)
Ministry of Social Action (Mozambique) (MICAS)
Save the Children Fund (UK) (SCF)

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Disabled Peoples' International, <<http://www.dpi.org>>.

The World Bank, <<http://www.worldbank.org>>.

Landmine Survivors Network, <<http://www.landminesurvivors.org>>.

People's Health Assembly 2000, <<http://www.twinside.org.sg/title/pha2000.htm>>.

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The Malfunction of Barrier-Free Spaces in Indonesia

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Introduction

Third World countries have a common heritage and legacy of colonialism and poverty (Drakakis-Smith 2000: 2). Indonesia, a Third World country in Southeast Asia, experienced Dutch colonialism for three and a half centuries, 1602 - 1945 (Bunge 1983: 15 & 42). More than half a century since its independence, the nation is still preoccupied with "coping and surviving" (Parnwell and Turner 1998: 148). Nonetheless, Indonesia as well as Asia in general has enjoyed economic gains since the early 1970s until the Asian currency collapsed in 1997 which led to unexpected regime change in Indonesia (Mehmet 1999: 117-118).

This financial collapse has engendered inflation, migration, unemployment, and unrest which are daily concerns across much of Southeast Asia (Chatterjee 1998: 5). In Indonesia this economic crisis persists even today as the national currency, the rupiah, continues to devalue. Prices for basic necessities are increasing making the problem of poverty and survival critical to the state. In this precarious situation, streets become the loci of social, economic, and political struggles against all kinds of adversity.

Authorities lose their power to prohibit illegal actions and stern prohibition may provoke contagious mass anger that aggravates the socio-economic chaos of the city. This is the overall social and economic situation of Bandung, the capital city of the province of West Java where I live and work. As a woman with an ambulant disability my familiarity with the barriers of the streets is based on personal experience in dealing with impediments in everyday activities.

In 2000 I was in Japan to research barrier-free design. Obviously, this post-industrial country in Asia is enormously advanced in the implementation of barrier-free design whereas ESCAP (Economic and Social Commission for Asia and the Pacific) developing countries, such as Indonesia, Malaysia, Thailand, the Philippines, India, and Bangladesh, only began to pay official attention to the removal of physical barriers in 1993 (UN ESCAP 1995: iii). Observing the curb cuts and orderly behavior of street users in Japan, I conclude that barrier-free environments in Indonesia will not materialize until people's quality of life is enhanced. This includes reduction of illiteracy and the increase of access to information and participation in economic and political decision-making (Hood 1998: 863).

With a focus on the street, this paper aims to understand the malfunction of barrier-free spaces in Indonesia by first studying the cultural background that situates people with disabilities in society. The way the general population uses and occupies the streets reflects the relative invisibility of people with disabilities. The city of Bandung is examined as a case study.

The Problem

Golledge (1996: 406) argues that poor and disabled people face similar disadvantages because both groups have limited access to personal unassisted travel, economic and social resources, political power, and activity spaces. This generalization allows us to see the similarities between disadvantaged groups. While people with disabilities throughout the world endure "social oppression and spatial marginalization" (Gleeson 1999: 2), in Indonesia poverty and "shame culture" exacerbate their difficulties.

On the streets one very rarely sees ambulant disabled people using mobility aids such as leg braces, crutches, walking canes, and wheelchairs. Occasionally one notices ambulant disabled and elderly people traveling without these aids and blind people with canes. For underclass people who are disabled and very poor, the streets are the public spaces most suitable for begging.

Generally, people with disabilities are not pedestrians (Gleeson 1998: 96). Being ever-conscious of their physical limitations they are on the streets for definite purposes such as waiting for public transport. They are not strolling consumers, people in circulation, and idlers (ibid).

Given these contingencies, I will consider the following questions: What kind of people with disabilities will appear in public? To what extent are barrier-free spaces useful? Which socio-economic class(es) will mostly use these spaces: the middle class, underclass, or both? The middle class makes significant progress because of their higher education and possible professionalism. Their preoccupation with coping and surviving is lessened and barrier-free spaces become relevant.

Background

The Culture of Respect for the Elderly

In the family-oriented society of Indonesia, disabled and elderly people can get human assistance for their physical limitations. The influence of lingering feudal relations (Komardjaja 2001: 82) is another determinant that upholds the respect for older persons and people in authority. The social system recognizes the unequal status of the "patron-client" relationship (Kleden 1990: 352). The patron is supposed to be more knowledgeable, to bear complete responsibility, and to undertake initiatives. The client is considered inexperienced, in need of guidance and advice, and obliged to carry out to patron's instructions (ibid). In such a culture the elderly are respected for their rich experiences. Very rarely do they enter a nursing home; not only is it costly, but it also brings disgrace to the family.

In developing countries of Southeast Asia the aging population is on the increase and co-residence between elderly members and young adult generation is a common arrangement (Knodel and Debavalya 1997: 7). The family provides care and as respected members elderly people are not supposed to live independently. A barrier-free environment would thus appear less useful for them.

The Culture of Shame for Persons with Disabilities

In determining whether barrier-free environments are essential for people with disabilities, we firstly need to understand the dynamic of human conduct. Heller's (1985) theory of shame focuses on the ethical regulation of human action and judgment. She makes a clear distinction between the moral feelings of shame and conscience both of which are formed by authorities of human conduct. The authority of shame is external and resides in the "social customs - rituals, habits, codes or rosters of behaviour," whereas the authority of conscience is practical and represented by the internal voice (ibid., p3). Shame is an inborn feeling, but conscience is acquired through life experiences (ibid., p52). In a society where forms control people's lives, the norms and rules remain uncontested and taken for granted and moral behavior is developed through shaming (Cote 1992: xx). Indonesians hold the general rule of sameness and fear

to step outside its boundaries.

In the culture of shame visible physical appearance is more significant than the invisible forces that control attitudes. In such a society it is not easy for disabled people to be accepted (Ototake 2000: 218 - 219). When persons with disabilities wish to be independent, they have to face the external authority of normalcy. The situation engenders conflict when they have to make a choice between values that they conceive to be superior, essential, real and rational, and the more conventional values (Cote 1992: xxi).

My friend Wati (a pseudonym), who uses crutches, pursued a Master's degree in a university where she every day she had to surmount a vexing obstacle: a concrete barrier that crossed the public sidewalk leading into the classroom building. She had to sit down on the barrier to lift up her braced legs, turn her body towards the school, and place her legs on the other side of the barrier before going down several steps to reach the classroom. This illustration exemplifies her inability to use the body in ways that are socially acceptable or normal (Butler and Bowlby 1997: 420). However, the authority of conscience ruled her behavior so she could ignore her embarrassment at appearing odd. Given our similar personal experiences, Wadi and I share the same motivation to "ignore people's thoughts and stares" and "be willing to get dirty" if we wish to take part in social life. However, we also feel very awkward asking for help from people we do not know. Sometimes we face unavoidable steps with handrails and we need a human arm to hold so that we can go up or down.

Coming from the middle class and being professionals, we are moving towards a "conscience culture" typical of modernity (Cote 1992: xxi). We take responsibility for our actions and this self-determination liberates us from feeling ashamed to appear in public despite our visible disability.

Movement on the Streets of Bandung

City streets in Asia are places where people spend most of their days (Harrison & Parker 1998), an indication that outdoors activities are more valued than indoor life. Like on the streets of Indian cities, it is difficult to move in a straight line in Bandung (Edensor 1998:209). Pedestrians confront obstacles underfoot and in front (ibid) and have to be alert to possible harm caused by the different speeds of various vehicles maneuvering for space. The slow movement of a tricycled pedicab that uses human energy results in the congestion of other vehicles and the faster speed of motor vehicles scares off pedestrians. The continuous flow of traffic and the quick timing of the red traffic light cause pedestrians to be indifferent to the rules of crossing the street. They cross at any time and from any point they wish since waiting for the traffic flow to subside is futile. Pedestrians assume drivers to be responsible for their safety (Komardjaja 1997). As vehicles literally cover the road,

pedestrians have to thread their way between the cars.

Sidewalks along main roads and thoroughfares are strategic sites for economic activities of low-income and informal traders who hardly leave space for pedestrians. Added to this are the tricycled pedicabs and motorbikes parked on the sidewalks. One can find at dawn ad-hoc wet markets that occupy half the width of the vehicular road and which may continue until late morning. Only when most of the items are sold out do hawkers and vendors vacate the space leaving behind a mound of litter. Walking down the street is often a sequence of interruptions and encounters that disrupt smooth passage (Edensor 1998: 209). There are many features of the built environment that prevent easy passage: high, cracked and uneven sidewalks, narrow and open drains, the absence of fences or barriers at the edge of a descent, continuous water flows, and haphazard construction.

In the disabled-unfriendly city of Bandung there is no space for the mobility of people with disabilities. The middle class usually have domestic helpers who can be ordered to run errands. While Wati and I treasure independent living, we also depend on our helpers who save us from troubles on the streets. Wati finds it impossible to negotiate the barriers of the street. I, on the other hand, must nerve myself to surmount obstacles of walking along the edge of a vehicular road, of getting on and off the public van, of crossing the street, and of walking on uneven sidewalks. These difficulties are not so much due to my disability since everyone on the street is likewise struggling for any form of survival.

Failures in accessibility

Three examples show how accessibility fails to function adequately after construction projects are completed, illustrating a lack of recognition of barrier-free access.

1. In Yogyakarta, a city in the province of Central Java, a pilot project of accessibility included part of the sidewalk along the thoroughfare of Malioboro. This was changed into a footpath with guiding blocks for blind people. Its length of 150 meters, notably in front of the parliament building, resulted in an obstacle to the long established practice of parking motorbikes on the sidewalk.

2. There used to be a ramp at the entrance of the bank I frequent. In 2000 a cubicle for the ATM was erected on this short ramp occupying the entire space. Since then, I use the staircase and have to ask strangers to lend me physical support as I ascend. I go down anxiously on my own.

3. In the central railway station of Bandung a platform was raised so passengers could easily enter the wagons. There was a steep ramp to get on the platform and the sign indicating wheelchair accessible hanged on a nearby pole. In 2000 the ramp was transformed into a staircase with a steep and narrow ramp next to it.

The value of independence, as understood in the West, is not in the tradition of a collectivist society. Prospects for the creation of barrier-free spaces in Indonesia are dim as a result.

Discussion

In response to the appeal of the Economic and Social Commission for Asia and the Pacific (ESCAP) to build barrier-free environments, the Indonesian government has made timely efforts such as issuing the technical guidelines for physical access in 1998, installing ramps in front of different buildings on the campus of the Ministry of Settlements and Regional Infrastructures in 2000, and conducting national seminars. These actions, however, do not lead to the realization of barrier-free spaces. The resulting ineffectiveness of these spaces is attributable to the following constraints.

Poverty in Indonesia

The government has to prioritize the improvement of per capita income, employment and education, health, sanitation and clean water, low cost housing and land acquisition. Its preoccupation with coping and survival leaves hardly any resources for the development of equity, social justice, the meeting of basic human needs, democracy, environmental awareness, and welfare (Drakakis-Smith 2000: 8; Parnwell & Turner 1998: 162). It is not surprising that the special needs of people with disabilities are not considered a priority in Indonesia's list of survival concerns.

The Economic Struggle for Survival

All sorts of economic struggles for survival that take place in public domains are tolerated at the expense of chaotic traffic and the transformation of mainstream pedestrians into jaywalkers. The ideal of disciplined behavior on the part of pedestrians, peddlers, and drivers is culturally unthinkable and the enforcement of rules remains weak. On the streets persons with disabilities are ignored (Kraus 2001). Each street user is so immersed in her/his own struggle, that there is hardly room for altruism (Parnwell & Turner 1998: 162).

Misuse of Street Accessibility

If ever curb cuts and ramps are installed, the main users might be the low-income people from the informal sector. The accessible facilities will most likely be used to push and pull carts and mobile eating-stalls, and by motorbikes and bicycles to access the sidewalk or vehicular road.

The Uncertain Lifespan of the Barrier-Free Spaces

The malfunction of the sidewalks fitted with guiding blocks for persons with visual impairments, as well as the transformation and misuse of ramps, reflect people's "sheer unfamiliarity" (Ototake 2000:215) with the needs of persons with

disabilities for convenient personal mobility.

Conclusion

Two conclusions may be derived from the foregoing discussion.

1. Marginalization of people with disabilities is not deemed a significant problem in contemporary Indonesia.

The current unstable social, economic, and political conditions impact on people from all sections of life. In a culture of coping, tolerance and survival, marginalization is not an issue. Only when basic human needs have been met and social justice and equity are assured can people with disabilities demand access.

2. Barrier-free spaces do not function effectively.

The misuse of the streets documented here, points toward the malfunction of other barrier-free spaces as well. Whilst the construction of barrier-free environments is meaningful and useful for people with disabilities, we must also be realistic and anticipate future breakdowns.

According to this pessimistic assessment, the creation of barrier-free spaces will not be immediately successful. Once the physical changes begin they will progress, albeit slowly (personal communication with Kose 2000). For the time being, people with disabilities should take advantage of the mainstream value of human assistance to access and make use of the built environment (Komardjaja & Parker 1999).

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Changing Attitudes Towards Persons
with Disabilities in Asia

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Introduction

We are in the last phase of the United Nations' "Asian and Pacific Decade of Disabled Persons" (1993-2002). It is timely to examine what has been happening in the Asia Pacific region, and the exciting changes that are set to take place in the first decade of the new millennium.

Before this UN Decade was declared there had already been previous United Nations initiatives, chiefly the "International Year of the Disabled (1982)" and the "Decade of People with Disabilities (1983-1992)" each stressing greater awareness of the need for equitable environments and full participation by all citizens in Asia.

Awareness and advocacy have been increasingly popular themes because the level of accessibility is, to some extent, a physical manifestation of society's acceptance and respect for persons with different ability sets. This is also seen in the on-going production of advocacy materials for people with disabilities to become involved in disability issues (accessibility et al.) by the United Nations Economic and Social Commission for Asia and the Pacific region (UN ESCAP). UN ESCAP, and especially the Disadvantaged Groups Section within the secretariat, is committed to work to show governments what can be achieved. The UN ESCAP region includes sixty-one governments and over three hundred

million people (over sixty percent of the world population).

In certain societies in Asia, disabilities can be perceived as being related to misconduct in a previous life. Also, in some instances, a family member with a disability is perceived as a disgrace to the family - which is another important reason for raising public awareness and destigmatizing disability issues. The effort to increase awareness must be accompanied by two key features: co-operation and commitment amongst all agencies (governmental and non-governmental organisations, voluntary and user groups, self-help organisations, professionals, educational institutions, etc.) and the positive involvement of mass media (press, television, radio, etc.).

Local Initiatives

Local initiatives in Singapore often arise from individuals who persuade others and organisations to become involved. For example the Singapore Polytechnic Centre for the Application in Rehabilitation Engineering (SP CARE), established in 1992, produces assistive devices every year, sometimes generic such as a height adjustable sink but often to aid a specific individual such as a breath operated computer interface (<www.sp.edu.sg/about_spcare.htm>). "Access Singapore" is a printed guide to accessible buildings in Singapore (and available at <www.dpa.org.sg/DPA/access/contents.htm>) and is the result of access audits by persons with disability - the attached accessibility map being an output from students on the Masters Elective "The Accessible Environment" at the Department of Architecture, National University of Singapore.

One of the high profile events that contributed to the raising of awareness in Singapore was the "Day in a Wheelchair" event, a mass simulation exercise, that was conducted in March 1999. This involved about 150 members of the public simulating what it was like to spend time in a wheelchair. The public responded to press announcements about the event and also the organisers invited politicians and locally-based embassy officials to participate. Teams of about twelve persons spent half a day to experience journeys and facilities in the built environment. The event was run in a professional manner, jointly organised by the Singapore Adventurers' Club (SAC), Handicaps Welfare Association (HWA) and Singapore Action Group of Elders (SAGE).

One example of the forward planning was the training, the week before, of trainers in how to handle wheelchairs - overseen by volunteer Occupational Therapists and persons with disability. It received press and television coverage which is an important feature as increasing the awareness of the general public was a prime goal. Questionnaires were provided to the participants before and after the exercise to judge any changes in attitude and the short-term effectiveness of the event. Both the 'before' and 'after' questionnaires had more than 100 respondents and the

negative expectations about the quality of accessibility to the built environment for wheelchair users were met and often exceeded (Parker 2000).

Another event in Singapore, repeated annually, is the Handicaps Welfare Association's "Wheel, Walk or Jog" consisting of a show and a sponsored promenade up and down part of Singapore's famous shopping nirvana, Orchard Road. This helps to raise awareness and break the stereotyping of persons with disabilities.

The Malioboro Pilot Project in Jogjakarta, Indonesia, commenced in July 1999 and is coordinated by the Gadjah Mada University (Parker and Sasiang 2000a). Although small in scale, concentrating on the accessibility features of one pedestrian thoroughfare, its approach of 'learning by doing' has aroused much interest from representatives of other Indonesian cities. Thus there is a likelihood of other, and larger, projects arising in Indonesia. For instance, there is presently a proposal seeking funding from the Japan International Cooperation Agency (JICA) for making Yogyakarta, a popular tourist destination, more people-friendly. Take-up has been slow due to political and economic difficulties, but these should ease in future years.

UN ESCAP Pilot Projects

On a much larger scale awareness can be raised and major players encouraged to become stakeholders in improving the built environment (buildings, streets and transportation) by full scale demonstration projects. UN ESCAP Pilot Projects in Beijing, New Delhi and Bangkok served this purpose. In each case approximately a square kilometre of city was made more accessible, each project being tuned to the local contexts and needs. Each project site was chosen for its high visibility and logistical arrangements for future demonstrations. Beijing and New Delhi are the capital cities of the world's most populous nations. China is expected to attain a population of 1.4 billion by 2010, whereas India has, presently, one billion citizens and various studies suggest that it will surpass China as the world's most populous nation by 2040. Bangkok has a strategic location and is the home base of UN ESCAP.

The intention of UN ESCAP is to work with developing economies that are doing something and are open to doing more. And not, as one might initially presume, to automatically select and work with the poorest and least developed economies. Japan has been a major contributor in terms of both financial assistance and technical expertise and support through the Japan International Cooperation Agency (JICA). Japan's Official Development Assistance (ODA) began in 1954 when it joined the Colombo Plan (an organization set up in 1950 to assist Asian countries in their socio-economic development). Lesser, but significant, contributions are received from Australia and New Zealand. These Pilot Projects are a physical realisation of how

the built environment (buildings, streets and transportation) can be improved for the whole user population. Officially, the Pilot Projects ran from May 1995 to June 1998 and were preceded by an earlier phase whereby model guidelines were developed (comprising planning and building design, access policy provisions and legislation, and the promotion of public awareness with respect to accessibility issues).

The Bangkok Pilot Project focused on eleven streets in commercial and tourist areas (possibly due to the influence of major funding contributions by the Bangkok Metropolitan Authority (BMA) and the Tourist Authority of Thailand). At the time of completion of the project, over 15 kilometres of footpaths, incorporating Braille blocks and user-friendly features, were installed together with over 5000 points of ramp access. By the middle of 1999, over 50 kilometres of continuous upgraded footpaths had been completed (but the total installed in and around Bangkok nearly doubled to about 100 kilometres after a further 15 months). New kerb ramps/cuts, for road crossing, presently exceed 10,000. Further spin-offs have been the improved accessibility of the Bangkok Metropolitan Authority's district offices and the completion of an accessible city park, the Phra Atit Park and Walkway. Work 'in progress' includes the improved accessibility of 70 health centres, 7 hospitals and the first school upgrade. Future initiatives will include enhanced legislative action and enforcement, greater co-ordination between the BMA and public utility organisations and transportation operators.

In Beijing the chosen site was a mixture of residential, commercial and educational facilities. The site had 23 specific targets and was the most demonstrative in terms of the variety of designs. The Fanzhuang area in Beijing was chosen as the Pilot Project site, instead of other proposed sites, because there were many who would benefit (about 4,000 persons with disabilities and 20,000 older persons in the population of 76,000). The Project delivered a range of upgraded facilities including 15 ramped entrances to public buildings, 18 ramped entrances to high-rise residences and about 8 kilometres of Braille blocks. By June 1998 in the city of Beijing there were 24 pavement routes with over 200 kilometres of Braille blocks and 20 underpasses and overhead walkways with ramps.

The New Delhi site consisted, primarily, of fourteen government buildings with large numbers of employees and visitors. In New Delhi there were problems in funding and, eventually, funding was secured from renovation and maintenance budgets. Due to the many levels of bureaucracy ingrained in the Indian decision-making and financial approval procedures, it became important to mix the accessible features into overall budgets so that they could not be isolated, modified or deleted. The impact of the Pilot Project in New Delhi is seen in both the on-going improvements in physical access to other government

buildings and in terms of legislative developments (new guidelines, model by-laws, and strengthening of enforcement on access issues).

Upcoming events in Bangkok and Beijing were also supportive of the Pilot Projects. The 7th Far East and South Pacific Games for the Disabled (FESPIC) Games in Bangkok, 1999, were mentioned as another reason to provide more accessible features in Bangkok's built environment. The FESPIC Games are for persons with disabilities in the Far East and South Pacific region which has 42 member countries. The games were attended by a wide spectrum of athletes, the physically disabled, the visually impaired, those with cerebral palsy and cognitive disabilities. In Bangkok, 15 sports were represented and 2,500 competed. Around Beijing there were a number of additional accessibility, barrier-free projects which were speeded by the wish to complete them before the fiftieth anniversary of the founding of the Peoples' Republic of China, the National Day (guoqingjie) celebration of 1st October 1999.

The Pilot Project outputs and impact have been tangible: media coverage, expansion to other areas, changes in intention in terms of making accessibility a key agenda and design requirement. Each of the Projects has developed its own momentum and will continue to demonstrate good practice for many years.

The Pilot Projects do not directly empower individuals. Instead they lead to a more universal and equitable built environment to enhance the quality of life of all citizens. This physical work goes 'hand in hand' with training in access issues in order to build up the number of persons with the skills necessary to advocate about and improve existing accessibility conditions. More work is needed in less developed economies, such as Vietnam and Korea, which have first to develop a thirst and a will to become more inclusive in servicing the access wants and needs of their total populations.

From Awareness to Advocacy

Brendan Gleeson (1999) stated that it is the "capacity to direct empowering knowledge against disabling practices and ideologies that will define an enabling Geography". Awareness campaigns and talks can focus on the benefits of barrier-free environments, concentrating on the abilities rather than the disabilities. But 'awareness' by itself does not effect change. Simply changing attitudes from a lack of knowledge, rapidly through 'sympathy', to understanding and empathy is laudable, but it is the channelling of awareness into action and empowerment of people that is vitally important. For the greatest effectiveness in making change, efforts and initiatives need to be targeted to professionals who influence and control the design, maintenance and operation of the built environment.

Singapore is a small equatorial island with scant natural resources. It is therefore very aware that it must trade and be

`ahead of the game' to survive. Because of this, economic arguments are the prevalent methodology to win support for change. Singapore is not a `welfare state' as might be understood by a Western audience (Parker 2001). For example, the cost of elevators was deemed too high for the few potential beneficiaries and hence the Mass Rail Transit (MRT) underground rail system was not made wheelchair accessible (fortunately, this is now changing). In Singapore there is no equivalent legislation to the Americans with Disabilities Act (ADA) or the U.K.'s Disability Discrimination Act (DDA). The demographic trend of increasing numbers of elderly persons is a major concern to the authorities and it is probably this, more than anything else, that has brought more attention to inclusivity in recent years.

One way to convince authorities, organizations and individuals of the advantages of barrier-free environments is, for example, to explain the cost implications of a fall (the occurrence of falls should decrease with fewer hazards in the built environment). Whereas attendance at a Singapore Accident and Emergency (A&E) department is S\$70 for the individual and S\$150 for the government, this rises to S\$4,000 and S\$7,000, respectively, if a fall results in a fractured femur. These figures are fully comprehensive in Singapore dollars for surgery, hospital stay, medication, etc. (the exchange rate is approximately S\$1.7 = US\$1).

Another argument is to explain how tourism for persons with a disability can improve the environment for everyone whilst increasing tourism revenues (Parker and Sasiang 2000b). This is especially of significance when, according to the World Tourism Organisation, about 12-15% of the potential travelling public has some form of temporary or permanent disability (World Tourism Organization 1997). Also, the number of tourists roaming the world is set to more than double by 2020 (The Straits Times 2000).

The first "Asia-Pacific Conference on Tourism for People with Disability" was held in September 2000. Mr. Abdurrahman Wahid, the blind President of Indonesia and the First Lady, Mrs. Sinta Nuriyah Abdurrahman Wahid, who uses a wheelchair, opened it. At the end of the Conference the delegates (over 250 from 15 countries) presented the Indonesian Minister for Tourism and Culture with a draft "Bali Declaration" for consideration by the United Nations relating to the needs and rights of travelers with disabilities (Asia-Pacific Conference on Tourism for People with Disability 2001). This was a good example of advocacy making full use of opportunities whenever they arise. This Declaration, when accepted, will be a powerful tool in disability advocacy in the Asia-Pacific region including garnering better governmental support.

A new and recent initiative was the holding of the first regional "training of trainers" course on "The Promotion of Non-handicapping Environments for Persons with Disabilities" in

Bangkok, Thailand, over the first two weeks of March 2000. It was so successful that it will be repeated in February/March 2002. Funding from JICA enabled people from nine cities in Thailand and some 60 participants from the ESCAP region to attend. They came from as far afield as Iran and Fiji with representatives of organisations coming also from China (including Hong Kong), India, Indonesia, Laos, Vietnam, Malaysia, Philippines and Sri Lanka.

Participants were drawn from a range of professions and organisations. These included design professionals (architects, engineers), policy-makers and others from government departments or ministries involved in activities which have a bearing on the design or realisation of built environments including tourism authorities. Other participants were people with an active record of advocacy for access promotion, drawn from non-governmental organisations and user-groups of disabled people, such as welfare associations, and also from universities, Gadjah Mada (Indonesia), Universiti Malaysia (Malaysia), and King Mongkut University (Thailand).

Attitudes to designing non-handicapping environments have become much more enlightened in recent years, especially where the need to design for increasing numbers of older and potentially frail people is being recognised. Design professionals, however, are widely unaware of the impact of barriers for older or disabled people and how these may be removed often by simple planning at both strategic and detail level. Equally, representatives of groups of disabled people may lack expertise in defining and articulating the needs of their members and be unsure of the range of practicable technical solutions which they could ask for and which could be provided at low, or no, cost. In this course, methods to close this gap between awareness of both of need and workable strategies and best-practice solutions were applied. By helping the participants to interact, share experience and develop their knowledge alongside each other, greater respect and empathy is built up, and working relationships established.

Project work, in design scenarios, where both users and implementers are given active roles, helped to establish confidence on both sides and provided participants with challenges to take away with them to be applied in their own countries and organisations. This work was consolidated by practical work, using group techniques, in disability simulation exercises, group design of access surveys and appraisal of built environments and transportation, including trying access features on the new Bangkok Skytrain system and its stations and an access audit of the World Trade Centre building. This workshop was the result of many earlier works, most notable of which was a one week workshop, in June 1998 (Pattaya, Thailand), developing materials to empower those with disabilities to become trainers and advocates on disability matters in developing economies.

Singapore's current "Code on Barrier-free Accessibility" (Public Works Department 1995) was developed as a useable working document and the first version included the increasing population of "the elderly" in its scope mainly because the numbers of disabled people alone were insufficient to justify its mandatory status. Although older persons may not be technically 'disabled' they become 'less able' as a natural part of the ageing process. It should be noted that this Code does not regulate on the interior of dwellings. Future revisions to the Code, to be published in early 2002, will include advisory information on design for elderly persons, children with disabilities, pregnant women and parents with young children. Also, it will include more mandatory requirements for the benefit of vision-impaired and hearing-impaired users, which will be of benefit to many elderly people.

Discussion

The initial work of UN ESCAP is to empower urban-based persons with disabilities in mainstream facilities, but the strategic intention is to work to raise disability issues in rural areas - a way to let persons with disabilities 'out and about'. But this next focus towards rural sectors will not be solely related to disability issues. It will be more holistic and include other social and developmental issues such as child labour, exploitation, and poverty alleviation.

This strategic intention is manifested in the UN ESCAP documentation (UN ESCAP 2000) that seeks to promote the inclusion of disabled persons in the development process. The 73 targets for action, formulated in 1995, are proposed to be expanded into 107 strengthened targets for action by 2002 when the evaluation of the Decade will be conducted. These targets cover all 12 of the policy areas of the "Agenda for Action for the Asian and Pacific Decade of Disabled Persons, 1993-2002": national coordination, legislation, information, public awareness, accessibility and communication, education, training and employment, prevention of causes of disability, rehabilitation services, assistive devices, self-help organizations, and regional cooperation.

It is exciting to witness the rapid move away from playing scant regard to the wants and needs of persons with disabilities, in the more developed Asian economies, by the trend towards the provision of high quality, centralized, facilities. But there has been a further, more mature, move to bring persons with disabilities back into the community, encouraging full participation in all aspects of living such as education, recreation and employment.

For education in Singapore there is the "Teach Me" initiative - providing access audits and recommendations to make standard schools more accessible. More accessible transportation features and systems are being introduced in Singapore - the

retrofitting of access features to MRT stations and accessible new lines, a new accessible Light Rail Transit (LRT) system, accessible taxis (the London Cab TX1), low-floor buses, etc. This is, effectively, a move from a concentration on economic growth per se to focusing upon improving quality of life issues, a reflection of more caring and equitably aware societies. An accessible place is not a luxury. It is an essential requirement for all places in the twenty-first century. With a barrier-free built environment there will be less hindrance to equalities being realized in many other, associated, areas, such as employment, education and life experiences.

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The Illusion of Inclusion: Geographies
of the Lives of People with Developmental
Disabilities in the United States

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Introduction

This article considers the historical and contemporary places of people with developmental disabilities¹ and discusses the role of location in fulfilling social goals through service design. A fundamental premise of social geography is that spatial patterns and social relationships are recursively related. At societal and individual levels, people place themselves and others whom they may control in locations that express on-going relationships. Space, and other geographical constructs such as distance and proximity, are used to create, constrain and mediate social relations (Wolch & Dear, 1987); and these goals are not mutually exclusive.

For people with developmental disabilities, as well as other disabilities and other minority status, space has been used to create and reinforce the prevalent social services mode that reflects the mixed and conflicting goals of those who fund services and supports. We will be addressing the spatial implications of two service designs: an initial design based on segregation and control by institutions which has dominated much of US history; and the more recently emerging community-based services design intended to redress the legacy of segregation and control.

Starting in the 1970s, Wolpert, Dear, Wolch and C. Smith, along with their many colleagues have greatly expanded the breadth and depth of geographical studies of mental health. In the 1980s Philo (later to be joined by Parr) began to describe the intricate historical geography of the "mad-business" in Great Britain. (Full citations to representative works by these authors can be found in the bibliography.) While the work of these geographers has relevance for people with developmental disabilities, it would be a mistake to simply generalize due to the "mental" adjective of developmental disabilities. In the 1980s, Radford, Park, Walker, and Metzger began to look more closely into various socio-spatial dimensions of the lives of people with developmental disabilities.

Now that most people in institutions have been re-located into communities, we are more concerned that this physical inclusion has not brought about social inclusion, full community membership and belonging, and valued roles for people with disabilities (e.g. Wolfensberger, 1972; Bogdan and Taylor, 1987; Schwartz, 1992) despite the claims that locations of services and supports are inclusionary. The first half of this paper examines the dubious inclusionary geographies of people with developmental disabilities from the colonial times through the mid-1900s. The

second section addresses issues of contemporary service designs and their impact on people's lives.

A Brief Historical Geography of Lives in the Community

Our reading of early volumes of *The Journal of Psycho-Asthenics* (a publication of the American Association for the Study of the Feeble-Minded) and of a variety of overviews and histories of services for people with mental retardation and developmental disabilities (e.g., Davies, 1930; Best, 1965; Wolfensberger, 1972; Scheerenberger, 1983) reveals that the American history of treatment for persons with developmental disabilities can be broken down into a number of distinct historical phases. When the impairment of feeblemindedness was strongly differentiated from other dependent conditions (see Trent, 1994), the locations of services began to reflect the "new" classification. As a graphic overview, Table 1 summarizes the documented service ideologies of the time and their predominant locations. In this table, the term "community" is used to contrast with formal facilities such as asylums and institutions.

Table 1
Period, Policy and Place of Services
for People with Developmental Disabilities

PERIOD	POLICY	PREDOMINANT PLACE
Colonial - 1820	Indoor Relief	Families, relatives, other community households
1820s - 1850s	Outdoor Relief	Almshouses
1850s - 1870s	Education	Schools in the community, then expansion into rural locations
1870s -1880s	Protection of with people developmental disabilities	Asylums in distant rural locations
1880s - 1920s	Protection of society from from people with developmental disabilities Colonies and parole	Institutions in distant rural locations In communities
1920s - 1950s	Custodial care	Institutions in distant

		rural locations
1950s - 1970s	Custodial care	Institutions in distant rural locations
	Initiation of community-based services	Schools, day activity & residences in the communities
1970s - 2000	Deinstitutionalization	Schools, day activity, & residences in the communities
	Continued growth of community-based services	

In colonial times poverty and dependency were not unusual nor unexpected circumstances and communities were generally prepared to help those individuals or families who became needy. However, there were some criteria for receiving assistance. People who were part of the community received local aid; strangers were encouraged to move on. The condition of dependency, not the specific cause of dependency, was reason for communities to arrange relief, but only the worthy poor - widows, orphans, and people with disabilities - were supported (Trent, 1994).

The colonial service design was either outdoor or indoor relief; both types were financed by the general community. Outdoor relief was intended to minimize disruption in the dependent people's lives while keeping them in the midst of the community (Rothman, 1971). This was accomplished by supporting them in local households which could be their own family, relatives, or neighbors (ibid.; Scheerenberger, 1983). Deutsch (1937) provided an example of John Deanne, an "Iddiot," who was "boarded out" to a Mr. Richard Henry in 1661. Not surprisingly, the household that offered the lowest fee for the service received the boarder. Yet while people who were considered feebleminded remained in their home communities, their social roles were not positively valued. While not feared, (Trent, 1994), village idiots were not highly valued community members.

Indoor relief referred to larger and congregate settings that were initially based on a household model and were called "almshouses" (Rothman, 1971). Almshouses were constructed and used when people who needed intense supports could not be taken care of in a local household (ibid.). Discussing an almshouse in Boston in the mid-1700s, Rothman identified the elderly and people with disabilities as the majority of the residents therein. While this almshouse was located at the head of the Commons, a central area in the colonial town (Savage, 1884), the social exclusion of the residents was evident when Rothman (1971: 41) states, "Both were disqualified from taking a place in the

community at large."

While there has been much written about the development of formal services in the mid-1800s for people, particularly children, with developmental disabilities, less is known about the home life of families and their members with developmental disabilities during that same time period. Recently Richards (Richards and Singer, 1998; Richards, 1999) has begun to address this gap by conducting archival studies of family experiences with members who had development disabilities. She provides meaningful context for these sources through an examination of the contemporary popular fiction. Some families were clearly supportive and loving and they valued their member with a developmental disability. But by the 1870s, the rise and growing dominance of professional expertise had changed these happy families to guilty families when children with disabilities were viewed as evidence of the sins and moral weaknesses of the parents.

In the United States, schools opened in the second half of the nineteenth century based on the belief that education would "cure" feeblemindedness and students would return to their families in a productive capacity. Physicians or teachers operated the small schools in their own homes located in the midst of the communities. As more students entered the schools, additions were built onto the homes or the schools relocated within the town or city (Journal of Psycho-Asthenics, 1940). Research on the geographical origins of the children and their social inclusion into the local community is lacking, but we can speculate that treated as a group such inclusion was unlikely.

Increased enrollments drove the relocation of these early training schools as children continued to be identified as feebleminded. Cheaper prices for land in the country undoubtedly contributed to the notion that the countryside was a preferable environment for schools for these children. Some students were funded by the state in these private schools, thus laying the foundation for the creation of state departments responsible for schools for the feebleminded, and it was not long before this "new social problem" of feeblemindedness required capital construction to contain the burgeoning numbers of students.

But where to locate these schools? Edward Seguin, a respected leader in education for feebleminded children, advised that the locations of the schools "should be located where future inmates are born and raised" (Talbot, 1964, cited in Scheerenberger, 1975: 10).² We can hope that this was to help maintain the students' local familial and social connections and to allow for their easier reintegration into their home community.

But this advice was blatantly disregarded. Capital cities, often themselves sited for geographical centrality, were a choice site for these facilities demonstrating the optimistic social policy of education as a cure for mental handicaps as well as

showcasing the legislators' self-serving beneficence (Fernald, 1893 in Wolfensberger 1975; Braddock, 1998; Trent, 1994). In "Historical Notes on Institutions for the Mentally Defective," (Journal of Psycho-Asthenics, 1940: 188) the unidentified author observed:

It is interesting to note that this first institution was located near Albany, the legislative seat of the State. The reason is found in the first report of the Trustees when they write, "As the enterprise was experimental there seemed great propriety in its being conducted so near the Capitol that the members of the Legislature might from time to time examine it and become acquainted with its success."

Since the institutions drew their residents from the entire state, children and youth were removed from their home communities, disrupted from their everyday lives, and thrust into an unknown and controlled environment.

Despite the great number of people who were institutionalized over time, the majority of children and adults with developmental disabilities were not. "The single overwhelming feature of the changes in policy toward retarded people between 1850 and 1875 is that they led to very little change in the daily lives of most of those individuals" (Ferguson, 1994).

In the 1870s, the training schools began to transform into asylums for the protection of the vulnerable children.³ Most of these children were the ones who had not been able to be cured by education. Their numbers increased as other severely disabled children were admitted. "By 1875 there were more than twenty-five State schools, almost universally spoken of as institutions" (Kuhlmann, 1940: 11). As feeblemindedness and delinquency began to be associated with the growing lower and immigrant class, institutions began to function to protect society from these potential troublemakers. The institutions expanded to meet the needs of "high-grade" and "low-grade" residents, designed to provide for every daily needs, thus there was little reason for a resident to enter the towns or cities.

Soon after in the 1880s, restricted marriages, sterilization of both men and women with developmental disabilities, and institutionalization were implemented as social controls to prevent the reproduction of "degenerate" people (Weiner, 1993). Thus began the period during which the dominant professional perspective attributed all social problems to heredity and the solutions to eugenics. However, Lakin, Bruininks, and Sigford (1981) have noted that social policies for people with developmental disabilities were not a great concern for most of the American population during the eugenics period and that people with developmental disabilities living among them was not particularly unusual. We are regrettably uninformed about

people's common daily lives and where they occurred.

From the 1870s through the 1920s, articles in *The Journal of Psycho-Asthenics*, a lead professional journal, focused primarily on issues concerning institutions and their residents. Yet professional interest in community services was growing hand-in-hand with the recognition that there would never be institutions big enough to contain all the "mental defectives" who allegedly needed their special services. Again, education for children who most likely had mild developmental disabilities was a primary community service. By 1930, fifteen states "enacted statutes making mandatory or permissive the establishment of special classes or schools for mentally handicapped children in connection with public schools" (Davies, 1930: 297). Articles reported on special education discussing competition among some major cities for the honor of being early innovators of exemplary programs. Special education classes, though physically in the communities and "connected to the public schools," were isolated from the regular classes in various ways that are still in use: in segregated classrooms in a regular school, in temporary buildings on shared school grounds, or in entirely separate buildings not on shared school grounds. In St. Louis, Missouri, classes for "subnormal children" were purposefully organized for complete segregation (Wiley, 1922: 231). He wrote:

The special schools were organized with the idea that not only should the children be segregated from normal children in their class instruction, but that they should also be segregated from the regular elementary school environment. Consequently nearly all of the schools have been established in locations set apart from regular elementary schools.

Such segregation was stoutly defended in St. Louis, despite the cost: \$197.20/special class pupil compared to \$59.70/regular class pupil.

Because of the high cost of maintaining these relatively small school centers there is occasionally questioning of the wisdom and necessity for the segregation of these classes for the feebleminded children from the environment of the regular elementary schools and it should be said that the experience had in recent years with the 3 schools conducted in connection with regular elementary schools has not been unsatisfactory. (Wiley, 1922: 232)

Despite the "not...unsatisfactory" experience, and the lower cost of being located "in connection with regular schools", the policy of segregation overrode experience and potential cost savings very likely signifying the preference of the professionals, thus the importance, of segregation. This service location, segregation within the community, foreshadows other

service locations that would be chosen in the decades to come.

Two service designs were developed to meet the goals of productivity that the professionals of the times had for people in the institutions. Both colonies and parole were directed towards employment. The farm colony, an institutional satellite agricultural operation whose purpose was to "... provide suitable homes and employment to the boys, and secondly to supply the home institution with fresh food" began in the 1880s (Journal of Psycho-Asthenics, 1896: 69). The colony concept was greatly extended by Charles Bernstein, superintendent of the Rome (New York) Custodial Asylum from 1902 to 1942, to include industrial and domestic colonies that relocated people from the institutions into communities that needed labor. Not only did people from the institutions work in factories, mills, and homes in the communities, but they often lived in those same communities. Forerunners of group homes for women have been described to indicate that two "colonies" were located near work sites in town (Trent, 1994). Once again, more research is necessary to determine the degree of any social inclusion.

In the 1910s, the parole plan was recognized as a "successful experiment" presaging deinstitutionalization. Again, people from the institutions were placed in jobs and residences in the communities, and after having proved that they could live on their own without supervision from the institution, they were formally discharged. Not only did the parole plan demonstrate the success, and therefore the continuing necessity of the institutions, but it also minimally relieved the overcrowding, fueled by increased institutionalization during the eugenics period.

Despite the more physically integrated locations of some colonies and the people on parole, the institution continued to be the dominant service provider and its staff the experts on people with mental retardation and developmental disabilities.

Service design and locations did not remarkably change from World War I to World War II. People continued to be institutionalized with the number of people increasing from a little over 115,000 in 1946 to nearly 200,000 in 1967, "nearly twice the rate of increase in the general population" (Trent, 1994). In the mid- to late-1960s, federal legislation provided funds for new construction of institutions. Eventually these residents were the ones who constituted the great deinstitutionalization movement in the next two decades.

The first service design, a physically segregated unit (e.g. schools, asylums, and institutions), was the core component in all of the above service designs. A second service design emerged after World War II, resulting in a developmental disabilities community services landscape that is still visible based on the development of formal community services, has been well-documented elsewhere in the mental retardation/development literature (i.e. Wolfensberger, 1972; Scheerenberger, 1983; for a

case study, see Metzger, 1983). Vacant and typically devalued spaces in the communities, often the archetypal church basements (Wolfensberger, 1972), became the sites for pre-schools and particularly for school classes for children with moderate and/or severe developmental disabilities who were excluded from public school special education classes.

As the children aged into adults, day activity programs, vocational training programs, and residences were sited in the communities. Though on a smaller scale, and much less physically isolated than the state institutions, this generation of expanded community and post-institutional services designs for people with developmental disabilities have clearly perpetuated the prevalent goal of serving society and promote isolation, exclusion and stereotypes with locations that emphasize congregation and segregation rather than individualization and inclusion.

The current generation of community services is struggling to increase community inclusion, membership and valued roles of people with developmental disabilities through the incorporation of person-centered planning, self-determination, and individualized supports. The next section of this paper reviews contemporary trends and issues in community services.

Current Issues in Community Living and Support Services for People with Developmental Disabilities

As a concept, deinstitutionalization was a corollary to the principle of normalization which emphasized integration and promotion of typical lifestyles (Scheerenberger, 1987; Wolfensberger, 1972). As a practice, deinstitutionalization began in the late 1960s spurred by lawsuits, exposes, and efforts by people with disabilities, parents, and professionals (Taylor, Racino & Walker, 1992). As of 1999, over 75,000 adults remain in institutions and other large facilities (16 people or more) for people labeled with mental retardation (Prouty, Lakin & Anderson, 2000). Also, as of 1997, 23,087 children and youth with developmental disabilities resided in out-of-home placements (Lakin, Anderson & Prouty, 1998).

While not everyone has moved out of institutions for people with developmental disabilities into community-based settings (e.g., some people moved into nursing homes and other types of congregate facilities), many more have moved into smaller residences located within typical neighborhoods and communities. This section first describes selected features of this community-based service system that developed and discusses some of its limitations and shortcomings.

As development of the community-based service system began, families who had children or adult members with disabilities were given limited respite and other supports. This was not adequate for those with severe disabilities. Instead, more intensive supports were offered in group homes and institutions forcing many children to miss the opportunities to grow up within their

family, neighborhood and community.

Traditionally, community-based services were part of a designed "continuum of services" approach with the continuum ranging from most restrictive to least restrictive environments. The residential services continuum, for example, involves such components as: Intermediate Care Facilities for the Mentally Retarded (ICFs), group homes, supervised apartments, supported apartments, and independent living. The intensity of supports was linked to the type of setting. As people gained skills and competencies, thereby requiring less support, they would progress along the continuum. Educational and day/vocational services were designed in a similar fashion.

There have been, however, a number of problems with the continuum approach to services (Taylor, 1998). First, people who moved along the continuum experienced much dislocation as they often had to move away from neighborhoods, jobs, and social networks. Second, those who needed the most intensive services never "progressed" along the continuum thus remaining in the larger and more restrictive settings. Others, with less severe disabilities, attained independent living, but then were at risk for "failing" at independent living if they had a change or crisis in their lives which required more support.

Another shortcoming of the community-based system was the continued congregation of people with disabilities, albeit on a smaller scale than institutions. People with disabilities were moved into group homes with often at least eight or ten others. They spent their days at sheltered workshops or day habitation centers and recreated in specialized, segregated programs. Often they were transported as a group in private vehicles to and from these sites. Participation in community places consisted predominantly of those types of places that offer little possibility for interaction with others (Walker, 1999). Thus, the round of daily life for many individuals with disabilities was still highly segregated from the mainstream of community life and their social worlds were mainly composed of others with developmental disabilities and staff, both not necessarily of their own choosing. In the mid-1980s, in response to the dissatisfaction with this traditional community-based service system among increasing numbers of people with disabilities, families and professionals, a more individualized support approach evolved.

In recent years, as an alternative to the continuum approach, innovative service providers began using an individualized supports approach. With respect to families, this is based on the principle that all children belong with families and that families should be offered "whatever it takes" to support the child and family (Taylor et al., 1987; Taylor, Knoll, Lehr & Walker, 1989). In terms of residential supports for adults, housing is separated from supports. The type of setting is not tied to the level of supports (Taylor et al., 1987;

Racino, Walker, O'Connor & Taylor, 1993). Rather than having to "fit into" a group setting of four, six, eight, or more other individuals, not necessarily of their own choosing, this approach opened up many more options for people with severe disabilities. They now had the option of renting or owning a home or apartment on their own or with others; of living in the neighborhood and location of their choice; and living with the number of people, and the particular people of their choice. The supports that people need, whatever their intensity, are provided in the person's home. If the person's needs change, the level of support changes accordingly.

This support approach also requires more individualized support for community involvement and interaction. This includes providing support for participation in community places and activities based upon a person's choice and interests. This means promoting social interactions and relationships with a variety of community members deliberately beyond staff and others with developmental disabilities, again based on personal choice and interests.

Implications for Community Membership and Inclusion

Traditional community-based residential services have contributed to the community presence of people with developmental disabilities. These services have not necessarily facilitated community membership and in some ways have been an impediment (Bercovici, 1983; Calvez, 1993) giving the illusion of inclusion. While living in the community is a first step, that alone is not sufficient to promote community membership and inclusion (Bogdan and Taylor, 1987). Individualized approaches have increased opportunities for community inclusion compared to traditional service delivery approaches. At the same time, there remain some constraints to community inclusion and membership.

One is that people with developmental disabilities, who often rely on SSI and Medicaid, still typically have very limited financial resources which limits their housing options. In response to this, advocates have been working to help people with developmental disabilities gain access to funds that support low-income, nondisabled home owners or renters. A second is that Medicaid funds are still heavily invested in institutions and nursing homes with less allocated toward support for people with high levels of need to live in their own homes. Again, advocates have been working on legislation (MiCASSA) that would ensure home care options for people with disabilities, including those with developmental disability labels. Finally, there are limitations to the extent that any service design alone can promote community inclusion. Providing individualized supports that offer opportunities for participation in places of one's choosing does not necessarily guarantee that people will experience a sense of membership and belonging. Furthermore, neighbors, community members and society as a whole have an obligation to confront and

dispel rejecting attitudes, stereotypes and practices. Continued efforts are needed to combat all of these constraints.

Conclusion

Our historical and contemporary discussions lead to the unsurprising conclusion that the dominance and designs of the service systems has, at every turn, unintentionally or intentionally prevented social inclusion when people with disabilities are treated as a group. Even if people with disabilities are supported in individualized ways that promote not only community presence, but participation, there still remain a number of constraints to the geography of their lives in the community. We are still learning how to provide support and services in places where people with developmental disabilities are that do not intentionally or unintentionally restrict them and devalue them.

Yet despite on-going constraints, an individualized approach support services design has made a significant contribution to expanding the social-spatial lives of people with developmental disabilities and to promoting increased control and spatial choice. In deliberate contrast to the traditional service models that perpetuated fear, stereotypes, and social exclusion, individualized approaches are designed to enhance social inclusion and community membership and to reduce fear and stereotypes.

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Notes

1. Examples of a developmental disability are: Down Syndrome, autism, cerebral palsy, epilepsy, and mental retardation. The Federal Developmental Disabilities Act (U. S. Public Law 101-496) defines a developmental disability as a severe, chronic disability of a person five years of age or older which:

A) is attributable to a mental or physical impairment or combination of mental and physical impairments;

B) is manifested before the person attains age twenty-two;

C) is likely to continue indefinitely;

D) results in substantial functional limitations in three or more of the following areas of major life activity: self-care; receptive and expressive language; learning; mobility; self-direction; capacity for independent living; and economic self-sufficiency; and

E) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are lifelong or extended duration and are individually planned and coordinated; except that such term when applied to infants and young children means individuals from birth to age five inclusive, who have a substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.

The label, "developmental disabilities," is currently in use in the US though lately "cognitively disabled" has emerged. Other countries use "mentally handicapped" or "people with learning difficulties." In this paper, the terms "feebleminded" and "mentally defective" are used for historical accuracy.

2. For a similar recommendation by Edward Jarvis on the siting of lunatic asylums in North America in the nineteenth century see Philo (1995).

3. For an excellent and in-depth analysis of custodialism, see Ferguson, 1994.

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Book Review: Clear, Mike (Ed) (2000) *Promises
Promises: Disability and Terms of Inclusion*,
Sydney, Australia: Federation Press
<[http://www.federationpress.com.au
/Books/Clear.html](http://www.federationpress.com.au/Books/Clear.html)>.

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Promises Promises documents the social justice struggle of people with disabilities in Australia and particularly New South Wales (NSW) over the last 25 years. It is based on people with disabilities telling their stories, involves a broad spectrum of the disability community, and presents an informed critique of the policy and legislative changes. The book developed from a Disability Council of NSW funded project "Telling Stories" which actively sought to present the lives of people with disabilities and the impact that government policy has had on their lives. As such, *Promises Promises* presents an openly social perspective on disability. This approach views the impaired person not as a tragic problem of the individual, but as a product of a disabling social environment and hostile social attitudes. This social perspective draws attention to the disabling economic, political, social and cultural systems that produce disabled people¹ in Australia.

The book is divided into three sections, has four appendices, extensive endnotes to each section and provides an

excellent selected bibliography. The sections and appendices are: Part I: Dialogues on Disability; Part II: Promises Forstalled; Part III: Social Forces in Personal Lives; Appendix 1: Information, Research and Rights-based Contacts; Appendix 2: Definitions and Accommodation Figures; Appendix 3: Employment Statistics for NSW and Australia; Appendix 4: Human Rights & Equal Opportunity Commission figures relating to the DDA.

Part I, Dialogues on Disability, presents the stories of five people with disabilities presented as conversations with an interviewer. They include: Diana Qian, a physically disabled woman from a non-English speaking background whose story presents an emerging political activism; Alice, a woman with a psychiatric disability in an ongoing dialogue with institutional practices and professional power; the photographic reflections of Trevor Whiddon, a man with a developmental disability; Tony Murphy, a man with Down Syndrome and his life at Sunnyfield Association and subsequent community integration; and Sondra Wibberley's experience as a blind woman negotiating work. These chapters introduce the reader to the practicalities of emancipatory research through the intensely personal stories of disabled people. However, it is this section of the book that does not have the same impact as the other two parts of the book. Greater thought needed to be given to when and in what format these conversations were to be used.

Part II, Promises Forstalled, is written by the editor of the book, Mike Clear, and provides the substantive critical analysis of the book. Chapters 6 and 7 review the disability related ideological, legislative and policy change in Australia and NSW over the last 25 years. Chapter 8 engages the title of the book by analysing the "promises" of government disability policy during this period and how this has been reflected in the lives of disabled people (positive, negative or uncertain). This is followed in Chapter 9 by a presentation and analysis of a variety of data that examines the persistence of alienation in the lives of disabled people and how this serves to marginalise disabled people's community involvement. Chapter 10 again personalises the analysis by providing a number of case studies (education, work, NSW Taxi Subsidy Scheme, the Disability Discrimination Act, and the market) highlighting a flawed reform process.

Part III, Social Forces in Personal Lives, returns to the involvement of disabled people by gathering five noted Australian authors with disabilities to write on four key social issues. These issues include social and political dimensions of access (Mark Sherry), representation and disability (Lynne Davis), telecommunications (Gerard Goggin and Christopher Newell), and models of care and perceptions of disability (Jo Harrison). In reading these sections one was struck by the unique Australian context that provides further insights into the social construction of disability rather than just the United Kingdom or

United States perspectives that dominate disability studies. This section is only disappointing in that the editor could have included many other issues and disabled authors.

Promises Promises identifies that there have been some important changes to social and cultural practices that affect the lives of disabled people in Australia. These changes have been heavily influenced by disabled people. However, their involvement has come about not always through an inclusive approach, but required a persistent determination to challenge the status quo of the day. The book shows the importance of and connection between: reflection on personal experience; understanding the political context of this experience; and the development of a movement for social change. *Promises Promises* does not claim to provide an anthology of the disability movement in Australia or NSW, but this book represents the first in a series of critical reviews on the Australian disability experience by the Federation Press and other publishers.

Promises Promises is an essential book for students, academics, policy makers, politicians, people with disabilities and anyone wishing to truly understand what a social and an emancipatory approach to disability involves. As such, *Promises Promises* is an important contribution to documenting the social justice struggle of people with disabilities in Australia, but particularly NSW over the last 25 years. However, it is more than this because it is based on people with disabilities telling their stories, involves a broad spectrum of the disability community, and presents an informed critique of the policy and legislative changes. *Promises Promises* is a significant contribution to disability studies in Australia. Nothing stands testament to the quality of this book from a disability perspective more than the fact that the NSW Minister for Ageing and Disability, the Hon. Faye Lo Po', refused to launch the book on the grounds that it was too controversial in content and critical in its analysis of the government.

Note

1. While "people with disabilities" is the generally accepted terminology in Australia, *Promises Promises* adopts the British nomenclature of using "disabled people" as a political signifier that they cannot become people "first" until society stops "disabling" impaired people as set forth in Mike Oliver, (1990), *The Politics of Disablement*, Macmillan, London.

From the Field

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Coming Out Disabled: The Politics of Understanding
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The experience of being disabled is one path into Disability Studies. But is it? Is this assertion as straightforward as it first appears? That such experience is a path into disability studies remained unambiguous for me until I began to prepare for the 2000 Society for Disability Studies conference in Chicago. To whom does the experience of being disabled belong? How do we read and identify what counts as disability experience? In the midst of a context where disability experience can be understood to ground both identity and knowledge production, my invisibility as disabled began to haunt me as an absent-presence and my obvious, darn near iconographic, appearance as "one of the normals" was a presence I wanted to make absent. This has provoked me to shift a way from a critique of abilist forms of knowledge production and toward an interrogation of the standpoint of disability as a place for knowledge as well as toward a consideration of arguments regarding what counts as such a stance. This is the politics of understanding that I will pursue in this paper and I do so by turning to an examination of pluralistic and even contradictory experiences.

Experience, Identity, and Access

Experience *of*, identity *with*, and access *to* the stuff of everyday life are tied up together not only in relation to disability, but in all situations. For example, three years ago, after completing my PhD, I moved from Toronto to a small town in Nova Scotia in order to teach sociology at St. Francis Xavier University. In the province of Nova Scotia it is illegal to sell cigarettes to anyone under nineteen years of age. When I attempt to buy cigarettes, and despite the fact that I am thirty four years old, some store clerks do not grant me the identity of "being of age" and thus ask for picture-identification, particularly a drivers licence. Driving is something that I have not learned how to do. So, I invoke *experience* as proof that I

possess the *identity* of being "of age" in order to access my desired end - cigarettes. I tell stories: "You know, I am 34." "I teach at the university." I show my faculty card. I show them too my many credit cards. Certainly, I argue, an under-aged person could not carry so much credit. If all this fails, I look to see if there are check-out clerks whom I know who might attest to my status of "being-of-age." Despite all this, somehow my experience of being "old enough" has been made invisible. Something to do with my appearance (long hair, style of clothing, stature, not-driving) covers over my age. Thus, I have to *work* to make my age appear to others. The obviousness of being old enough to myself marks those who seek out proof of it as ridiculous to me. As invisible as my thirty four years appears to some marks me as a little strange or as trying to pull a fast one. Some say, "Dear, think of it as a compliment." Regardless, I find my self trying to draw out my age for others.

In the face of trying to make visible to others what does not appear to them, the typical set of practices pursued is the seeking and the offering of "proof." This holds true, as much if not more, in relation to those lived experiences glossed by the terms "invisible disabilities" and "learning disabilities." The social-political consequences of seeking, securing, and offering proof of these disabilities are certainly more messy and dramatic, life altering and death defying, than those involved in the proof of age and the procurement of cigarettes.

The proving of learning disabilities is an incredibly messy situation: the proving enterprise has grown exponentially over the last couple of decades and the tendrils of diagnostic desires and procedures reach out into classroom practices, psychological and intelligence testing, brain imaging, gene mapping. Students who have "proof" of learning disabilities may, indeed, share very few experiences in common with one another: what counts as a learning disability is becoming more and more diverse. Some people have spent a life time being treated as learning disabled and others only a week or two. Learning disabilities are tied into the inequalities surrounding race, class, gender, state, and nation.

Diversity of definition, diagnosis and treatment, diversity of embodiment, and diversity of social location all impact on and organize the proof generating enterprise. Despite all this diversity, those learning disabled students who reach university in Canada or the United States will more than likely share in common the fact that all will have received a great deal of training on how to prove to others that they possess legitimate proof. (Professionals in the field of learning disabilities often refer to these proof-giving practices by the more sophisticated term of "self-advocacy.") The generation of proof requires the reconfiguration of diverse experiences into a single organized category of identity - dyslexia, ADD, mental illness, etc.

It was just such proof with which I was going to begin this

paper. But, if I want to do more than conform to the normal order of things, I need ask: "If the experience of being disabled is a path into disability studies, who is understood as traveling this path, how, and what does this teach us?" This kind of questioning requires me to treat proof-giving practices as something to think about and not just something to do. I do not ask after the relation between the experience of being disabled and the doing of disability studies so as to draw unquestioned boundaries around qualified and unqualified speakers and researchers. Rather, I am considering this relation so as to gain some understanding of the social significance of disability experience conceived of as a critical space for critical inquiry while, at the same time, following through on the promises of understanding disability as just such a space.

So again, my preliminary assumption was that I should "give proof" - come out and self-identify - say "I am dyslexic." Unlike the clerks who do not sell me cigarettes, I would assume the reader's good will, I would not provide a medical assessment or brain image, but I may have told a story about my own or others' experiences with me that have come to count as dyslexia. I could begin to describe that which I assume would otherwise remain invisible to the reader: anomalous and different relations to space, time, numerical and logical order, sequential, memory and linguistic mix-ups. I could tell stories about how dyslexia remained invisible to me too, the consequence being that I spent my childhood and adolescence thinking that I had a form of mental illness. In so doing, I would reconfigure diverse experience into signs of dyslexia thus making *not passing* as "ordinary and normal" an active practice.¹ Through such accounting practices (Garfinkel, 1967) I could begin to pass into and pass as an instance of disability.

Herein lies something unusual.

Coming Out

As a way to begin to consider the social significance of the activity of not-passing, consider a contrary experience as articulated by Rosemary Garland Thomson (1996:xvii) in her introduction to *Freakery*:

The notion that someone with a very visible physical disability might "come out" perhaps seems oxymoronic to those for whom the cultural assumptions that structure the normal remain unquestioned. Indeed, pressures to deny, ignore, normalize, and remain silent about one's own disability are both compelling and seductive in a social order intolerant of deviations from the bodily standards enforced by a quotidian matrix of economic, social, and political forces.

Here, passing as at-one-with, or as closely-connected-to, the "cultural assumptions that structure the normal" is depicted as a compelling activity. So compelling is such passing that one does not only come out *to* others, but one must come out *from under* the seductive power of an unquestioned sense of normalcy - come out *for* one's self. Practices of denial, of ignoring, of normalizing, and of silencing can be understood as the activity of passing, of not coming out, even if Abilist Others "see" this person as an outright example of, and nothing other than, "Disability." In Thomson's account, diverse experience is reconfigured into more singular unified identities - one is a passer or one is not-a-passer. Either way, both are achieved in relation to abilist assumptions that have already organized the complexity of another person's life into the sign of disability.

The problem, implies Thomson, is that a person may be seen as, understood as, treated as, and contained by stigmatized conceptions of disability and yet, that same person may be engaged in activities, such as denial or silence, which unquestionably assume the good of securing a place among the cultural structures of normalcy. Through passing, stigmatized conceptions of disability, at best, remain undisturbed, at worst, are re-deployed. The activity of passing in light of a very visible physical disability is described as compelling, coming out as potentially oxymoronic. Whatever else disability studies says that disability is, or whatever model of disability one follows, visible disabilities are the signifiers in relation to which people develop identities (e.g., this person is a passer, that person is a conundrum) and in relation to which people can develop knowledge. In this case, we come to know that culture *propels* as much as it *compels*.

Coming out as disabled, in the absence of what a culture typical envisions as disability's typical presence, seems a slightly different matter. If a dyslexic person, for example, is to come out, she must actively deny her own stance in, as Irving Zola (1993) has put it, the "world of the normal." It is the very visibility of normalcy that must be silenced, ignored, denied. It is the person's assumed and apparent stance in the ordinary that makes coming out as, and passing into, disability a different matter for people whose differences do not readily appear to others who unquestioningly assume, and thus "see" only, the structures of normalcy.

For the "very visible physically disabled person" to come out to and out from under normate² culture means making disability signify something other than what culture has in mind. In Thomson's account, disability must now come to signify something other than embodied lack separating one from the normals and something more than the supposed omnipresent desire to get as close as is possible to the structures of normalcy. And yet all this is done in the midst of the power and seduction of the structures of normalcy that serve capitalist economy and

abilist culture. However, coming out does not mean freedom from normalcy. It does mean being in a position to question it. Yet, as Rod Michalko (2000) says, "The least normal thing we can do is to think about normalcy."

What makes this a difficult process is that everything about a visibly physically disabled person can be made to signify lack which is tied to on-going rationalizations of disabled peoples' marginalization. Passing as normal is not some sort of abstract ill state of affairs. It is seductive precisely because securing some sort of stance in normalcy is a possible path toward a version of participation (e.g., becoming "able" to serve, or be, the status quo). For those with non-readily apparent disabilities the difficulties are different - everything about us can be made to signify normalcy. Nothing "apparently" blocks our path into normal routine affairs. No-thing about us can be readily observed and used to justify marginalization. In other words, so called "invisible disabilities" are made invisible by something and that something is the multivarious but taken-for-granted appearance of normalcy. Disabilities are covered over, and made invisible, by the structures and assumptions of normalcy.

"Visible" or "invisible," the meaning of disability is bounded by, articulated through, and is often made apparent in "very normal ways." Visible or invisible disabled people who "come out" understand that their experience of disability has been organized in relation to the structures of normalcy.

As an adolescent, I made sense of my experience of having trouble negotiating my way through the physical and verbal realm of print culture by interpreting this trouble as mental illness. No one told me that I was mentally ill. Instead, "mental illness" is an identity category that our culture has ready made for anyone who deviates from the normal structuring of ordinary life for no "apparent" reason. At the age of 20, I found myself going to school in Mexico, trying yet again to learn a second language - a requirement for my B.A. In Mexico I lost "mental illness" and was diagnosed as dyslexic. Dyslexia now became my way to make sense of what I was unable to do.³

Notice that coming out from under the normal sense making device of "mental illness" means getting my experience to fit into another category structured by and for the order of normalcy. If I am to prove my experience is the experience of disability, I will have to rely on normal conceptions of disability in order to do so. I would have to say that I possess an embodied impairment and this means that I lack. Or, I could engage in the set of normal practices that are typically used to make this particular invisible impairment appear. I will have to show that despite my appearance of normalcy, I embody a difference that I want the reader to experience as "disability" and I could be seduced into using a very normal conception of disability as lack and impairment in order to do so. Such self-identification does not adequately represent the disruptive power

of coming out to which Thomson refers. "Coming out" cannot mean giving or receiving the "correct diagnosis" for this would simply mean that I am being compelled by "a social order intolerant of deviations for the bodily standards generated by a ... matrix of economic, social, and political forces."

Coming out so as to reveal the complexity of disability for identity, thought, and politics means, instead, questioning the connection between normalcy and disability. Such questioning arises in that space in-between assumptions structured by normate culture and the experience of not fitting neatly into those same structures. (Titchkosky, 2000) There are, after all, very normal ways to make disabilities appear that do not normally appear to others. Indeed, it is compelling to experience disability as ordinarily as is possible. This is not a coming out, but a sinking into the normal and ordinary ways our culture has ready made for all of us to imagine disability.

I could, for example, give you a list of the problems, readily apparent to me, that have come to be called dyslexia. I could dwell, as the social model theorist put it, on impairment. (Oliver 1996, 1990; Barnes 1998) But this is more than a focus on the wrong things. It is a non-self-reflexive focus. The problem lies not in the "object" (differential embodiment), the problem lies in what relations do we establish to these so called objective renderings of disability. Simply proving that I count as a disabled person does not necessarily move me, or anyone else, toward following through on the promise that disability can be a critical space for critical inquiry. In fact, engaging in proof-giving practices might do little else beyond showing the compelling and seductive nature of fitting in somewhere, some how. While fitting in, or as Cornell West (1995:16) says, that "deep visceral need to belong," is certainly a worthy end, much more worthy than the buying of cigarettes for example, coming out to face the complexity of disability experience means questioning *to what and for what do I belong.*

Like Thomson's very visibly physically disabled person, coming out means moving into that space that exists between the seductive world of normate culture and experiences that say "You are not that!" It is that space which allows disability studies' researchers and activists to begin to critically understand the unquestioned ways of making sense of both disability and of everyday life. This is the politics of understanding the experience of disability.

In an essay called "Understanding and Politics," Hannah Arendt (1994:307-327) attempts to think about what understanding totalitarianism might look like. Of the uniquely human faculty of *understanding* she says that it is a means to confirm and reconcile ourselves to a world where such things as totalitarianism are possible at all. In a world where totalizing, marginalizing structures of normality, are inscribed upon the bodies, minds, and senses of all people, disability studies has

the uniquely human task of understanding how such things are "possible at all." The politics of the pursuit of such understanding, says Arendt, does not mean forgiveness nor does it mean a quick fix. Instead,

Understanding is unending and therefore, cannot produce final results. It is the specifically human way of being alive; for every single person needs to be reconciled to a world into which [s]he was born a stranger and in which, to the extent of his [/her] distinct uniqueness, [s]he always remains a stranger... Many well-meaning people want to cut this process short in order to educate others and elevate public opinion... [But] Understanding begins with birth and ends with death. (Ibid.:308)

I have tried to use my experience of disability as an invisible-presence that I wanted to identify to the reader as an opportunity to think about what counts as the experience of being disabled and what disability studies can make of such experience. My initial inclination was to cut short the process of understanding and simply educate and inform the reader as to my desire to be identified as a person with a very *invisible* disability. Instead of this, I attempted to confirm and reconcile myself to my unique distinctness in a world structured by unquestioned standards of normalcy. This allowed me to use and provide an image of "disability experience," such as coming out, as that which is best understood as a strange experience, one that should not be ignored, but an experience that should be understood as a space for questioning.

Conclusion

To return then to the questions I initially raised: the experience of being disabled is one path into disability studies, but this is not a straightforward assertion. Disability experience, like all things uniquely human which do not make us readily "at one" with the world, is ambiguous. It seems to me that one of the primary tasks of disability studies is to make disability belong to the world even though it remains a stranger in this world. Being either visibly outside the normal orders that structure everyday life or being mistaken as an instance of such orders, are experiences that belong to the realm of that which needs to be *understood* and not simply enunciated.

Claiming disability is not enough. "Coming out" is entering into a space of questions: How do we experience the experience of disability? How is such experience possible? How can we relate to the experience of disability so as not to make it a once and for all project, nor a singular announcement, but rather an essential space of questions? While the emphasis is different, while the

political and social consequences are different, both the appearance and the disappearance of disability mark the occasion of considering what it means to be positioned between visibility/invisibility, normalcy/abnormalcy, and ordinariness/extraordinariness, and thus being able to ask questions which are strangers in and to the normal order of things. "Coming out" is positioning, and thus identifying, ones self as such a questioner.

Endnotes

An earlier draft of this paper was presented at the Society for Disability Studies conference, Chicago (2000). I am grateful for the incisive audience comments as well as much encouragement.

1. For an account of such passing as it relates to Deaf and deaf experience see Brueggemann (1997:647). See Michalko (1998) for an analysis of passing as sighted when visually impaired.

2. "Normate" is a term that makes reference to unmarked categories of persons that are culturally regarded as "definitive human beings." (Thomson, 1997:8, Goffman 1963:128) The mythical American normate is, as Goffman (ibid.) says, the "young, married, white, urban, northern, heterosexual Protestant father of college education, fully employed, of good complexion, weight, and height, and a recent record in sports." Looking "normal" and operating from a "normal" stance means wielding authority and power that comes from fitting into the status quo. It also means being regarded as the "type" of person who is generally intended and expected by the normal order of interaction, the physical environment, and the structures of knowledge production. Insofar as normalcy is more of an ideological code (Smith, 1999:157-171) than actual embodied beings, "normate culture" is a way to refer to how this ideology works to exclude, oppress, and remove definitional power from so many different people. While disabled people face death, torture, and other severe forms of oppression under the normate regime, all people are oppressed by and within normate culture - even if they are positioned so as to wield its power.

3. A fuller analysis of this process can be found in my *Disability Stays* (manuscript under-review of University of Toronto Press).

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Implementation of Disability Studies

within Post Secondary Education:
An Australian Perspective

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The last two decades have been a period of unprecedented change for Australian higher education and vocational training. These changes involve structures, finances, policy directions and public accountability. Historically, the educational and cultural tradition had been to separate general education and vocational training. This was reflected in senior secondary educational and higher education structures providing academic or general education, but vocational education and training was the province of technical schools, Technical and Further Education (TAFE) Colleges, private colleges and training providers and the workplace. The impetus for change originated in the economic reform process which has seen a greater emphasis on creating a higher level of skills formation requiring a greater contribution from industry and closer cooperation between education and training providers and industry to meet Australia's rapidly evolving skill needs.

Australia has a three tier system of government comprised of the Federal or Commonwealth Government, the six individual states and two territories who have their own legislatures, and a Local Government system. The Commonwealth and State/Territory Governments aim to improve the quantity and quality of vocational education and training through substantial reforms which acknowledge that access to training for groups of people under-represented in the labour market must be increased. Through the National Training Reform Agenda, the Commonwealth Government, in collaboration and co-operation with the States, Territories, employers and industrial parties, are developing a more diverse and responsive national vocational education and training system for all Australians. This system is based on the development of agreed national Competency Standards, a National Framework for the Recognition of Training, competency-based training, self-paced learning, the recognition of prior learning, and the delivery of training in an open and flexible manner.

Some key elements include complete reform to entry-level training arrangements through the implementation of the Australian Vocational Training System (the AVTS), the provision of national accredited and recognised, structured training in the workplace and a new qualification system, known as the National

Qualification Framework, which replaced all the certificates and diplomas awarded by various state and industry agencies.

The Australian National Training Authority (ANTA) was established to ensure close interaction between industry and training. It aims to promote training which is responsive to industry needs and to assure funding to bodies delivering that training. The AVTS was introduced to rationalise apprenticeships and traineeships, and most importantly, to create recognised training and new qualifications in areas where no formal pathways previously existed. It is important to understand that there is no single institution or set course through which new pathways are created. In keeping with the notion of flexibility that underscores the new training system, AVTS pathways are created by partnerships between relevant industries and vocational education and training providers.

In the higher education arena, the Commonwealth Government has used its direct funding responsibility for Australian universities as leverage to encourage the policy changes required to make higher education more responsive to national needs and priorities in both economic and social terms. The agenda is to increase numbers and provide greater equality of access and participation and outcomes for all members of the community. There is increasing cooperation between universities, TAFE institutions, schools and enterprises to meet the needs of post compulsory education students by sharing resources, credit transfers and joint programs.

The traditional approach to training is being questioned and old roles and responsibilities are under challenge. No longer are people confined to the classroom, but learning can take place in a multitude of locations using a wide variety of technology. Increasingly, distance education and open learning opportunities are being created, where people can receive training and be assessed in the workplace and receive a nationally recognised certificate.

Goals of post compulsory education and training

Efforts are being made to ensure a coherent post compulsory education and training system operates nationally to provide comprehensive opportunities to all young Australians (Figure 1). Increasingly, policy themes and activities have focussed on: a desire for a better education and more highly skilled society with an interest in life-long learning; the need for a broader and more relevant curriculum at the senior secondary school level; the need to make post compulsory education and training arrangements more consistent both nationally and between and within sectors; an emphasis on education and training outcomes; and the need to link training arrangements more closely to the requirements of industry.

Figure 1
 Typical Avenues of Post-Secondary
 Education and Training in Australia

UNIVERSITIES	TAFE COLLEGES	PRIVATE COLLEGES	SPECIALIST SERVICES
Undergraduate & Postgraduate degrees Teaching Research	Vocational education & training awards Industry training boards	Training Full fee paying	Employment training & support Competitive employment training Individual supported jobs training
Commonwealth funding HECS charges Research funds Consultancies	States funding	Self-funded Government training assistance	Commonwealth funding Department of Human Services & Health DEET

Massive structural changes during the 1980s and 1990s resulted in fewer, larger institutions, a growth in the number of people participating in higher education and a substantial change to funding arrangements for institutions through the introduction of the Higher Education Funding Act, 1988. Universities operate under Acts of various state parliaments and are publicly funded, in large measure by the Commonwealth Government. This can be supplemented by endowments and consultancies.

TAFE colleges provide industry related training and are organisationally and financially the responsibility of State Governments, although special funds are provided by the Commonwealth Government to promote particular initiatives in vocational training. Courses generally run on a fee-for-service, cost recovery basis. All disability provisions are funded by the state and variations occur between states.

Private colleges charge full fees to students or trainees, but may attract Government training assistance. They offer courses in areas such as office skills, hospitality and child care. Evening Colleges are supported by subsidies and provisions from local Government or are self funding. Some Community Colleges, Voluntary and Community Groups obtain small subsidies from state governments though Community Adult Education Boards.

Definition and prevalence of disability

Disability is usually conceptualized as a multi-dimensional experience for the person involved. There may be effects on organs or body parts such as impairment of the ear's structure or function or both. There may be effects on certain activities such as understanding or producing messages. There may be consequences for a person's participation in aspects of life such as education, work or leisure. Participation can be facilitated in various ways; for instance, by the provision of assistive technology or sign language interpretation.

Correspondingly, three dimensions of disability are recognized in the International Classification of Impairments, Disabilities and Handicaps (ICIDH): body structure and function (and impairment thereof); activity (and activity limitations); participation (and participation restriction) (WHO 1997). The classification also recognizes the role of physical and social environmental factors in affecting disability outcomes. The first ICIDH was published by the World Health Organization in 1980. It is now in the process of revision to take account of the developments in the field since then. WHO is developing the revised classification, ICIDH-2, in co-operation with a number of countries, including Australia, as well as specialist task forces and organizations representing people with a disability.

The most recent national population survey of disability is the Australian Bureau of Statistics 1988 Survey of Disability, Ageing and Carers (ABS, 1999). This survey defined "disability as the presence of one or more 17 limitations, restrictions or impairments". To be consistent with the draft of ICIDH-2, the survey used the concept of "activity restrictive" instead of "handicap". In 1998, 12.5% of the population aged less than 65 years had an activity restriction. Of these people, 4.0% reported a profound or severe core activity restriction meaning that they always or sometimes needed person assistance or supervision with activities of early living.

For people aged 0 to 64 years most disabilities arose from main disabling conditions that were likely to be related to physical disabilities: 10.7% of the population in this age group reported such main conditions. The most common physical main disabling conditions were arthritis and other musculo-skeletal disorders. The next most frequent group was disabling conditions affecting intellectual abilities (1.6%) followed by sensory (1.2%) and psychiatric (1.1%) conditions.

The intellectual disability group had the largest difference in prevalence between males (2.2%) and females (0.9%). These data do not indicate the overall prevalence of these conditions since they count each person only once according to the main disability condition.

This population is not static as incidence of disability is related to such factors as genetic pre-disposition, accidents, injuries and illness. Other factors which influence population data are the various methods employed in collecting the data, the definition of disability and the willingness of people to self

identify. A recent focus of attention has been on the variable interpretations of the definition of disability particularly for the purposes of special education funding and eligibility criteria to disability support programs.

Policies and legislation

In the past decade there has been a significant change in community perceptions of how services should be provided for people with disabilities. These changes have resulted in a major shift from segregated services to the present demand for a more inclusive form of community support. Accordingly, government policies and legislation have undergone changes which reflect this world-wide social and political trend towards community support and inclusion of people with disabilities in their local communities.

(a) Commonwealth Disability Services Act, 1986

Growing awareness of the rights of people with disabilities was acknowledged in the Commonwealth Disability Services Act, 1986 (DSA). The introduction of this Act provided services with: a philosophical frame of reference about the expectations people with disabilities and their families should have about services funded through the Commonwealth; a legal frame of reference through which to interpret the Disability Services Act; a distinct value base about the rights of people with disabilities to be given the same opportunities and services similar to those open to all members of the Australian community.

National Standards and guidelines in applying the Act, developed in 1992, have clarified the administrative requirements and provided processes for standardised national practice. To locate the DSA historically within the Australian legislative and policy environment a timetable of events relevant to the development of services for people with disability is attached in Appendix 1.

(b) Anti-discrimination legislation

Australia also has a package of anti-discrimination legislation which is underpinned by international obligations as a member state of the United Nations. There are five Commonwealth laws based on a number of Covenants and Declarations made by the United Nations General Assembly. They comprise The Racial Discrimination Act, 1975; the Sex Discrimination Act, 1984; The Human Rights and Equal Opportunity Commission Act, 1986; The Privacy Act, 1988; and the Disability Discrimination Act, 1992. These Commonwealth Laws are administered from the Human Rights and Equal Opportunity Commission and this body is responsible for monitoring the legislation to ensure consistency with the following international obligations: the International Covenant on Civil and Political Rights, Declaration of the Rights of the Child, Declaration on the Rights of Mentally Retarded Persons and

Declaration on the Rights of Disabled Persons.

The Disability Discrimination Act (DDA), 1992, came into effect on 1st March 1993 and this Act makes it unlawful to discriminate against people on the grounds of their disability which includes physical, intellectual, psychiatric, sensory, neurological or learning disabilities. It also includes physical disfigurement and the presence in the body of a disease-carrying organism, for example the HIV virus.

In the area of education and training, the DDA protects against discrimination in admission or access and against personal harassment while undertaking education or training. Reasonable Adjustment is the principle for making adjustments which allow a focus on a person's abilities without causing unjustifiable hardship to the people involved. Adjustment measures may include changes to training or work practices, changes to program design, modification to equipment or premises and extra training or other assistance.

In applying the principle of reasonable adjustment in education and training settings teaching support and administrative staff are expected, whenever possible and reasonable to do so, to consider the person's disability and make appropriate adjustments to the organisational, learning and physical environment to lessen the impact of the disability. This concept covers college design, the provision of equipment, physical access, curriculum design, delivery and assessment. Currently, a set of standards is being developed to better inform employers of what actually constitutes "reasonable adjustment" and "unjustifiable hardship".

Being a Commonwealth Act, the DDA legally binds State, Territory, local governments, private industry, incorporated and unincorporated organisations, and private citizens to uphold the rights of all citizens with disabilities and ensures uniformity across all States. The DDA is the most recent anti-discrimination legislation, and as it is relatively new, its effectiveness in serving the best interests of people with disabilities who are experiencing discrimination will only become clear over time. However, people with disabilities now have a mechanism for legally enforcing their right to be treated fairly.

The DDA has provision for standards to be developed in relation to the delivery of certain services for people with disabilities. Those relating to vocational education and training were scheduled from 1996. It is envisaged that these standards would set legislative deadlines for achieving adequate access, provide more definite benchmarks for accessibility than is presently provided within the Act and provide a time line for achieving compliance to the above.

The Australian Standard Design for Access and Mobility, (AS1428 Pts 1-4) has been developed to specify design requirements for specific elements of buildings, related facilities and sites to permit access to and access within non-residential buildings for people with functional disabilities. It

is intended this standard be used during the design phase of a project.

(d) State and Territory Laws

Complementing Commonwealth legislation, individual States and Territories have enacted similar Anti-Discrimination and Disability Services legislation or are in the process of developing the same.

(e) Commonwealth/State Disability Agreement (CSDA) 1992

Under the CSDA agreement funding for services for people with disabilities was rationalised to eliminate duplication in Commonwealth, State and Territory administration of disability services. The aim was to further develop, on a national basis, integrated services for people with disabilities to ensure that they have access to appropriate services which meet their individual needs. The Commonwealth administers employment services and the State/Territory Governments administers accommodation support, recreational, respite and other support services for people with a disability. The responsibility for advocacy services and research is by both levels of government.

The Commonwealth/State Disability Agreement has achieved a number of outcomes including: complementary disability legislation enacted by all States; the provision of additional funding by the Commonwealth for disability services over the life of the agreement; the establishment of joint planning processes and the creation of joint advisory bodies in each state as an avenue for community sector advice to the ministers; and increased co-operation and co-ordination between the Commonwealth and State Governments

Teacher training

Traditionally, teacher training in Australia has been segmented into initial or pre-service teacher training of equity groups some projects focus on specific disability groups. One of these national projects is providing university accredited training in the transition process for teachers of students with disabilities through the key competencies. The course combines theoretical and practical components, uses a mixed mode, open learning approach and is available to teachers in secondary school sectors and TAFE across several states.

In another project AccessAbility, disabilities training for staff and volunteers was funded by the Queensland Open Learning Project, Queensland Department of Education. This resulted in a kit the aims of which are to enhance the expertise of higher education and TAFE college staff who teach and lecture to students with disabilities to assist the development of support networks and to address the note-taking, study skills and tutoring needs of such students. It was designed for use as pre-service and in-service training of staff, students and volunteers. This kit is being used on licence, as a resource for

internal TAFE staff training.

ResponseAbility People with Disabilities: Skilling Staff in Vocational Education, Training and Employment Sectors

ResponseAbility is a national staff development program funded by the Department of Education, Training and Youth Affairs. The program aims to equip staff to make equitable provision for students with disabilities across the full range of vocational education and training options in TAFE colleges throughout Australia. The curriculum is a model of best practice and is in Competency Based Training (CBT) format. The key elements are interactive and involve people with disabilities themselves in the training process. There are four modules which have applications across the full range of TAFE staff: Mandates for Change, Enhancing Access, Communication and Instruction, and Action Planning for Change. Underpinning themes which recur in the materials are those of rights based service delivery, mutual accommodation, networking, anti-discrimination, equity principles, valuing diversity, enacting key concepts of social role valorisation, confidentiality, building on existing skills, inclusive practices, and ongoing consultation with people with disabilities. Although based on these themes, this is not a theoretical or philosophical study. It is a practical work-based system of training focussed on outcomes which lead to the equitable provision for students with disability.

Sponsored as a national initiative, training has been provided to facilitators from each state and territory who then further the progress of staff training within their own systems. In New South Wales data for a 9 month period in 1994 indicated 36 trained facilitators had held 35 workshops for 370 participants. Implementation has been rapid with reports from states and territories indicating that most TAFE staff have been involved in at least the first level of awareness raising activities. Guidelines have been developed for ongoing implementation. The curriculum has been made available as a National Development Product, and extended to staff beyond the TAFE system, including Disability Access Support Units for the Skillshare network. It can also be used for university staff. Expansion plans for impacting the large number of sessional and part time staff in higher education are required.

FlexAbility

A further significant initiative has been the development and implementation of FlexAbility - People with Disabilities and TAFE: A strategic framework for people with disabilities in TAFE 1994-1996. This training program has been shaped by six national Vocational Education and Training goals: (1) a national training system; (2) quality; (3) outcomes and opportunities for individuals; (4) the needs of industry; (5) equity; and (6) training as an investment. Objectives and strategies are designed

to ensure relevance for people with disabilities across the range of vocational education and training programs and student services within TAFE.

Three significant themes are pursued within each goal and associated objectives and strategies. These themes are participation, fair and equitable practices and outcomes. FlexAbility promotes a training system which is free of bias against people with disabilities. It requires that skilled TAFE staff: meet the learning, participation and assessment requirements of people with disabilities; adopt the principle of reasonable adjustment to improve training opportunities for people with disabilities; adopt the principle of reasonable adjustment to improve training opportunities for people with disabilities; and promote partnerships to improve the quality of training outcome with industry, Industry Training Advisory Boards (ITAB's), employment agencies and the community.

This framework has been developed to assist State/Territory TAFE systems to equalise opportunities for people with disabilities in vocational education and training. It is anticipated that this framework will improve the capacity of TAFE systems to respond to the particular requirements of people with disabilities by: providing a framework through which State/Territory TAFE systems can develop implementation plans and strategies which are relevant to local conditions; clarifying TAFE's role in the provision of programs and services for people with disabilities; and providing the means to complement the national training reform agenda and other societal changes likely to impact on the provision of vocational education and training for people with disabilities. The success of implementation depends on each State/Territory's ability to apply available resources equitably, efficiently and effectively.

Courses for workers in the disability field

Most disability specific agencies and organizations have their own induction programs for incoming staff and staff are encouraged to join professional and industry associations through which some networking and in-service occurs. According to a recent review of Disability Services Programs, there can be few industries in greater need of professional development than the disability industry where many support workers have minimal training for tasks that are demanding and which require specific skills. The authors advocate a career structure for this industry to help retention rates and assure high quality service for clients (Baume & Kay, 1995).

A growing range of staff training provisions are being offered, however, including specific university courses: pass and Honours degree in Bachelor of Applied Science (Disability Studies), Flinders University of South Australia, Adelaide, South Australia; Master of Applied Science (Disability Studies), Flinders University of South Australia, Adelaide, South Australia; Bachelor of Applied Science (Intellectual Disability

Studies), Graduate Diploma in Intellectual Disability Studies, Royal Melbourne Institute of Technology, Victoria; Diploma in Education (Habilitation)/Bachelor of Habilitation, Australian Catholic University, Sydney, New South Wales; Bachelor of Applied Science (Habilitation) and Associate Diploma/Bachelor of Health Science (Leisure and Health), Charles Sturt University, Wagga Wagga, New South Wales; Graduate Certificate and Graduate Diploma of Disability Studies, Deakin University, Melbourne, Victoria; Master of Health Sciences (Disability Studies), Institute of Disability Studies, Deakin University, Melbourne, Victoria; a Graduate Certificate and Masters Degree in Developmental Disability Studies is currently being develop by College of Health Sciences, The University of Sydney, Sydney, New South Wales; Disability Studies at the University of New South Wales; Graduate Program in Developmental Disability Studies, The University of Sydney; Master of Disability Studies, University of Newcastle. Additional disability specific programs are also available at Universities in Queensland, Western Australia, Tasmania and the Australian Capital Territory.

Courses in Colleges of TAFE

Examples of courses available in Colleges of TAFE are: Vocational Education and Training (Disabilities) Certificate III and IV; Disabilities Issues: Responding to customers, legal obligations, Statement of attainment; Disabilities Issues: Awareness, Statement of attainment; courses for people working with people with disabilities in accommodation, employment, post school options and community access programs, Certificate III and IV, and Diploma levels (on line in 2001).

Barriers to further developments

Presently Australian Universities and higher education generally are being seriously affected by the overall diminution of resource allocation by Commonwealth and State Governments, a trend that commenced in the 1990s as governments of all political parties adopted neo-classical market-driven economic policies. School retention rates are now falling rather than increasing and there has been a significant drop in resources allocated to research and development. At the University level these policies have resulted in savage staff cuts and an increased emphasis upon cost recovery for both undergraduate and postgraduate programs, a far cry from the 1970s when the then Commonwealth Government abolished university fees. An emphasis upon attracting higher fee paying overseas students has restricted places for Australian students in several popular programs.

In order to initiate a new program of study the proposal must assure in most cases not only a cost recovery, but also the promise of a profit to assist the institution's overall infrastructure costs. To many observers this would appear to be an entirely prudent process. However, if one were to compare the Australian system with that obtaining in the USA, the major

difference is the degree to which major research funding bodies in the USA support research across the range of bio-psychosocial issues in the disability field. These research grants in turn support University teaching. Historically, in Australia the teaching component has been supported by per capita student allocations from the Commonwealth Government. The reduction in the per capita grants, together with a squeeze on overall research monies, is making it extremely difficult to mount courses in areas such as disability studies where the capacity of the industry to support employees gaining qualifications is fairly limited. Moves towards the implementation of compulsory quality assurance procedures in government-supported disability services programs, and proposals to introduce an accreditation system for support personnel, may result in pressures for additional disability studies courses in the tertiary education sector.

Despite these current problems, Australia has been able to meet many of the challenges that the contemporary philosophies and policies in disability have presented. While not everyone working in this field has adequate knowledge and skills, the existing disabilities studies programs are, to some extent, preparing a cadre of professionals who will provide leadership into the next decade. It is also encouraging that increasing numbers of people with disabilities are accessing higher education programs, not only in disability studies. People with disabilities are also gaining a tentative foothold in research programs, a process that is being encouraged in several research centres. School inclusion policies are having a positive impact upon students, both those with and without disabilities, to aspire to higher education courses in disability studies. The most pressing challenge is to strengthen the political support for disability research, teaching and development. We have certainly lost the momentum that was evident in the 1980s and early 1990s.

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APPENDIX 1

Timetable of events relevant to the development of services for people with disability

- 1908 Invalid pensions introduced, commencing 1910
- 1919 Repatriation Commission established
- 1941 (Forerunner of) Commonwealth Rehabilitation Service established 1944 Sickness Benefits introduced, commencing 1945
- 1954 National Health Act
- 1961 First National Conference - Sheltered Workshops
- 1962 Disabled Persons Accommodation Act
- 1960s Principles of normalisation developed in Scandinavia and the United States
- 1967 Sheltered Employment (Assistance) Act
- 1971 United Nations Declaration on rights of Disabled Persons
- 1974 The Handicapped Persons Assistance Act, Nursing Home Assistance Act, and Handicapped Child's Allowance introduced
- 1975 Meares report (Volume 2 of National Committee of Inquiry
- 1976 United Nations declares 1981 as International year of Disabled Persons
- 1977 Royal Commission on Human Relationships
- 1981 International Year of Disabled Persons
- 1982 Review of Handicapped Persons Assistance Act
- 1985 Home and Community Care Act, New Directions Report, and Office of Disability established
- 1986 Disability Services Act (DSA)
- 1987 Commonwealth Rehabilitation Services (DRS) decentralised
- 1988 Social Security Review report on income support for people with a disability
- 1991 Disability Reform Package launched, Commonwealth/State Disability Agreement (CSDA), and National Technical Assistance Unit established
- 1992 Disability Services Act (DSA) amended, Disability Discrimination Act, and Disability Services Standards developed
- 1993 UN Draft Standard Rules on the Equalisation of Opportunities for Persons with Disabilities and Australian Disability Strategy drafted

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The Changing Nature of Disability Policy
and Its Distributive Impact

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Abstract

The focus of disability policy changes over time. Starting with vocational rehabilitation programs for disabled veterans of World War I and continuing down to the Americans with Disabilities Act of 1990, the policy slowly evolved from paternalistic handouts to civil rights legislation. Nevertheless, the intended outcomes of these public policies were based upon need (equity) to a large degree. The literature contains some findings that persons with developmental disabilities and persons who are severely disabled are the beneficiaries of assistance more than others. However, conclusions from a study of the Disability Community in Massachusetts indicate that class considerations are highly associated with receiving benefits from disability policy of all types. The same is true of the Americans with Disabilities Act. It is a case of class politics operating in the guise of need (equity). The implications of these conclusions for disability policy are discussed.

Disability - like sex and like aging - is a common experience. Everyone who does not now identify as a person with a disability will, before he or she dies, be disabled. Maybe just minutes before death from a heart attack or in a car accident, but everyone will be disabled. Most people will spend a considerable length of time as a disabled person and so will some loved one. As a consequence of this fact disability policy is of immediate concern to everyone and not just to people who presently identify as a person with a disability. (Stone, 1988)

Disability Policy

Disability policy in this country can be categorized in a number of ways. One schema which identifies the policy areas receiving the most attention generally and which is somewhat

chronological is the following: (1) rehabilitation policy; (2) income replacement policy; (3) independent living; and (4) civil rights.

Mental health policy, which is not overtly included in these four categories, is almost a world unto itself. While persons with disabilities which can be called mental impairments or disabilities fit into these four policy areas, there is always something more difficult, more obscure, more complex, or, to all too many people, more frightening about them than persons with physical disabilities. However, the distributive impact of mental health policy is largely the same as that of the four listed categories of disability policy.

Many persons spend time discussing policy concerning disabled veterans. In fact, the first law granting benefits to a person with a disability (in what was to become the United States) was passed in 1636 in the Plymouth Colony. It provided that: "if any man shall be sent forth as a soldier and shall return maimed, he shall be maintained competently by the colony during his life." Other colonies passed similar laws as did the Continental Congress during the Revolutionary War. The Continental Congress provided that disabled veterans of the Revolutionary War as well as their dependents would receive a pension. The last dependent of a disabled Revolutionary War veteran died in 1901. (Schwartz, 1984; Linehan, 1976-77)

The Congress established under the 1789 Constitution continued this policy and gradually included disabled veterans of subsequent wars. However, the discussion of disabled veterans policy never reaches the intensity of other policy areas. In addition, as will be noted below, veterans are considered to be the most worthy of all persons with disabilities so only in rare cases are there heated debates over such policy.

In order to oversee the payment of veterans' pensions a series of government agencies were created. Today the Department of Veterans' Affairs (VA) is a cabinet level agency. About one third of the population (about 90 million people) are eligible for some VA benefit as veterans, dependents, and survivors of veterans, although not all of them utilize VA services.

The VA has the largest medical care system in the country. Starting with 54 hospitals in 1930, the VA in FY1985 had 172 medical centers which is approximately its size today. They have a total of nearly 80,000 beds and treat 1.3 million patients a year. It also has over 200 outpatient clinics which have over 18 million visits each year. There are more than 100 nursing homes plus other residences which care for some 30,000 persons. And there were, at one time, 189 Vietnam Veteran Centers which provide counseling to some 40,000 veterans and their family members on employment, marital problems, and post-traumatic stress disorder. (Linehan, 1976; Schwartz, 1984)

The VA conducts or supports a great deal of medical and rehabilitation engineering research. It helped in conquering tuberculosis, developing the heart pacemaker, perfecting kidney

transplants, and developing laser care for the vision impaired. It is a world leader in prosthetic device innovation such as the Boston elbow, motorized wheelchairs, and vision aids. It supports research on the care and treatment of spinal cord injuries and the psychological effects of war experiences.

For persons with disabilities who were not disabled veterans the earliest policy in this country began in the middle of the nineteenth century. Anyone who was not able to attain a minimum educational level was labelled "feeble-minded." Persons who had a mental impairment, anyone with a communication problem (vision, hearing, or speech impairment), and anyone with a mobility problem were labelled feeble-minded because these conditions prevented the socialization necessary to learn or prevented their attendance at the village school.

Persons with disabilities were the object of scorn generally in the mid-nineteenth century. The policy of the time resulted in dehumanizing, custodial confinement in an institution where they were compelled to work in order to pay the cost of their imprisonment. It also led to their wholesale sterilization since "feeble-mindedness" was considered to be genetically inheritable. (Smith, 1985, Pfeiffer, 1994) However, the deinstitutionalization of persons with disabilities largely shifted the discussion of such policy to other arenas such as the ones here proposed.

The best way to examine the changing nature of disability policy and its distributive impact will be to focus on the four areas of rehabilitation, income replacement policy, independent living, and civil rights.

REHABILITATION. In the early part of the twentieth century concern for returning disabled World War I veterans and for persons injured in industrial accidents produced the Smith-Hughes Act of 1917 and the Soldiers Rehabilitation Act of 1918. These two pieces of legislation set the pattern for the Vocational Rehabilitation Act of 1920 which was the first of a long line of federal acts serving as the foundation for one of the largest disability policy areas today: rehabilitation for persons with disabilities. (Burkhauser & Haveman, 1982; Berkowitz, 1987: chapter 5) The Rehabilitation Act of 1973 (note the change in name) established the basis for today's policy.

The public sector rehabilitation programs are primarily federally funded and under the guidance of the Rehabilitation Services Administration (RSA) within the U.S. Department of Education. Besides administering the funds which go to the state rehabilitation agencies, the RSA has funds for innovations in service delivery, improving relations with employers, research, demonstration programs, training, construction, and other things.

There are two criteria which must be met for a person to become eligible for RSA funded services: "1. The individual has a physical or mental disability which constitutes or results in a substantial handicap to employment. 2. The services may reasonably be expected to benefit the individual in terms of employability." (RSA terms quoted in Bitter, 1979: 9) A disabled

person is not automatically eligible for RSA funded services. The eligibility of a person for RSA funded services is determined by the state rehabilitation agency, often called the VR agency harkening back to the days when vocational rehabilitation was that agency's main job.

Although many persons with disabilities have benefited greatly from VR assistance, its results are uneven. (Pfeiffer, 2000; Gilmore, Schuster, Zafft, & Hart, 2001; Slavin, 2001) The best which can be said is that with further training and post-secondary education people with disabilities are more likely to be employed and (if employed) to earn a higher income.

Workers' compensation has a different statutory basis than rehabilitation. It deals with persons who become disabled through occupationally related injury or illness, but since it is largely funded by private insurance companies and self-insuring companies, its politics are different than RSA funded rehabilitation. Most of what is said about rehabilitation can also be said about workers' compensation.

INCOME REPLACEMENT POLICY. One of the significant pieces of legislation coming out of the New Deal was the Social Security Act of 1935. Among other things it set up a system of retirement benefits for older persons and their survivors. Even though there was considerable discussion about the need for health care in general and disability insurance, nothing was contained in the 1935 legislation. When he signed the Social Security Act, President Franklin Roosevelt established an advisory group to examine the questions of medical and disability insurance; however, they failed to produce anything which was pursued by the federal government.

During the late 1940s more discussion about federal disability insurance for workers occurred. A proposal considered by Congress contained a very strict definition of disability, a six month waiting period before benefits could start, a deduction for any other government aid received, and the need for recent and substantial work history. Temporary disability and allowances for dependents were removed from the proposal because of objections from the business community. Even with these parts removed, there was vehement objections from representatives of business such as the insurance industry and the U.S. Chamber of Commerce.

The objections to the proposal were: (1) disability could not sufficiently defined to keep ineligible persons from receiving benefits; (2) the payment of benefits would destroy the disabled persons incentive to work; (3) the insurance concept would lead people to believe that they were entitled by right to receive the benefits; (4) the administrators of the program would always decide in favor of the applicant; (5) the costs were not controllable; and (6) the program was an intrusion upon the rights of the states. Instead, it was proposed that the federal government grant funds to each state for assistance only to low income disabled workers.

The Social Security Administration (SSA) proposed a more liberal plan which would not depend as much on recent work history, would provide for dependents, would recognize temporary disability, and which would require only a small deduction for other government assistance. However, the business community's proposal carried the day. In 1950 Congress passed legislation which established a program of restrictive grants to the states for low income disabled workers.

Another problem for disabled workers at the time was the requirement that a minimum number of quarters be worked in order to be able to receive social security retirement benefits. The retirement benefits were based on past contributions to the fund. Disabled workers who faced a number of years of not working before age 65 realized that they could not receive full benefits when they qualified for social security retirement. Other disabled workers who had not yet worked the minimum amount of time would receive nothing. In 1952 SSA asked that a "freeze" be enacted for disabled workers in the sense that their non-working time due to disability would not count against them.

There was considerable opposition to this "freeze" proposal. The American Medical Association called it the first step toward socialized medicine because it provided for federally employed physicians to make the determination of disability. The U.S. Chamber of Commerce and the insurance industry called it the first step toward a full program of disability insurance. But Congress passed the "freeze" legislation in 1954 when the Eisenhower Administration supported it with major changes. The states were to administer the program and there was to be a vocational rehabilitation component in hopes of quickly returning disabled workers to the labor force. Eligibility for the "freeze" was limited to persons unable "to engage in any substantial gainful activity because of any medically determinable physical or mental impairment that can be expected to be of long continued and indefinite duration." (quoted in Weatherford, page 40)

In the Congressional elections of 1954 the Democrats regained control of both houses of Congress. In 1955 the SSA brought in a proposal for a full-fledged income replacement program for disabled workers. The Eisenhower Administration - essentially the White House since at the time federal agencies still proposed legislation on their own - opposed it. However, Lyndon Johnson had become Majority Leader in the Senate. Senator Walter George of Georgia had always opposed such legislation. Since Senator George was chair of the Senate Finance Committee through which any disability insurance legislation had to pass, it was usually defeated. But in 1956 Senator George gave up that chair in order to become chair of the Senate Foreign Relations Committee. The new chair, Senator Harry Byrd of Virginia, also opposed the legislation and it was defeated in committee.

However, Johnson, as Majority Leader, had no trouble bringing it to the floor of the Senate. To everyone's surprise, Senator George took the lead on the floor to pass the

legislation. (It is speculated that he did so due to a heated Senate race that year.) With Johnson working behind the scenes and George working on the floor, the bill just barely passed 47-45. It is the SSDI program we have at present. (Weatherford, 1984)

Typical income replacement programs for disabled persons are the federal disability insurance program (SSDI) and the federal supplementary security income program (SSI) to which states can add additional monies. (Burkhauser & Haveman, 1982; Berkowitz, 1987: chapters 2-4) There are other federal Social Security Administration programs such as one for miners who develop Black Lung Disease. In addition there are publicly supported programs such as fuel assistance, housing subsidies, and food stamps. (Worrall & Butler, 1986; Berkowitz, 1987: chapter 1; Social Security Programs in the United States, 1989) The National Council on the Handicapped (1986) - now the National Council on Disability - listed 45 federal programs which provided substantial funding for programs dealing with disabled persons. Finally, there are private disability insurance programs.

INDEPENDENT LIVING. In 1978 P.L. 95-602, the Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978, was signed into law by President Jimmy Carter. It added a new title to the Rehabilitation Act of 1973 entitled "Comprehensive Services for Independent Living." Under it severely disabled persons who were judged not potentially employable were made eligible to receive such services as needed so as to enable them to live independently. A number of severely disabled persons who are now working and living in the community would not be there if it were not for independent living services.

The Education of All Handicapped Children Act (20 USC 1401), often called PL 94-142 and which was modelled on Massachusetts' Chapter 766, is important. Recent amendments have changed the name to IDEA or the Individuals with Disabilities Education Act. The Developmental Disabilities Assistance and Bill of Rights Act of 1975 (42 USC 6001), created state developmental disabilities councils for planning and advocacy and it has had a great impact.

Special education and developmental disability policy partakes of the characteristics of independent living. That is, they are policies which provide something to the disabled person which will (hopefully) assist him/her to live independently. Many of the analysts concerned with these two policy topics are specialists not in policy, but in service delivery. Consequently the policy discussions are different from the present viewpoint, but much of what is said about independent living can also be said about special education and developmental disability policy.

CIVIL RIGHTS. Until the Americans with Disabilities Act was passed, the most far reaching civil rights statute for disabled persons was Section 504 of the Rehabilitation Act of 1973 (29 USC 794). It reads:

No otherwise qualified handicapped individual in the United States...shall, solely by reason of his [or her] handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.

Except for the opening phrase, 504 is almost identical in wording to the parallel part of the 1964 Civil Rights Act. So, too, are the relevant parts of the Americans with Disabilities Act. But the opening phrase of 504 ("no otherwise qualified handicapped individual") and a comparable one in the ADA means that disabled people, unlike other groups protected by civil rights statutes, have to establish first that they are "qualified." For other groups there is a presumption of qualification which must be upheld in a hearing, but not for disabled persons. It seems that even among the discriminated against, we are second class citizens.

Equally as important as 504 is Section 503 which prohibits discrimination by private individuals and companies holding federal contracts. However, 503 has not had the impact that 504 has because the former is a requirement placed upon employers and not a civil right of an individual.

There are other laws which relate to civil rights. The Voting Accessibility for the Elderly and Handicapped Act (PL 98-435), which was effective for elections starting in 1986, requires that all polling places in federal elections be accessible for elderly and disabled citizens. The Air Carrier Access Act of 1986 (PL 99-435) prohibits discrimination "against any otherwise qualified handicapped individual, by reason of such handicap, in the provision of air transportation." The Fair Housing Amendments of 1988 brought protections to disabled people in the field of housing.

The American with Disabilities Act (PL 101-336; 42 USC 12100) is the most conspicuous piece of civil rights legislation for disabled persons today (Burgdorf, 1991) and is intended to protect the civil rights of persons with disabilities. It also extends these protections from the public sector (where they were secured by Section 504) to the private sector and it places the public sector protection on a more firm basis.

Other. There are other important federal statutes. The Urban Mass Transportation Act of 1964, as amended, (49 USC 1612) requires that systems accepting the federal monies authorized under the Act must make those systems accessible to elderly and handicapped persons. The Architectural Barriers Act of 1968 (42 USC 4151) requires that all buildings built with federal funds be accessible. Although important statutes, these two are more often ignored than enforced.

In August of 1998 the Workforce Investment Act (WIA) was signed by then President Bill Clinton replacing the earlier Job Training Partnership Act (JTPA). Through a one-stop employment centers the WIA tries to create a system of work preparation and

employment assistance which is designed to meet the needs of people looking for work and wanting to advance in their jobs as well as the needs of employers. People with disabilities are included in the target groups. (Jahier & Graf, 2001)

Most states have a number of statutes relating to disability policy. In addition, six states have some version of protection against discrimination based upon a disability in their constitutions.

The Distributive Impact of Disability Policy

There are at least three ways in which to view the distributive impact of disability policy. The first way is to emphasize the gradual independent role attained by persons with disabilities. The second way is to point out that the morality of the community makes some persons with disabilities more worthy than others. And the third way is to use class politics (as opposed to policy rationale) to explain the distributive impact of disability policy. In one sense the third way explains the first two views.

GRADUAL INDEPENDENCE. In reviewing the rationale and the purpose of these examples of disability policy a pattern emerges. The first policy - rehabilitation - was premised on the assumption that disabled persons had a deficit or were not normal. The professional - at first the medical professional and then the rehabilitation professional - would diagnose the problem of the person with a disability. The professional would then prescribe what was needed to make the disabled person normal or as close to normal as possible. The disabled person had to follow the professionals orders or else he/she would not receive any services at all. A strong paternalism runs all through the policy.

However, some disabled persons had impairments which could not be "fixed." They would never get "well" or would progressively become "worse." If those persons had worked long enough in the right jobs and thus paid enough money into an insurance fund, then they could draw money on which to live. The amount depended on how long they had worked and their past earnings. To retain the incentive to work, the disabled persons who collected this income replacement never received as much as they had earned - and they never received any raise. Again a paternalistic policy in which other people would decide if the person with a disability was entitled and how much he/she would have to live on, a true disability allowance from a paternalistic government.

With the advent of independent living the balance began to shift. Early independent living programs required that disabled persons live in a supervised residence or dormitory. Later participants outright rejected such an idea and luckily they were at colleges and universities which were just accepting the idea that undergraduates might be mature enough to make their own

decisions about living arrangements. Although paternalism was still present, it had diminished in influence.

Then the independent living movement focused upon severely disabled and supposedly unemployable persons. With some income support and having learned the skills of living independently, many severely disabled persons not only moved into the community, but they also obtained the training and education necessary to become employed. The paternalistic tendencies were still present in many programs, but to a lesser amount.

With the implementation of Section 504 of the Rehabilitation Act of 1973, the Air Carriers Access Act of 1986, the Fair Housing Amendments of 1988, and the Americans with Disabilities Act of 1990 persons with disabilities arrived at a new level of independence. Richard Scotch (2001) published a book on the passage of Section 504 which chronicled this gradual move to independence. He entitled it *From Good Will to Civil Rights*. He could not have picked a more incorrect title. It should have been titled "From Paternalism to Civil Rights." However, the battle is still not over.

The shift from paternalism to independence is one way to view the changes in the distributive impact of disability policy. As Berkowitz (1987: chapter 6) portrays, it was a long, slow battle for persons with disabilities to overcome the paternalistic policy and to assert their independence. The professionals controlled the policy at the start and determined what was wrong with the disabled person. By the time of the Americans with Disabilities Act the individual with a disability has the right to access and equal protection.

WORTHINESS. However, there are other ways to view the distributive impact of disability policy. Since it is true, as Joel Handler writes, that "...the characteristics of...[any] program [or policy] reflect the moral characteristics that society ascribes to the potential category of eligible recipients...", (Handler, 1987-88: 484) it is worthwhile to ask what characteristics are reflected by disability policy and programs. These characteristics are sacrifice, hard work, and bad luck.

Beginning with the earliest law in the Plymouth Colony there was a hierarchy of persons with disabilities. Disabled veterans are considered to be the most worthy of all persons with disabilities. They are the ones who are considered to have made a sacrifice for the nation. Military service is considered to be hard work, except for many who do know what happens in the armed services. And disabled veterans are viewed as having the bad luck to have sustained wounds which left them disabled. They clearly fit all three necessary characteristics.

While there are complaints about the level of care in veterans' hospitals, generally speaking no one complains about the level of benefits for disabled veterans. A 100% disabled veteran today receives approximately \$4000 a month tax free, free medical care, a new car every two years, an ample amount to use

to purchase and/or renovate a house, and other benefits.

On the next level down in regard to worthiness are disabled industrial workers. They showed sacrifice in the sense that they obtained jobs, but not the sacrifice of being in the armed forces. It is assumed that they worked hard and then had the bad luck to be injured. Although workers' compensation claims are often fought intensely by the employer (because losing raises premiums), the benefits can be large. A disabled person who qualifies for SSDI (due to an occupationally related injury or illness) can receive (on the average) \$900 a month plus Medicare and Medicaid.

The bottom level is mixed. Agricultural or clerical workers disabled as adults probably have not earned enough (paid enough into SSDI) to obtain more than the minimum benefits. People disabled at birth or as a child may gain from special education or generic services, but much criticism is levelled at these benefits. Certainly there is no income supplement except for the miserable SSI payments. This group is certainly viewed as the least worthy of all persons with disabilities. They are not disabled because of sacrifice nor have they worked and become disabled. All they have is the bad luck to become or to be born disabled.

One way to explain why the middle and bottom levels of persons with disabilities are viewed so poorly is presented, inadvertently, by Joel Handler himself in his work on the Family Support Act of 1988. For Handler the "core issue is whether the applicable category [of poor person] is morally excused from work." (Handler, 1987-88: 460) He states that today the Afro-American, single, female head-of-household is no longer morally excused from work. This fact explains most, if not all, of the features of the Family Support Act of 1988. In his article, however, he continually states that only "able-bodied recipients" (Handler, 1987-88: 462) of welfare benefits will be expected to work as if persons with disabilities can not work.

To further explain the Family Support Act he reviews the history of welfare policy in the US. One of the four features Handler found in the formative period of welfare policy was what he called "a hostage theory: those who are truly needy are given relief under such conditions as to deter those capable of work. . . . The truly needy were segregated, stigmatized, and sanctioned." (Handler, 1987-88: 470) Among the truly needy were "the blind, the deaf, and the insane." (Handler, 1987-88: 470) Apparently Handler does not know very many persons with disabilities.

What was at one time called the General Relief program is Handler's best example of the hostage theory. The conditions of receiving General Relief are so onerous that many persons do not even apply. The recipients are "...children, the severely disabled, the mentally ill, and the aged, [persons who] were usually totally unemployable." (Handler, 1987-88: 483) The final irony of Handler's article is that when he gives an extended

illustration of the problems with General Relief, he presents a case study of the difficulties faced by a man labelled mentally retarded. Although he states that such a case is one of several easily available, perhaps he is unaware of the numbers of persons labelled mentally retarded who go to work every day.

Apparently not only is worthiness based upon the attitudes of the community at large, but it is also based upon the attitudes of the scholarly community. While I concur with his analysis of the Family Support Act and that it is essentially racist and sexist, he amply reflects the attitudes of society at large that persons with disabilities are not expected to work and therefore not expected to be able to be independent, capable citizens. It is ironic that a leading proponent of the position that moral values shape policy continually gives handicapist illustrations. Worthiness is in the eye of the beholder - and the value presuppositions.

CLASS POLITICS. There are many studies which find that certain disabilities cause low income and/or unemployability. Other studies show that severely disabled persons are the ones unemployed or who receive low income.

For example, many researchers find that persons with a vision impairment have high unemployment rates and, if employed, receive lower wages than non-disabled persons. (Dixon, 1983; Fuqua, Rathbun, & Gade, 1984; Hill, 1989; Johnson & Hafer, 1985) Other researchers find that the more severe the disability the more likely the person is to be unemployed or to receive lower wages. (Bowman, 1987; Hasazi, Gordon, & Roe, 1985; Kuh, Lawrence, Tripp, & Creber, 1988; Lichtenstein, 1987; Taler, 1986) An early onset age of the disability apparently allows the person with a disability to plan an education and become employed. (Taler, 1986) At the same time persons with multiple disabilities (DeLoach, Sparger, & Pullen, 1988) or psychological disabilities (Sink, 1987) have higher rates of unemployment and lower wages no matter what is the age of onset. Stuttering (Hurst & Cooper, 1983), hearing impairment (Barnartt & Christiansen, 1985; Brown, 1987; Cesare, Tannenbaum, & Dalessio, 1990; McCarthy, 1989), and cognitive impairments (DeLoach, Sparger, & Pullen, 1988; Fuqua, Rathbun, & Gade, 1984; Gibson & Groeneweg, 1986; Godowsky, 1987; Greenwood, Johnson, & Schriener, 1988; Johnson, Greenwood, & Schriener, 1988; Kuh, Lawrence, Tripp, & Creber, 1988; Minskoff, Sautter, Hoffmann, Hawks, 1987; Richardson, Koller, & Katz, 1988) are all related to unemployment and lower wages for persons with these disabilities.

However, almost no researcher looks at the entire spectrum of persons with disabilities who are working or looking for work. There are a few, but they are lacking in some way. A narrow study, Kuh, Lawrence, Tripp, & Creber (1988), had a sample of persons with disabilities, but only ages 16-25. Another study, Bolton (1983), correlated employment with having an optimistic outlook on life. Were the disabled persons optimistic because they were employed or employed because they were optimistic?

There is no way to know from his study.

Clark & Hirst (1989), who used socio-economic variables and made comparisons with non-disabled individuals, had a small sample of 39 individuals. DeLoach, Sparger, & Pullen (1988) had a sample of 49 college graduates who had graduated over a six year period. While making a contribution, these studies and the others are too limited.

There are questions which go unanswered in these studies primarily because they are not asked and therefore the data does not reflect the answers. The main question relates to the influence of race, gender, and education upon employment and income of persons with disabilities. Pfeiffer (1991), Burkhauser, Haveman, & Wolfe (1992), and Clark and Lipset (2001) demonstrate that the structural factors which play a major role in the US society at large are also the predominant variables which operate within the disability community. That is, better educated white males are the persons with disabilities who are most likely to be employed and who earn the most.

There are some reported statistics (not really parts of research studies) which support my thesis. For example, federally gathered statistics in Ficke (1992: Table 24) present data which supports this view of the distributive impact of disability policy. The data is for full time workers ages 16-64 with a work disability in 1987. The mean income for men was \$24,000 and for women was \$15,796. The mean income for white men was \$24,454 and for black men was \$20,790. The mean income for white women was \$16,202 and for black women was \$12,620.

Ficke (1992: Table 24) on full time workers ages 25-64 with a work disability in 1987:

<u>ed in years</u>	<u>men</u>	<u>women</u>
LT 12	\$17,224	\$10,150
12	\$23,773	\$14,955
13-15	\$28,200	\$17,223
GE 16	\$33,901	\$24,591

Ficke (1992: Table 25) occupations of workers ages 16-64 with a work disability in 1987:

	<u>men</u>		<u>women</u>	
	<u>white</u>	<u>black</u>	<u>white</u>	<u>black</u>
managerial and professional	18.6%	10.7%	17.7%	7.5%
technical, sales, & admntive support	18.6%	7.7%	41.2%	28.3%
service	10.4%	31.8%	23.7%	47.7%
farm, forestry, & fishing	4.4%	7.7%	1.5%	0.8%
precision, produc-tion, craft, & repair	20.8%	10.5%	2.4%	0.5%

operators, fabrica- tors, & laborers	27.0%	31.3%	13.2%	14.9%
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Similar relationships can be inferred from N.O.D. (2000). The statistics on education, employment, and income compares people with disabilities with people without disabilities, but always the better educated white males come out on top.

Class politics also explains the other two ways of describing the distributive impact of disability policy. Better educated disabled white males refused to play a subjugated role and gradually moved disability policy from paternalism to more independence. Better educated disabled white males - being either disabled veterans, having avoided the dead end of special education, or having received education before becoming disabled - influenced the moral attitudes of society which shape the worthiness hierarchy of disability.

It is the contention of this paper that better educated white males are the ones who have and will continue to benefit from disability policy. While this finding may not surprise some people, it runs counter to the policy research done in the field of rehabilitation. It also runs counter to the expectations of policy makers on both the federal and state levels.

In June 1992 the National Council on Disability held public hearings on the implementation of the Americans with Disabilities Act, the legislation which is heralded as the emancipation doctrine of persons with disabilities in this country. (Pfeiffer, 1992) One of the persons testifying was John R. Dunne, Assistant Attorney General, Civil Rights Division, U.S. Department of Justice. In his testimony he said that the ADA is fair and balanced and takes into account the ebb and flow of resources. It balances the rights of disabled persons with the need of government and business for efficiency and profitability. He went on to say:

Attorney General Bill Barr and I are committed to enforcing the ADA vigorously, effectively, and fairly. Our compliance strategy is a simple one and can be summarized in a phrase: educate and negotiate and litigate only when compliance is refused. What this means is that we are seeking to promote voluntary compliance with the ADA through an active outreach and public education effort. We will first seek to resolve a complaint through a process of technical assistance and negotiation and only resort to litigation when these avenues have proven unsuccessful. . . . In the relatively brief period we have been working with this revolutionary statute...I have come to one clear conclusion. The ADA is not a zero sum game.... Every sector of society can benefit from the ADA's swift and effective implementation.

There is no recognition that women and non-whites have not had the opportunities nor the successes as better educated white

males have. There is no suggestion that some parts of the disability community will benefit from the "business as usual" attitude while others will remain unemployed or in low income jobs.

Another person who testified was one of the disability advocates usually given major credit for passage of the ADA, Justin Dart, Chairman of The President's Committee on Employment of People with Disabilities. He said: "Let's make friends. Friends don't sue friends. Friends don't discriminate against friends who have disabilities and want jobs." But, one needs to ask, how many white males have friends who are non-white or women?

Among the members of Congress who testified were many of the ones given the credit for passage of the ADA. For example, US Representative Steny H. Hoyer said:

For far too many Americans the course of their lives is predicted and defined not by their talents, dreams, or desires, but by their disability. Unnecessary attitudinal and physical barriers make the words 'full opportunity' ring hollow for 43 million Americans with disabilities. We can make the ADA a successful reality.

The ADA might relate to discrimination based upon disability, but what about the additional burdens of racism and sexism?

Representative Benjamin A. Gilman, Co-Chair of the Republican Task Force on Disabilities, said that the ADA is very important. "Americans with disabilities are a valuable source of talent. . . . [And] are not a dysfunctional part of our society." But who participates in our society?

US Senator John McCain said: "The Americans with Disabilities Act is the most sweeping civil rights legislation since the 1964 Civil Rights Act. Its impact on the lives of countless millions of Americans will be great. But more importantly, our Nation will benefit from the ADA."

Finally, John Wodatch, Director of the Office on the Americans with Disabilities Act, U.S. Department of Justice, said:

The ADA is - as said by several people today - revolutionary legislation. It calls for fundamental changes in the American way of life. It is a truism to say that change, especially significant change, is never easy. . . . I can report to you that there has been an unprecedented coordinated effort by the federal government. I can also report that there is a growing understanding of what the ADA is by the American business community and, even more enheartening, an acceptance of it.

Hopefully all of these policy makers and implementers know the role which class politics (racism and sexism) play in the US

political, social, and economic systems. However, not one person during these two days of testimony bothered to mention it. For the ADA, presumably, it does not exist.

Conclusion

Why is the impact of class on disability policy not recognized? Why do policy makers, implementers, and evaluators deny it? Why, even though our literature contains extensive class references, is it denied? (DeMott, 1990) There is no conspiracy to hide the functioning of class. Instead, the denial of the impact of class politics supports the idea in the US that we should be optimistic and through hard work will obtain "the American dream." Or, to put it into the words of a very large and pervasive federal agency, by working hard we can be all that we can be. It is maintained that no one is held back by class origins.

When the mass media discusses (supposedly in depth) non-middle class persons - such as dope dealers - it is said that a lack of intelligence and a lack of morality explains why they do not behave in middle class ways. Their illegal and immoral activities are contrasted with working for minimum wage, saving for retirement, and having health insurance. I would hope that people would know that minimum wage jobs have no surplus wages for saving and no health insurance. But then I am optimistic.

Scholarly treatises describe any non-middle class behavior as deviant, ignorant, and mentally unstable. Since classes are presumed not to exist, class based explanations are not put forth. Non-middle class behavior is seen as counter productive and not legitimate. Persons with disabilities are trained in job searching and how to behave on the job - if they are ever hired. If the person with a disability behaves in too "bizarre" ways, then he/she will not receive rehabilitation services because the prospect of employment is non-existent. Unless disabled persons behave in middle class ways, they can not live independently in society. Unless they behaved as a member of the middle class and worked in covered employment, they are not eligible for SSDI. Unless they conduct themselves in middle class ways they are not "otherwise qualified" and can not obtain civil rights protection.

It is a myth in this country that public schools and higher education are means for achieving personal goals. If one is middle class - dresses, looks, speaks, and behaves in a middle class manner - then that statement may be correct. Otherwise it is a joke. Media writers, opinion shapers, policy analysts, teachers, policy makers, and policy implementers do not have to be reminded that only middle class values are legitimate. They are socialized into that position. If they object, then they are forced out of the comfortable occupations.

There is a class based explanation for these facts. Disability policy is evaluated by better educated white males. When they see that better educated white males are successful

under existing disability policy, they conclude that existing policy is effective and efficient. Less educated persons, non-whites, and women are not expected by better educated white males to be "successful" (as they define it) so when they have more difficulty achieving anything at all it is to be expected. A self-fulfilling prophecy of failure by non-middle class persons justifies inadequate funding for disability policy.

There are three positions taken by most policy analysts which reinforce the prevalence of middle class values. Most policy analysts believe that the government can never do better than the private sector, that a public agency always acts to inflate its budget, and that central planning is doomed to failure. Many voters, elected officials, policy makers, opinion shapers, and policy implementers also agree with these positions. They shore up the self-fulfilling prophecies which produce the class based impact of disability policy.

What can be done? I do not know. I do know that the ADA has little chance of success as long as the middle class sexism and racism dominate the disability community and the US society. If we want disability policy to be directed toward equity, we must change the distributive impact of disability policy.

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Book, Video, and Film Reviews

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Clark, Gary M., Patton, James R., and Moulton, L. Rozelle.
Informal Assessments for Transition Planning. Austin, TX: Pro-Ed,
2000, 171 pages, \$41.20 softcover.

Reviewed by Mary G. Maciel Klinger, SUNY Empire State
College, Corning, NY.

Transition planning is a process to identify and put into
action a sound strategy to allow a student to successfully move
from school to a variety of postsecondary opportunities. *Informal
Assessments for Transition Planning* is an excellent book to
assist in this planning process. The authors begin by discussing
three important elements that are needed for success:
comprehensive development of a plan that includes the assessment
of individual needs; the implementation of the plan; and ongoing
coordination among all the providers. The purpose of this book is
to provide a comprehensive reference for practitioners who wish
to have a variety of tools and techniques to do this work
effectively.

This book can be used as a stand-alone or in conjunction
with Clark and Patton's *Transition Planning Inventory* (Austin,
TX: Pro-Ed, 1997). After a solid introduction loaded with
information, the authors offer a variety of informal assessment
instruments as well as directions and options on their use.
Included also is a comprehensive inventory of knowledge and
skills, and instruments to assess employment, further
education/training, daily living, leisure activities, community
participation, health, self-determination, communication, and
interpersonal relationships. The book concludes with a case study
illustrating the process of using the instruments successfully.

Informal Assessments for Transition Planning is an extremely
useful resource for anyone involved in transition planning. The
variety of ideas and techniques available in this book are
abundant and practical.

DePoy, Elizabeth, and Gitlin, Laura N. *Introduction to
Research: Understanding and Applying Multiple Strategies* (2nd
Edition). St. Louis, MO: Mosby, 1998, 352 pages, \$36.95
softcover.

Reviewed by Marcia J. Scherer, Ph.D., M.P.H., Author, *Living
in the State of Stuck: How Assistive Technology Impacts the Lives
of People with Disabilities* (grounded theory method).

This is a book for us. Both authors are health and human
service professionals who actually do research with individuals

with disabilities and many of the examples used throughout the book are ones that we can grasp and relate to quite easily. Additionally, the last chapter (Chapter 22) is devoted to the authors' own stories from the research field.

This book gives equal weight to the value of quantitative and qualitative/naturalistic approaches. In general, however, the book's organization is typical of texts in research methods. The twenty-two chapters are divided into four parts. Part I consists of two chapters introducing the research process. The six chapters in Part II are quite theory-rich and address research traditions, topic identification, reviewing the literature, design selection, and research question formulation. Part III has chapters devoted to experimental designs, naturalistic inquiry, and case study designs. The last section, Part IV, has three chapters on boundary setting, two on collecting/gathering information, and one each on reliability/validity, data analysis, and reporting research results.

The chapter that stands out as being particularly well done is the one on naturalistic inquiry. Here, the authors make understandable and clear distinctions among participatory action research, critical theory, phenomenology, heuristic research, life history, and grounded theory. These terms are familiar to us in Disability Studies, and they are methods we frequently employ, but we are not always clear about what distinguishes one from the others. No longer do we need to have any confusion.

I highly recommend this book as a methods text for students in Disability Studies. I would have students read Chapter 22 (the authors' own research experiences) first before beginning with the introductory chapters. If you have already committed to using another text, I would make sure that students have access to the chapter on naturalistic inquiry (Chapter 10). They will thank you for it.

Dickson, Donald T. *HIV, AIDS, and the Law: Legal Issues for Social Work Practice and Policy*. New York, NY: Aldine de Gruyter, 2001, 198 pages, \$49.95 hardcover, \$24.95 softcover.

Reviewed by Charles Goldman, a Washington, DC, attorney and mediator who has been involved with disability issues for many years.

This book is a winner! If you are involved with disability issues, whether or not your focus is HIV/AIDS, you should know about this mini-treatise. It is a comprehensive treatment of a sensitive subject.

The author reviews AIDS not only in the confined world of the Americans with Disabilities Act and anti-discrimination laws, but also in realistic settings such as insurance, social worker ethics, and criminal justice (including correctional institutions). The legal analyses are generally quite good, but the author does not make clear that, while the federal government vacillated in the 1980s as to whether or not AIDS was a disability (then a "handicap") under Section 504 of the

Rehabilitation Act, many states, such as the District of Columbia and Maryland, had no such problem when interpreting state anti-discrimination laws.

A few minor suggestions that might enhance the next edition of this tome. Since the author points out issues and state law concerns, such as those dealing with confidentiality, it might be very helpful for him to offer up a model or form for providers to use when seeking to make authorized disclosures. In the area of employment practices, the author missed the opportunity to point out the importance of universal first aid practices (such as masks and gloves) that maintain privacy for ALL people with disabilities (not only persons with AIDS/HIV). Practical hints for employers to use, as well as what not to do in the workplace (good and bad practices) would help.

Finally, I do think that books on disability issues should be sensitive to readers with disabilities. The size of the print in the paperback copy I reviewed seemed to be too small.

Gerber, David A., ed. *Disabled Veterans in History*. Ann Arbor, MI: The University of Michigan Press, 2000, 356 pages, \$49.50 hardcover.

Reviewed by Susan Prokop, Associate Advocacy Director, Paralyzed Veterans of America.

As the title suggests, this book explores the roles and experiences of and attitudes toward disabled veterans in various nations throughout history. Each chapter is a separate essay written by a different author on topics ranging from social reintegration of war-injured veterans, the evolution of public policies governing their benefits, differences in treatment of veterans in victorious versus defeated countries, to the cultural milieu in which veterans with disabilities are portrayed.

A word of caution to readers is in order. The book features small print, many endnotes, and frequent use of "academic" language. Exploring its commentaries a chapter at a time might make it an easier read.

Particularly interesting to this reviewer was a chapter on the Canadian Paraplegics Association (CPA), which was founded after World War II by a group of Canadian veterans with spinal cord injuries (SCI). Once they had succeeded at their own rehabilitation and return to society, the CPA reached out to the civilian SCI community to promote an inclusive approach to disability policy. CPA leaders used their veteran status to fight for an agenda that would help not only fellow veterans with SCI, but also those in the general population with spinal cord injuries.

The editor notes the more "typical" approach of veterans' groups, such as the "Paralyzed Veterans Association [sic] in the United States, which did not include civilians nor broaden its work to assist civilians with spinal cord injuries" (p. 14-15). PVA's leadership would argue that its mission, in fact, does support policies in areas such as housing, employment, and

transportation that enhance independent living for all people with disabilities. Still, PVA's membership, unlike its Canadian counterpart, remains closed to its civilian brothers and sisters.

Several pieces focus on the distinction in benefits, treatment, and societal position between veterans and civilians with disabilities. Compensation and services for veterans with disabilities sustained in far-off battles often receive more public support than similar programs for civilians with disabilities. In the introduction, David Gerber notes that "except perhaps when war touched the home front directly, exacting tremendous sacrifices from civilians, and incentives have been required to achieve solidarity and raise civilian morale, governments have rarely sought to dismantle any of these boundaries" (p. 15). The events of September 11, 2001, may call for further reflection on such policies.

Grbich, Carol. *Qualitative Research in Health*. Thousand Oaks, CA: Sage Publications, 1999, 320 pages, \$78.00 hardcover, \$25.95 softcover.

Reviewed by Kristine A. Mulhorn, University of Michigan-Flint, Health Care Department, Flint, MI.

Finding a usable research methods textbook for students in health studies is challenging. Grbich has created a reference and a usable text grounded in social sciences and filled with classic references designed precisely for this purpose. The detail, theoretical perspective, and classical references offered by the author make this a superior methods text in the area of health research. A format that includes detailed guides and recommendations is found in most chapters, but it is especially useful in the section on interviewing in which there is an outline of recommended strategies for interviewing persons with disabilities. The notable shortcoming here is that there is no discussion of persons with speech or communication impairments. This is an area that needs to be more widely known among all, but is especially key for persons conducting research on health. Another weakness in the section is the lack of a discussion of the use of proxy measures and the legal issues involved in interviewing persons 18 and under.

The first chapter places qualitative research in health in context by including a discussion of approaches (e.g., paradigmatic and non-paradigmatic), orientations, and history of the qualitative-quantitative debate and the role of newer theories in changing research. The second chapter addresses the question of what it means to apply different sociological theories and criticisms of theories. The works of Mead, Goffman, Weber, and Habermas are highlighted securely seating qualitative research in the history of social research. Grbich also postulates on the methodological implications of poststructuralism and postmodernism. The breadth of the theoretical approaches in this section is impressive.

The text also includes the basic design issues that must be

covered in any research methods course: objectivity, reliability, and validity. These topics are the main topics in the third chapter. The chapter provides a historical perspective by paraphrasing Habermas and Weber in its contrast of bias and objectivity. This chapter is limited by a severely underdeveloped discussion of literature reviews. Other sections complete the book with a discussion of field-based methods, action-based methods, data analysis, and presentation of data, all of which contribute to a fine text that may be used in a graduate-level course for future social scientists or as an ideal reference for their instructors.

Hart, Kylo-Patrick R. *The AIDS Movie: Representing a Pandemic in Film and Television*. New York, NY: The Haworth Press, 2000, 134 pages, \$39.95 hardcover, \$17.95 softcover.

Reviewed by Beth Haller, Towson University.

Those who study media know of their power - to frame, to represent, and to shape understanding about a variety of disability-related topics. Kylo-Patrick Hart's book reiterates this succinctly by focusing on one high-profile disability, HIV/AIDS. His goal is to analyze the presentation of AIDS in narrative films during the first 20 years of the pandemic. His reason for the study is clear: "The treatment of AIDS in news accounts, documentaries, television programs, movies, and other mass media offerings over the past two decades has undeniably shaped the way the American public thinks about and responds, socially and politically, to the pandemic" (p. 8).

His analysis is grounded in social constructionism and the book provides an excellent literature review on the topic. He is trying to discern how movies sway American ideology about the pandemic. Hart is exactly on target with his study when he says AIDS "representation is a form of social action involving the production of meanings that ultimately have real effects" (p. 13). This is what many of us who study media representations of disability have been saying for a while - that media images have real consequences in the lives of people with disabilities and, subsequently, on government policies directed at them.

What he finds in his analysis of 32 AIDS-related films are several ideological themes each of which he breaks into a chapter. Expectedly, the overarching theme he delineates in the films is "otherness." He delves into that theme in three more specific chapters on: the "us" (innocent victims) vs. "them" (guilty ones) message; the gay man as "sacrificial other" theme; and the deviant-filled city vs. pure, moral country dwellers representation.

The book makes a clear and significant statement about the media's role in casting a whole country's outlook on the AIDS pandemic. Its conciseness makes it helpful as well; at 120 pages, it is just the right book to use as an additional text in a Disability Studies course that deals with media images.

Lemke, Jay L. *Textual Politics: Discourse and Social Dynamics*. Bristol, PA: Taylor & Francis Inc., 1995, 206 pages, \$23.00 softcover.

Reviewed by Patrick J. Devlieger, the University of Leuven, Belgium.

Textual Politics is a complex book about the way we produce meanings in the social world through language and its products, namely texts and discourses. This production of meaning is always social and political. The book is supported through a build up of contemporary theory, practical examples, and last, but not least, a critical look at the way the book itself is analyzed as an example of the author's involvement with the dynamics of discourse. Doing that, Lemke does not seem to leave any stone unturned. Although this is not a book about disability, this is a book that Disability Studies scholars can find of interest because of the theoretical complexity in dealing with the dynamics of text, power, and politics, and the methodological refinement in the analysis of particular texts.

The strength of this book is that it offers a disciplined effort to integrate critical and post-modern thought. Central here is the production of texts, from utterances to discourses. Discourses are linked to dynamic communities and positions within systems, but also to heteroglossia (i.e., socially defined discourse types in a community), dialogue, and intertextuality, and, from there, to discourse formations, registers, social semiotics, the discourse habitus.

Chapter 2 introduces these concepts with clarity, drawing upon such theorists as Bakhtin, Halliday and Bernstein, Foucault, and Bourdieu. Chapter 3 is the most didactic and, perhaps also, the most interesting for Disability Studies scholars. It provides a concrete example of the way meaning and conflict is found in texts. The examples show clearly how homosexuality/gay rights are politically constituted. Disability Studies scholars will see that the dimensions of meaning-making can be applied equally to disability. The following chapters extend the argument with issues dealing with the political uses of discourses and the constitution of the subject and with ecology and change.

The book is also convincing in confronting the more ethical issues surrounding the production of discourses in our society. It does so in suggesting a critical praxis and its application in education, literacy, and politics. Critical praxis "assumes that we are part of the problem, that even our most basic beliefs and values should be suspect. Critical praxis should lead to changes in these beliefs and values as well as to changes in our actions" (p. 131). Critical praxis tends, however, to be more of a post-modern, scholarly, and inward-looking effort than a call for direct action.

Textual Politics is a book for scholars who wish to expand their theoretical and analytical toolboxes when it comes to analyzing disability texts and discourses.

Michaels, Craig A. *Transition to Employment*. Austin, TX: Pro-Ed, 1998, 67 pages, \$12.80 softcover.

Reviewed by Beth Omansky Gordon, The George Washington University.

In the preface of this school-to-work manual for professionals working with disabled students, Michaels describes the "challenges" of special educators "to prepare our students to challenge society's expectations and assumptions about people with disabilities, and to develop the requisite skills within our students to back up their challenge and to empower them to participate fully in the world of work" (p. ix).

While Michaels advocates for new models of service provision to help break the cycle of economic oppression of disabled people, his practice strategies consistently rely on individual functional assessment tools to measure employability and job success. The book contains numerous worksheets, graphics of models, and functional assessment tools all focused on the student's ability to accept, adjust, adapt, and acquire skills. To assess service outcomes, Michaels relies on two models of "quality of life," a notion often refuted by Disability Studies scholars as being ableist, since such attributes are most often created and judged by nondisabled service professionals.

Michaels' "person-centered approach" to service provision, e.g., building on students' dreams and ambitions instead of on "deficits," and on shared decision-making rather than on arbitrary professional goal setting, runs amok when applied to practice. His team-building approach places the student in the center of family, school, agency, and community with all having equal say about the students' future. Michaels writes, "By involving these community representatives, the balance of power is shifted from professionals in control to shared power and decision making among all involved stakeholders" (p. 14). While this may be so, I fear that, with so many voices in the chorus, a student, especially a disabled minor, might not be heard. The goals, while commendable, tend to be unrealistic. Michaels writes, "From this giftedness perspective it is clear that disability becomes another diversity issue, and from the community point of view (as with other diversity issues) the community becomes richer through fully embracing the diversity of its members" (p. 14).

The language used in this manual is problematic in that it represents medical model thinking. For example, in his discussion of career decision-making models the author uses the word "normal" to describe the process for nondisabled students, and he writes more about "acceptance" and "support" than about "opportunity." Michaels' eight-step program for career building is named "PATH" which stands for "Planning Alternative Tomorrows with Hope." Spare me!

Like many disability service providers, Michaels appears to be grappling with how to translate social model theories into best practice. At least, he is on the right "PATH."

Shoenbrodt, Lisa, ed. *Children with Traumatic Brain Injury: A Parents' Guide*. Bethesda, MD: Woodbine House, 2001, 494 pages, \$17.95 softcover.

Reviewed by Timothy Lillie, Ph.D., The University of Akron, Akron, OH.

Woodbine House is active in publishing parent-friendly guides for mothers and fathers who suddenly find themselves in a very different place regarding their children than they had intended. What this book does is provide parents with the kind of clear, simple (but not simplistic) information they need - likely the only kind they will be able to absorb when dealing with a child who is typically-developing one moment and, often, very different after the traumatic brain injury. Parents need to have this kind of information in order to make sense of what is -to them - the senseless.

I recommend this book because its perspective on disability is a good one. The message that is sent is that having a disability means things might not happen the way we once hoped, but life does go on and it can be good. The professionals who have contributed to this book show a decent respect for parents - they do not talk down to them or sugarcoat or hide the problems parents will experience. Particularly gratifying to me and (I think) to parents of children with disabilities is a pronounced absence of the old-fashioned pity and charity approach. Children are not seen as tragically blighted or as having a disability they must "overcome," but as people who will develop in unique ways after a traumatic brain injury. This book would be an excellent item for parent groups to have on hand; it should also be readily available at children's hospitals.

Shorter, Edward. *The Kennedy Family and the Story of Mental Retardation*. Philadelphia, PA: Temple University Press, 2000, 263 pages, \$74.50 hardcover, \$22.95 softcover.

Reviewed by Martha L. Rose, Truman State University, Kirksville, MO.

Edward Shorter uses personal records of the Kennedy family and other, official documents to trace the philanthropy concerning mental retardation during the last decades of the Twentieth Century in the U.S. The book consists of eight chapters and a postscript and it includes eight pages of black and white photographs of such subjects as Eunice Kennedy Shriver making welcoming remarks at the Special Olympics which she created.

Shorter breaks new ground in interweaving the Kennedy records with the phenomenon of mental retardation, and his use of the primary material - records that have been mostly off-limits to scholars - is impressive. Disappointingly, Shorter does not build much on the foundation of Disability Studies scholars and he writes from the point of view of mainstream assumptions about mental retardation. A historian of medicine, Shorter recognizes that "the history of mental retardation (MR) is massively

important, and almost nobody knows anything about it" (page ix). But while he lists the key works on the history of mental retardation in the U.S., such as Steven Noll's *Feeble-Minded in Our Midst* (Chapel Hill, NC: University of North Carolina Press, 1995) and James Trent's *Inventing the Feeble Mind* (Berkeley, CA: University of California Press, 1995), he does not draw on them.

Curiously, when discussing the horrors of institutionalization of people with mental retardation in the chapter entitled "Useless People," Trent and Noll are mentioned only once and in a note that merely states the existence of their work. Instead, Shorter relies heavily on sources such as the writings of Pearl Buck and Peter Tyor's 1972 Ph.D. dissertation. Even more curiously, in light of Trent's immaculate and detailed work on institutions, Shorter's source for the description of an institution for the mentally retarded is a 1972 report by Geraldo Rivera.

The Kennedy Family and the Story of Mental Retardation is good scholarship, but the narrowness of the study limits its use in the Disability Studies curriculum. As Bogdan and Taylor, Noll, Sarason and Doris, Trent, and others have pointed out, mental retardation is not an observable reality, but a cultural construction. More attention to such key issues in Disability Studies scholarship would have helped.

Tymchuk, Alexander J., Lakin, K. Charlie, and Luckasson, Ruth, eds. *The Forgotten Generation: The Status and Challenges of Adults with Mild Cognitive Limitations*. Baltimore, MD: Paul H. Brookes Publishing Co., 2001, 415 pages, \$32.95 softcover.

Reviewed by Marjorie F. Olney, University of Illinois at Urbana-Champaign.

The Forgotten Generation is the result of the efforts of a national working group summit co-sponsored by the President's Committee on Mental Retardation and the Social Security Administration. This edited book provides a comprehensive overview of the myriad issues confronting adults who are considered to have mild cognitive disabilities.

Both within and outside of the disability field, there has been a tacit assumption that, upon exiting school, the "six hour retarded child" magically and seamlessly disappears into the fabric of community life maintaining his/her job and raising his/her family with minimal support from others. While it is demonstrably true that individuals with mild cognitive limitations do disappear, the economic, personal, legal, and social hardships they endure provide strong evidence that such individuals are not fully included. This text amply demonstrates that, due to economic hardships and lack of adequate supports, people with mild cognitive limitations have many unmet needs.

The book is divided into six parts. The first section imparts key concepts and definitions. Each of the five parts that remains explores a major life issue: employment, housing and community living, health, family and spirituality, and

citizenship and civil rights. Although the issues are explored with candor, sensitivity to the concerns and sensibilities of persons with cognitive impairments is evident throughout.

The text is comprehensive with one exception. While it is apparent that women's concerns are substantial in terms of lower pay, greater burden in parenting, higher school drop out rate, and domestic violence, the concerns of women are not addressed directly. Instead, issues of women with mild cognitive impairments are discussed under the broader topic "family life."

The Forgotten Generation is a sobering examination of the impacts of social programs and policies on individuals. Each chapter provides specific recommendations for social change and/or policy development to improve the situation of citizens with mild cognitive impairments. The book provides an important contribution to the literature. It should prove to be an indispensable resource for researchers and policy-makers.

Vogt, W. Paul. *Dictionary of Statistics & Methodology: A Nontechnical Guide for the Social Sciences* (2nd Edition). Thousand Oaks, CA: Sage Publications, 1999, 334 pages, \$56.00 hardcover, \$21.95, softcover.

Reviewed by Corinne Kirchner, American Foundation for the Blind.

Preparing to review Vogt's useful reference work, I was challenged by DSQ's Review Editor's guideline: If a book "does not deal specifically with disability or chronic illness [as this one clearly does not] focus . . . on [its] implications . . . for the field of Disability Studies." Initially, I saw only a general, quite unedifying linkage, to wit: Disability Studies scholars can benefit from a resource that concisely fills the inevitable blanks in our knowledge of technical language and tools of social research. But that is almost like recommending that they should own Webster's Dictionary (or Random House's, or whatever brand).

But help was at hand. I have been tackling the monumental new tome, *Handbook of Disability Studies* (Albrecht, Gary L., Seelman, Katherine D., and Bury, Michael, eds. Thousand Oaks, CA: Sage Publications, 2001) and realized that several of its chapters might lead nontechnical readers, and some technical ones as well, to seek Vogt's volume which not only defines statistical and methodological terms, but gives helpful examples of how they are applied.

So, as a (decidedly non-scientific) experiment to test the relevance of Vogt's book to Disability Studies, I skimmed three of the *Handbook's* early chapters (those by Fujiura and Rutkowski-Kmitta, Altman, and Brown) and easily harvested more than 20 terms that I guessed would perplex some readers. I wondered, "Would methodologically-challenged (said with tongue in cheek!) readers of the *Handbook* find applicable explanations in Vogt's dictionary?"

The results were promising. All but four of the test terms

are addressed; certainly, some omissions are forgivable. For example, "epidemiology" is not in Vogt's compilation, but "demography" is (p.78), (so is "epistemology" [p. 97], which is not in my test chapters, but does appear later in the *Handbook*.) I was surprised that "prevalence" and "incidence" are not explained in Vogt, but more surprised - and gratified - that "participatory action research" is there in slightly different form ("participatory research" [p. 208] with a cross-reference to "action research" [p. 4]).

In spite of Vogt's book featuring the term "statistics" in its title, and giving much space to describing statistical procedures, it does address qualitative approaches which are so important in Disability Studies. Vogt argues that the distinction between qualitative and quantitative methods is often overdrawn since good research of each type has elements of the other. (Vogt's occasional statements of opinion are refreshing in a book billed as a dictionary.) Nevertheless, while "positivism" (p. 217) is defined, referring to both laudatory and invidious perceptions of that approach to knowledge, there is no entry for "constructivism." ("Construct" is defined [p.53], however, from a quantitative research point-of-view.)

The book's utility rests heavily on extensive cross-referencing even though it is not completely consistent in doing so. This reviewer succumbed to the appeal of entering at one definition and following cross-references until dead-ending, learning things along the way, but, mainly, just being intrigued. That addiction, of course, is a danger/delight with any dictionary.

Space limits prevent sharing more "findings" from my pursuit of the relevance of Vogt's book to Disability Studies. Bottom line: Readers of the *Handbook*, a major compilation of disability scholarship, can benefit from the topics covered by Vogt. By extension, Vogt's *Dictionary* can help readers work their way through journal articles in this field. Indeed, since diversity of methods is a distinctive feature of Disability Studies, a resource like Vogt's contribution is especially appreciated, even if it does not fully encompass the range of methodological terms that we, like more established fields, not only use, but generate.

Webb, Kristine Wiest. *Transition to Postsecondary Education: Strategies for Students with Disabilities*. Austin, TX: Pro-Ed, 2000, 83 pages, \$9.00 softcover.

Reviewed by Debra Swoboda, New York University, New York, NY.

Despite the fact that an increasing number of students with disabilities are pursuing a college education, many students leave high school without employment or further educational plans. *Transition to Postsecondary Education* outlines the factors shaping successful transition to college by students with disabilities and provides useful thought exercises for students

to utilize in the decision-making process.

The author points out that while the factors shaping the college selection process are not that different for students with disabilities than for students in the general population, "the planning process . . . is a transition cornerstone for college-bound students with disabilities" (p. 4). Formal transition planning is not only a legal mandate for most students with disabilities, it also increases the likelihood of postsecondary enrollment.

The text presents a model titled OPEN, or Opportunities in Postsecondary Education Through Networking, to assist students, parents, and school personnel to engage in the planning process. Various time lines, questionnaires, activities, and portfolio suggestions are offered as a road map for actualizing the model. The majority of text information is presented in a workbook format with exercises that address transition issues such as career interest clarification, understanding postsecondary institution options, decision-making time lines, differences among disability services programs, student/college goodness of fit, and the college application process.

The text is an extremely useful hands-on guide for students with disabilities and their parents for navigating the college transition process. High school teachers and guidance counselors should also consider adopting the text as a useful and inexpensive transition tool.

Young, J. Gerald, and Ferrari, Pierre, eds. *Designing Mental Health Services and Systems for Children and Adolescents: A Shrewd Investment*. Philadelphia, PA: Brunner/Mazel, 1998, 500 pages, \$59.95 hardcover.

Reviewed by Richard K. Scotch, School of Social Sciences, University of Texas at Dallas.

This volume is the product of an international conference of prominent child psychiatrists and other mental health professionals concerned with the design of mental health service systems for children and youth. It features thirty-five short chapters by conference participants who represented behavioral health disciplines such as pediatric psychiatry, social work, and psychology, and who worked in diverse societies including the United States, several nations in Western and Eastern Europe, Latin America, and Asia.

The special strength of this volume is its broad focus. As well as its international and interdisciplinary nature, the selections not only address treatment issues for mental disorders among children and adolescents, but also epidemiological patterns and public policies such as how services are financed. Many of the selections report on empirical studies, including clinical research and quantitative studies, while others provide a conceptual basis for understanding the distinctive mental health issues involving children and youth.

The book's major limitation also stems from this breadth.

Each of the pieces included is rather short and many are so schematic that they do not cover their topic in a satisfying manner. For example, some of the empirical work do not provide enough context for the reader to understand its significance beyond the population being studied. While more explicitly integrating such a disparate collection would be a daunting task, it would constitute a major contribution beyond the sum of the volume's many parts. Another limitation for readers who are not mental health professionals is that many of the selections commonly employ technical terms, both from behavioral health and from research design, that may render them inaccessible.

The collection does include some recurrent themes, however. One major finding involving nations with both advanced and developing economies is that many children and adolescents with potentially serious psychiatric diagnoses have not been identified and/or are not receiving appropriate services. Many authors conclude that broader outreach and public awareness campaigns are badly needed.

A second common theme found in chapters addressing the United States and other nations in which managed care is becoming the primary mode for organizing and financing services is that treatment decisions are too often made to reduce costs without sufficient attention to their therapeutic consequences. While most authors concede the realities of limited resources, many argue that more and better data on outcomes of various treatment strategies would allow far more appropriate guidelines to be developed. A final related theme is that significant research advances have occurred in recent years, but that much more work is needed.

This volume falls short of being a handbook that systematically covers what is known about child and adolescent mental health. Nevertheless, it is a diverse and very informative collection, the pieces of which complement each other well. The book would be of interest to practitioners in the field, advocates, scholars, students, and anyone concerned with children's mental health.

Books for Kids

Zimmert, Debbie, and Fremaux, Charlotte Murray. *Eddie Enough!* Bethesda, MD: Woodbine House, 2001, 44 pages, \$14.95 hardcover.

Reviewed by Peggy Quinn, University of Texas at Arlington, Arlington, TX, and Clair Daly, 2nd Grade, Bramlett Elementary, Longview, TX.

The book's back cover states, "For children with Attention Deficit/Hyperactivity Disorder (AD/HD) and their parents, friends and teachers, *Eddie Enough* rings true." That description seems quite accurate.

This small book recounts the experiences of a third grade boy who moves too fast, talks too much, and gets himself into so

much trouble that his teacher finally exclaims, "Eddie, enough!" The comment immediately becomes a nickname chanted by his classmates, "Eddie Enough thinks he's tough."

The story is told by Eddie. He notes that his grandmother tells him he was born running and his mom says he even listens fast. On one fateful day he spills orange juice on his dad's suit, arrives at school late for his spelling test, spills a jar of sea monkeys, and then releases the class rat to clean up the mess. That was all before lunch. The next step was a trip to the principal's office.

To Eddie's good fortune, the principal had similar experiences as a child. After a parent/teacher conference, Eddie was sent for a comprehensive physical exam culminating in a diagnosis of Attention Deficit/Hyperactivity Disorder. A prescription for "special medicine" and regular sessions with the school counselor helped Eddie to calm down, pay attention, and succeed in school.

The book is short with nicely drawn illustrations that enhance the narrative. The story is certainly understandable for elementary school-aged children. The reading level was comfortable for Clair, who is seven. Eddie's description of his actions is straightforward. He seems as surprised as his family and classmates that he can get into so much trouble while doing what would seem to be ordinary activities. The book successfully meets its purpose of "normalizing" Eddie's situation and making it more understandable.

This book could be used to help children with AD/HD, their classmates, and their families to understand what these children experience. This may be a book that professionals will want to have in their toolkit. For some kids and families, the information and presentation will be just right.

Film Clips

Dubo, Elyse (Producer), and Vasic, Boja (Producer/Director). *The Other Side of Blue: The Truth About Teenage Depression* [video]. Boston, MA: Fanlight Productions (4196 Washington St., Suite 2, Boston, MA 02131, 1-800-937-4113), 2000, 31 minutes, \$195.00 purchase, \$50/day rental.

Reviewed by Barbara Granger and Paula Phy, Matrix Research Institute, Philadelphia, PA.

In a brief half hour, we are introduced to the teenage world of clinical depression - an experience of hopelessness and without future. Four young people - two young women and two young men, along with helping professionals - tell the story of their experience with clinical depression. Topics covered include the specific facts about clinical depression differentiating traditional teenage experiences from clinical depression, family reactions and interactions, other symptoms of the depression that interfere with daily functioning, the relationships of drug and alcohol use to depression, and the problem of suicide.

The presentation provides facts to counter myths and stereotypes, and specific recommendations for how people might be helpful. However, the primary message is directed toward the person who might have depression. It provides encouragement and hopefulness engendered in reaching out for treatment and recovery supports to help oneself. Each of the four young people has obtained treatment and has moved on to attending college or working.

The only weakness of the video is the limitation of the cultural context. While stating clearly that a mental illness can happen to anyone in any cultural or socioeconomic setting, the stories in the video are of four people who appear to be middle class, urban, and not of any minority status. This video should be considered for direct education to young people (perhaps middle school as well as high school students) and their families. Furthermore, *The Other Side of Blue* could also be useful as a resource for the education and training of psychiatrists, social workers, guidance counselors, and teachers, as people from each of these professions are interviewed or mentioned and the importance of their roles is discussed or implied throughout the video. This film might also be used as a health promotion tool in school assembly programs and health classes where an individual or his or her friends might encourage discussion about seeking help from professionals.

Welsh, Mathew (Producer/Director). *Breakaway - A Tale of Two Survivors* [video]. Boston, MA: Fanlight Productions (4196 Washington Street, Suite 2, Boston, MA 02131. 1-800-937-4113), 2000, 45 minutes, \$225.00 purchase, \$50.00 rental/day.

Reviewed by Charles D. Palmer, Ph.D., C.R.C., Mississippi State University, MS.

Meet Robert and Doug, both young men recovering from severe traumatic brain injury (TBI). As stated in the film's promotional literature, the story focuses on the conflicted relationship between the two men and the disparate consequences associated with TBI.

The film begins with descriptions of how each of these men was injured. Robert was playing hockey when he sustained a head injury that left him in a coma for two months. Upon reviving, Robert, with the aggressive support of his father, approached his physical therapy with almost compulsive fervor making what is referred to in the film several times as a "miraculous" recovery.

Doug, the survivor of a drunk driving accident, spent six months in a coma. When he recovered consciousness his injury left him unable to talk, walk, or even minimally care for himself. His family, unable to cope with his extreme physical limitations, placed him in a nursing home.

The relationship between the young men develops when Robert begins working as Doug's personal care attendant at the nursing home. Robert approaches the job of assisting Doug with the obsessive zeal that seems to have worked so well for him pushing

Doug to set goals (such as walking) that family members and medical professionals view as beyond Doug's abilities. Robert and Doug's relationship develops to a point at which, with Robert's prompting and support, Doug moves out of the nursing home and into a house.

As the story evolves, Doug's family, medical support personnel, and even a friend of Robert's express concern about Robert's aggressiveness with Doug's conditioning and the harm that may result from isolating Doug from his family. For example, Robert was away for a week so he asked a friend to take over assisting Doug while he was gone. Upon Robert's return, the friend questioned the way he "was pushing" Doug. "Is this for Doug or for yourself?"

The ending of this video leaves this viewer with the same unanswered questions that are raised throughout the documentary: what is accomplished by comparing two people as if their similar injuries somehow equate their potential for rehabilitation? Is "being in recovery" a sufficient credential for a person to enable effective change in another individual? What "message" does the documentary seek to convey?

Although this video presents a poignant overview of the lives of two men living and coping with severe traumatic brain injury, the lasting message for this reviewer is that regardless of the ability of medicine to increase the physical survival of individuals who have experienced brain injuries, we still possess only a rudimentary ability to predict the functional capacity of individuals who have experienced TBI. Any attempt to force such a characterization creates more barriers for the individual than it resolves.

Resources

From the University of Chicago Press: *Crippled Justice: The History of Modern Disability Policy in the Workplace* by Ruth O'Brien; paper \$19.00.

Crippled Justice, the first comprehensive intellectual history of disability policy in the workplace from World War II to the present, explains why American employers and judges, despite the Americans with Disabilities Act, have been so resistant to accommodating the disabled in the workplace. Ruth O'Brien traces the origins of this resistance to the postwar disability policies inspired by physicians and psychoanalysts that were based on the notion that disabled people should accommodate society rather than having society accommodate them.

The University of Chicago Press
1427 East 60th Street
Chicago, IL 60637
www.press.uchicago.edu

Announcements

DISABILITY STUDIES NEWS & NOTES

DSQ is re-activating its section that contains news, announcements, and information about Society for Disability Studies (SDS) members and others engaged in disability studies research, both in the U.S.A. and internationally. This section will cover conference, convention, and publication announcements, calls for papers, new job appointments, grants obtained, awards won, and other information of interest. All individuals engaged in disability studies research are encouraged to submit information about their activities.

Submissions may be edited to conform to DSQ style and space limitations. If deadlines have passed for conference, conventions, or calls for papers, they will not be included, so all are encouraged to submit these announcements as early as possible. Please try to keep all News & Notes items under 250 words when possible.

Finally, only electronic submissions will be accepted. They should be sent as an E-mail or an MS Word attachment to Beth Haller, bhaller@towson.edu <mailto:bhaller@towson.edu>. If you have questions, please contact Beth Haller.

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Communications

The Fall 2001 issue of *Hypatia: A Journal of Feminist Philosophy* is a special issue on "Feminism and Disability Studies 1." Edited by Eva Fedder Kittay, Anita Silvers, and Susan Wendell it includes articles by Jenny Morris on "Impairment and Disability: Constructing an Ethics of Care Which Promotes Human Rights"; Susan Wendell on "Unhealthy Disabled: Treating Chronic Illnesses as Disabilities"; Mairian Corker on "Sensing Disability"; Alexa Schriempf on "(Re)fusing the Amputated Body: An Interactionalist Bridge for Feminism and Disability"; Andrea Nicki on "The Abused Mind: Feminist Theory, Psychiatric Disability, and Trauma"; Kate Lindemann on "Persons with Adult-Onset Head Injury: A Crucial Resource for Feminist Philosophers"; and Lucia Carlson on "Cognitive Ableism and Disability Studies: Feminist Reflections on the History of Mental Retardation"; as

well as an introduction by the editors.

Issues of "Feminism and Disability Studies 1" are priced at \$16.95 each (plus shipping and handling). However, if you visit our secure web site at <www.iupjournal.org> and enter discount code KPRF, you may purchase copies at a 20% discount. You may also phone 1-800-842-6796 or fax credit card orders to 1-812-855-8507.

The Society for Disability Studies

The Society for Disability Studies (SDS) is an international non-profit organization that promotes the exploration of disability through research, artistic production, and teaching. Disability studies encourages perspectives that place disability in social, cultural, and political contexts. Through our work we seek to augment understanding of disability in all cultures and historical periods, to promote greater awareness of the experiences of disabled people, and to contribute to social change.

Further information on membership and the annual meeting can be obtained from the national office of the Society. The mailing address is: Society for Disability Studies, c/o Professor Carol Gill, Department of Disability and Human Development, University of Illinois at Chicago (MC 626), 1640 Roosevelt Road #236, Chicago, IL 60608-6904. The email address is: <cgl16@uic.edu>.

Subscription Information

Subscriptions to *Disability Studies Quarterly* are on an annual basis and are part of membership in the Society for Disability Studies, except for library and institutional subscriptions. If you are not certain about the status of your subscription, please contact the Society for Disability Studies office in Chicago at the address below, by telephone at 312-996-4664 (V/TTY), or by email at <cgl16@uic.edu>. Additional information about the Society is available at our website, <www.uic.edu/orgs/sds>.

The Samuel Gridley Howe Library in Waltham, Massachusetts, is the repository for past issues of *Disability Studies Quarterly*. The papers and books of Howe, of Irving Kenneth Zola, of Rosemary and Gunnar Dybwad, and some (but eventually all) of the papers and books of David Pfeiffer are also deposited there. Bonnie Stecher is the librarian at the Howe Library. The Library is available for research into all aspects of disability.

Past issues of *Disability Studies Quarterly* are available for purchase for \$10.00 each although the price may increase due to factors beyond control. Please specify the theme of the issue and the volume and issue number. Your request with a check made out to Friends of the Howe Library should be mailed to Howie Baker, MS #044, Brandeis University, P.O. Box 9110, Waltham, MA

02254-9110. The subject matter of available past issues will soon be available on the SDS web site: <www.wipd.com/sds>. Howie Baker <baker@binah.cc.brandeis.edu> can answer questions.

Instructions for Symposium Editors and Contributors are available from the Editor, David Pfeiffer, on the Internet at <pfeiffer@hawaii.edu>.

All books, films, and videos to be reviewed must be sent to Dr. Elaine Makas, 10 Sheffield Street, Lewiston, ME 04240, USA. Persons wanting to volunteer to do reviews should contact her with your field of specialty.

Future issues of Disability Studies Quarterly

Winter 2002: A generic issue of papers relating to disability studies.

Spring 2002: Counselling, Therapy, and Emancipatory Praxis, Deborah Marks <D.S.Marks@sheffield.ac.uk>.

Summer 2002: Sexuality and Disability, Linda R. Mona <LRMona@aol.com> lead editor and Devva Kasnitz <devva@wid.org>.

Fall 2002: Disability Culture II, Steve Brown <SBrown8912@aol.com>.

Winter 2003: Disability Geography - II, Deborah Metzel <dsmetzel@yahoo.com> and Michael L. Dorn <mdorn@zoo.uvm.edu>.

Spring 2003: Disability and the Life Course, Mark Priestley <m.a.priestley@leeds.ac.uk>.

Summer 2003: open.

Fall 2003: Humor and Disability, Beth Haller <bhaller@towson.edu>.