Emerging geographies of impairment and disability: an introduction

This collection of papers originated from a conversation between Vera Chouinard and myself on the high incidence of chronic illness among tenured female geographers in Canada. Our discussion subsequently expanded into a broader dialogue about disability, ableist environments, and the need for critical geographic research in these areas. Since that initial conversation we have seen the creation of GEOGABLE (an electronic discussion group on geography and disability), path-breaking sessions at the 1997 RGS-IBG and AAG conferences, and the formation of the Disability and Geography International Network (DAGIN)(1). These developments mark the coming of age of geographic work on disability. There are growing efforts to recognize and support people within our discipline who have impairments. In addition to its research focus, DAGIN seeks to bring together disabled geographers, and to lobby for better organizational recognition and accessible conference facilities. Such efforts will help to empower those marginalized and excluded from spaces of academic life because of impairment.

The collection appears as disability issues are receiving greater attention both from academics and from the media. This reflects developments in academic theory and broader social change. First, as Ruth Butler and Sophia Bowlby note, disability theory is itself in a time of transition, with its frameworks and policy goals under scrutiny. Increasing attention is being paid to differences among ‘the disabled’, including impairment, gender, class, ‘race’, and sexuality. There has been growing criticism that the social model of disability does not sufficiently consider bodily experiences of impairment. As the papers in this collection demonstrate, geographers have much to contribute to these theoretical and political debates.

Second, as DAGIN notes in its statement of purpose, the number of disabled academics is slowly increasing. Technological advancement, better educational provision for disabled children, and government legislation mandating equal opportunities and physical accessibility, have enabled people with impairments to enter, and remain, in the academy. However, substantial physical and social barriers remain. These issues are explored in Reginald Golledge’s account of his academic rehabilitation after the onset of sudden vision impairment.

(1) Further information about GEOGABLE and DAGIN can be found on the latter’s Internet site at http://web.qub.ac.uk/geosci/research/geography/disbib/disgeog1.html.
Third, this collection appears at a time when social services for disabled people are being significantly restructured in many First World countries. Former geographies of ableism are being transformed and contested, while new geographies of disability continue to emerge. Changes in social service delivery for people with impairments are not unprecedented. The past thirty years have seen the closure of asylums for the mentally ill, and the integration of many children with hearing, mobility, or learning impairments into regular classrooms. These initiatives have shaped, and are also to some extent the outcome of, geographies of physical impairment and mental health. As Hester Parr notes in this collection, for example, policies of 'deinstitutionalization' for services of mental health users have led to new forms of marginalization but also to new spaces of resistance.

Although not historically unprecedented, the present restructuring is nonetheless very substantial. Demand for many services for disabled people has increased because of population aging. The proportion of elderly people in First World countries has risen, with particular growth of the 'very old', the cohort aged 85 and over that is most likely to experience impairment. Disabled people are also particularly affected as national welfare states are dismantled or rolled back. Their relative place within social welfare structures is also changing. Some forms of social welfare provision have been eliminated, while others have been substantially modified, shifted to other levels of government (which may not have adequate financial resources), or privatized. Hence population aging, combined with fiscal pressures on governments (whether real or constructed discursively through neoliberal ideologies) are fueling growing debate and political struggle over what services should be provided to disabled people, who should have access, and on what terms. These debates are increasingly accompanied by discourses of the ‘deserving’ and ‘undeserving’ disabled. Underlying this is a widely held view that people with impairments have no automatic right to assistance. Any help given is an act of charity meted out to those who ‘deserve’ it, as Ruth Butler and Sophia Bowlby note in their paper. These political struggles and debates will intensify. However, their outcomes may vary significantly across space. As welfare service provision is shifted to lower levels of government, conflict will be increasingly manifested and differentiated at the local scale. Meanwhile the growth of the Internet and greater communication between groups of disabled people across national boundaries will see more organization and information sharing at the international level.

One example of the changing place of disabled people in social welfare structures is legislation currently under debate in Ontario, Canada's most populous province. The Social Assistance Reform Act introduced by the Conservative government of Mike Harris would legally redefine disability and substantially alter the place of 'disabled' people in the welfare system (as well as officially introducing workfare for many non-'disabled' recipients of social assistance). Disability would be determined by “substantial restrictions in the activities of daily living” and “restrictions that result directly from a physical or mental impairment expected to last at least one year” (quoted in the Globe and Mail 1997). People deemed to meet the new definition will be transferred from the general welfare system to the newly created Ontario Disability Support Programme. They will be encouraged to seek work through a job-support programme run by local service providers, and no longer considered permanently unemployable. Those who qualify for the programme will be allowed to keep a larger share of their liquid assets, compensation awards, and gifts and inheritances. Ontario's 'disabled' would also have a higher limit on life insurance policies. These new social welfare provisions may indeed be positive for those who make the cutoff point. However, they will create hardship for people who do not. For example, those with substance addictions will no longer be automatically classified as 'disabled'. The harsh
reality is that the level of general welfare payments is not sufficient to cover the additional costs of a disability.

Another consequence of population aging and changes in the welfare state is growing conflict between disabled persons over who should be entitled to the state-provided services which remain. These issues will have a strongly geographical character as responsibility for funding and/or operating these services is more and more shifted to the local level. The ugliness of this conflict, and the construction of the 'deserving' disabled associated with it, hit home in the summer of 1996 when I conducted reassessment interviews for an accessible transit service in a major Canadian city. This service had previously served a variety of disabled people, including those using wheelchairs, scooters, walkers, canes, or requiring personal assistance; dialysis patients; and persons with visual and/or cognitive impairments. Prospective riders had been granted access upon receipt of a medical certificate stating they were unable to use public transit. However, in 1996 the service decided to introduce new criteria for eligibility. Ridership would be limited to those who could not climb or descend more than several steps or walk 175 m. All active, inactive, and prospective users were required to come for a short reassessment interview at a downtown location (unless they could attend interviews held in seniors' residences and medical facilities throughout the metropolitan area). The approximately 20000 people already on the system had to book an interview within a specified time period, or lose their eligibility. The official reason given for the new service criteria was limits on funding from the provincial government. The reassessment procedure was needed to ensure that those who needed accessible transit the most would receive it, and that the service would be able to provide for their needs.

As an interviewer, I daily encountered resistance to the process. Individual interviewees, and/or those who accompanied them, attempted to justify continued access to the system on grounds of physical impairment, age, poverty, employment, inability to depend on others to drive them around, or having paid income tax for many years and wanting something back. In some cases they persisted after being told that only functional mobility would be considered when determining their eligibility for service. On occasion clients would try to present documentation from medical practitioners (which they had been told would not be considered in initial interviews), or exposed impaired parts of their body to interviewers. Some, clearly under considerable stress, became highly emotional, even breaking into tears. Other users (and those accompanying them) asked pointed questions about the reassessment procedure, tried to peek at my list of questions, or vehemently announced they would appeal should they be denied service. Frequently other groups of accessible transit service riders were labeled as 'undeserving'. The reason why the system had been meeting only about 40% of ride requests, I was told, was because many others abused it or did not need the service. Alleged culprits included bingo players, residents of seniors' homes which had their own buses, people with relatives who could drive them places, other dialysis patients who did not use wheelchairs, and those who used the service to go shopping.

One of the most unsettling aspects of the reassessment process was that frequently the people most vociferous in asserting their 'right' to accessible transit were elderly people who had developed impairments later in life and who were still able to travel in nonadapted vehicles. They would describe at length the difficulties of having to use a cane or a walker, the hassle of coming for an in-person interview, and the perceived injustices of the process. A number complained that the building in which interviews were held was not accessible (the legally required level access having been cleverly blended in by the architect, which seemed to pose no difficulties for wheelchair users).
Others argued that they were entitled to accessible transit by virtue of their age as few, if any, younger people allegedly needed the service. It was the concerns and ridership experiences of this group which received greatest attention in local media coverage of the reassessment process.

In contrast, interviewees born with serious mobility impairments, and those who had begun to use wheelchairs later in life, were often cooperative, even passive. Having had considerable experience with the medical profession and bureaucracy, they would wait patiently for an interview and then answer questions succinctly and politely. Their complaints about the reassessment procedure were fewer and generally less vocal. A number of caregivers made it clear that the trip downtown had been difficult to arrange. Several expressed surprise that other applicants in the waiting room required only a cane or a walker, or no assistive device at all, to get around. A few younger wheelchair users informed me that they had legal training, and intended to challenge the reassessment process in court. The concerns of these riders with greater mobility impairments were given much less attention in the local media. I began seriously to question whether the political empowerment of Canada’s more active elderly might be at the expense of those with the most need for accessible transit, especially younger wheelchair users who travel to school or work. Michael Dear, Sharon Lord Gaber, Lois Takahashi, and Robert Wilton’s paper alerts us to the ways in which able-bodied persons’ perceptions of distance from different disabled people can enter into the political process of distinguishing between ‘deserving’ and ‘undeserving’ disabled people.

In summary, disability issues are receiving increasing attention from academics and the media in the First World. Population aging, the rolling back of welfare state systems, and the transfer of service provision and funding to local governments, will ensure an even higher profile for these issues. New geographies of disability will continue to emerge, as will opportunities for political action and spaces of resistance. For example, as Parr notes, the market orientation of the UK National Health Service has led to greater acceptance of user groups. Users of mental health services have significant power for the first time. In the midst of significant organizational changes those involved in these groups often know more about the services they use than do employees. However, the groups now have to interact both with medical professionals and with business-oriented Trust staff, whose interests are very different.

This collection is not without limitations. Many forms of impairment, and the geographies associated with them, are not addressed. The collection is also written from a First World perspective. It reflects on academic theory developed in the North, and gives voice to the experiences of disabled people from there. The realities of physical impairment and ‘madness’ in the South are admittedly very different. For example, impairment caused by explosions from landmines has been recognized as a significant social and economic problem in countries such as Mozambique, Afghanistan, and Cambodia. There has been growing pressure from nongovernmental organizations for the stockpiling, trading, and use of these deadly devices to be eliminated. Issues of designing built environments that facilitate use by all members of society, regardless of able-bodied status, will likely receive greater attention in the more wealthy countries of the South in coming years. This collection is, then, a preliminary step towards a much larger geography of disability.

Lisa Cormode

Reference