Book Reviews

The Disability Rights Movement: from charity to confrontation
DORIS ZAMES FLEISCHER & FREIDA ZAMES, 2001
Philadelphia, PA, Temple University Press
278 pp., £55.39 (hb), £17.38 (pb)
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This is a fascinating book, meticulously researched and comprehensively covering all aspects of disability rights issues and how disabled people have engaged in the struggle for rights in the USA. I found it very difficult to put down and frequently re-dipped into its pages for information. However, it took me some time to recover from the shock of discovering that, apparently, the disability rights movement has only happened in the USA. Once you have grasped that there is no allusion to any activity anywhere else in the world—with the implication that it is only in the United States that anything has ever happened, and that only attitudes and events in the USA impact on disability rights—then it is well worth reading this book. It becomes very clear how similar experiences are across cultures and that, despite dissimilar environments, financial status and opportunities, the barriers to inclusion are the same and the way disabled people have come together, reacted to each other and involved themselves in the great struggle have a unifying commonality. Because of the depth and analysis of the research, that it is only focused in the USA does not detract from what this book has to tell us. It just would have added to its importance if it had recognised that what was happening in the USA was part of a world-wide movement and that events in other countries could have an impact on the whole disability rights movement.

The authors, who are sisters, academics and one of whom is a disabled person, have really looked in depth at images of disability, the impacts of services, benefits, technology, policies and legislation, and how the activities of disabled people and their organisations have effected change. They have also been refreshingly balanced and honest in their reporting, giving a clear picture of problems that have arisen within the disability movement through different organisational approaches or through conflicts of interest between disabled individuals. And they have done this without in any way being detrimental to the overall thrust of the movement for rights.

The book starts with a chapter on ‘Wheelchair Bound’ and ‘the Poster Child’, and gives an interesting analysis of F. D. Roosevelt’s innovative support of what we would now call independent living, while at the same time ensuring that no visual images of his impairment were made public. The fact that he had polio and did all that he could to disguise that he could not walk is well documented, but it is less well known that he started an innovative rehabilitation centre dedicated to ensuring that
disabled people could live an independent life and not, as was the practice at that time, be interned in an institution. All this, despite the annual Birthday Balls held from 1934 to 1945 to celebrate the President’s birthday and raise money for the March of Dimes to ‘Dance—that others may walk’! (p. 7) As this chapter shows, similar images were used by Jerry Lewis and his telethon: ‘Jerry’s kids are people in wheelchairs on television raising money to find a way to prevent their ever being born’ (p. 11).

The authors are rigorous in keeping their historical analysis tied into the experiences of organisations of deaf and blind people, but at no point in the book do they define disability—it is taken as read that disability is another word for impairment. Yet they espouse the social model of disability, are absolutely clear that disability is a rights issue and that it was only through social change that disabled people were effective in obtaining rights.

Inevitably, after an account of the rise of the independent living movement, a great deal of the book covers the implementation of legislation: the Rehabilitation Act (1973), the Americans with Disabilities Act (1990) and the Individuals with Disabilities Education Act (1975) being the most far-reaching. There is a fascinating acceptance throughout the whole book, from which we can learn lessons, that one of the best solutions to a problem is for a disabled individual or an organisation to sue for damages. To non-American eyes this is the one really important advantage the disability movement in the USA has over movements in other countries. Evidence in this book shows overwhelmingly the effectiveness of these actions, although also showing that demonstrations and sit-ins have their value. There is also useful evidence of the nature of the political backlash against disabled activism and rights legislation and the well-recognised habit of the media to ignore the voice of disabled people when discussing disability issues.

The organisation, ‘Not Dead Yet’, and their struggle with eugenic and proeuthanasia attitudes are well documented. In a later chapter on disability and technology, the elimination of disabled people through the various advances in genetic sciences is also discussed. All these issues merit a book each, but the authors have managed to give a good overview of attitudes and problems, and pose very relevant questions, such as ‘how can we assert the primacy of the individuals served over the “business ethics” of biotech and pharmaceutical companies or “a deficient health care system”?’ (p. 168) Their question is preceded in the earlier chapter by a quotation from ‘Not Dead Yet’s attorney, Diane Coleman, at the conclusion of her 1998 congressional testimony: ‘Our society is wrestling with what is perhaps the most pivotal issue of our time: whether cost-benefit analysis will determine the value of a human life, whether people with disabilities, including terminal illnesses, belong in our society as a part of humanity’s diversity, or whether we [people with disabilities] will be pushed, subtly and not-so-subtly, toward the Final Exit solution’ (p. 148).

The final chapter is concerned with identity and culture. There is a suggestion that the movement is divided—not into disabled people and non-disabled allies, but between those who live in institutions and those who experience independent living. There is no doubt, however, that the disability rights movement in the USA celebrates its diversity and relishes activism. Despite the high profile status of some individuals,
it is recognised that the disability rights movement as a whole is not regarded as having the same political or establishment status as, for example, the women’s rights movement. As Judy Heumann, one of the most significant players in the movement and Assistant Secretary for Special Education and Rehabilitation during the Clinton administration, is quoted in this chapter as saying:

... the disability rights movement has to be an integral part of the overall movement for change. We have to appreciate what poverty means in this country because poverty is a significant cause of disability and poverty adversely affects disability. It is critically important that we look to our other civil rights partners and the larger economic picture. Then we can become a bigger player, and diversified movement will naturally evolve. Though the gains of the disability rights movement over the last thirty years have been impressive, they are relatively few in relation to what we yet have to do. (p. 214)

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Disability and the Life Course: global perspectives
MARK PRIESTLEY (Ed.), 2001
Cambridge, Cambridge University Press
252 pp., £14.95 (pb), £40.00 (hb)
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What do prenatal eugenic tests and other bio-medical technologies, socially stigmatising special schools for children classified disabled, poverty-induced impairments and struggles for survival, and the disability rights movement have in common? They constitute core issues at the nexus of disability and life course research, uniquely linked in this edited volume. In introductory and concluding chapters, editor Mark Priestley frames this diverse collection, which references an impressive array of personal experiences and research projects in more than a dozen countries. Offering a multitude of personal, political and theoretical perspectives on changing life courses and disability, this book presents both historical and current developments in disabled people’s lives, and in culturally-specific thinking about impairment, disability and ageing.

Melding micro- and macro-levels of analysis, the chapters focus on experiences of people with a variety of physical, sensory and cognitive impairments in all life course phases and on their struggles for survival and for more inclusive, less disabling societies. It exemplifies the utility of the life course perspective for disability studies in contributions that ‘present a very wide range of life course experiences and issues, in different countries, across different generations, and from different perspectives’ (p. 240). Issues of disability, age, class and caste, gender, race and ethnicity, religion, as well as sexual orientation are addressed in 20 chapters referencing research on differing life chances across five continents. The book’s three parts—‘Concepts’,
‘Methods and stories’, and ‘The politics of transition’—show disability’s ubiquity simultaneously with its cultural and historical specificities, exploding the notion that there can be one ‘normal’ life course progression, despite social policies, international organisations’ and societal attitudes that determine and defend particular pathways and transitions.

In Part I, Priestley presents disability increasingly at the centre of the international human rights debate, and as the subject of national and supranational legislation. Disabled people worldwide struggle to empower themselves, claiming equality, and demanding access to full participation in education, employment and welfare. Extending life expectancies and rapid population growth in many world regions ensures growing prevalence of impairment and disability, regardless of their highly dynamic, variable definitions. Irwin tells of disabled people who have shifted their claims from individual needs to challenges against disabling social relations. She clearly articulates the power of a life course perspective for understanding the social institutions and processes that shape individual lives. Ghai, writing from India, questions the existence of a universal meaning of disability, referring to the importance of traditional religious understandings in disability’s social construction. She makes an appeal that poverty, in causing impairment, represents the gravest, most common threat to disabled people. Also focusing on poverty, Stone argues for attention to the differential effects of impairment and disability as we analyse sociocultural constructions of personhood, also an inherently relational concept—sometimes measured in degrees—that varies across the life course. Sustained medical model approaches to disability bring increasing risks as societies ration resources, expand use of bio-medicine to solve social problems and support large-scale usage of predictive eugenic tests. Wolbring calls urgently for debate on eugenic ‘solutions’ that he warns unleash a ‘war of characteristics’ pitting social groups against one another, undermining the human rights movement.

Part II presents a variety of biographical accounts from around the world. Borrowing concepts from event history analysis, a statistical research method, Kasnitz develops graphic models to identify ‘essential life domains’, charting the life histories of leaders in the US independent living movement. Corker emphasises the need for critical—and interdisciplinary—life course accounts within their historical and locational contexts. She asserts the importance of self-reflexivity among researchers engaged in life course research. McNeil describes her childhood in India, migration to England, late awakening as a blind person and eventual role as advocate. Kalekin–Fishman, who migrated from the US to Israel, writes of her shifting positions between the discursive poles of normality and abnormality. Morgan uses life histories to examine disabled South Africans’ experiences before and after apartheid. Similarly, Iarska–Smirnova explores disabled people’s lives in the pre- and post-Soviet periods. Writing his own biography, Kikkas locates factors affecting disabled people’s lives in Estonia.

In the book’s third part, Philpott and Sait emphasise disabled children’s vulnerability as a function of generational and ability statuses, examining the multitude of disabling social barriers that reduce children’s developmental opportunities. Tisdall calls for a long-overdue cross-fertilisation of the transition-orientated
literatures on disabled youth, youth and childhood. Rowlands discusses the importance of family and friendship networks in supporting disabled youth to reach their goals, and to increase their inclusion in communities. Focusing on the effects of access to paid work on disabled people’s relationships, their self-autonomy and their participation in society, Turmusani emphasises that paid work is not only a marker of adulthood, but a matter of survival. In a comparative study of intellectually disabled women in Australia and Iceland, Johnson et al. describe the painful, struggle-filled process these women went through in deciding whether to have children in societies in which the dominant discourse still rejects their motherhood. Iwakuma, who studied acquired impairments in Japan, the country with the longest life expectancy, maintains that ageing and disability cannot be discussed separately. Affirming that ageing is relative, Breitenbach contrasts the parallel myths of disability and old age, compares the significant identity differences between ageing impaired people and older people who acquire impairments, and the challenges and opportunities of increasing longevity for intellectually disabled people.

Among the first works explicitly joining disability studies and life course perspectives, this book will strongly influence and encourage further developments. Disability and the Life Course highlights the need to further investigate several areas of research in future. These topics include:

- explicit and direct comparative cross-national or cross-regional research, especially on social policies;
- culturally-specific, dynamic definitions and categories of impairment and disability change across the life course;
- the need for relational theoretic framework to gather the particularities of individual life course stages, and of differing birth cohorts over time into generalisable pathways and trajectories.

Unfortunately, quantitative life course studies including demography and longitudinal studies are largely missing from this very diverse volume. Despite the challenge of the multiplicity of voices and methods, this book shows just how fruitful truly international and multidisciplinary collaborations can be.

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**Americans with Disabilities: exploring the implications of the law for individuals and institutions**

**Leslie Pickering Francis & Anita Silvers (Eds), 2000**

New York, Routledge

432 pp., £50.00 (hb)

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The Americans with Disabilities Act has been a beacon for disability rights activists around the world, and served as a model for anti-discrimination laws for disabled
people in many countries. On its tenth Anniversary, there is a corresponding widespread interest in understanding how that law is operating in practice. The editors of *Americans with Disabilities* set themselves the task of bringing together leading philosophers, legal scholars and political theorists to remedy what they identify as the failure to examine the conceptual, philosophical, political and legal foundations of the ADA.

And a very excellent job they make of it. This thoughtful, challenging and comprehensive review opens with critiques from a variety of perspectives of the ADA’s philosophical underpinnings, moves through some explorations of the definition of disability, to a series of examinations of the operation and practical implications of the ADA. This wide-ranging section goes far beyond the usual focus on employment (adequately discussed by four different authors) to tackle less obvious subjects. These include an excellent analysis of the limited implementation of the ADA’s requirements relating to the provision of services to the public by Ruth Colker, and four contributions considering what a non-discrimination law means for disabled people in the context of the health care—a subject which I have not even seen discussed elsewhere. Similarly considerations of hate crimes and disability, and claims of ‘wrongful birth’ (where, in effect, an individual claims damages for ever having been born) are relatively rare, and here feature in two separate, thought-provoking chapters.

If I had one complaint about the book it was that it was a bit too heavy of the social philosophy side compared to politics and practicalities. In part, this must reflect the backgrounds of the editors, but it also reflects a sense that the ADA is beleaguered and requires defending from criticism from the right-wing of American politics. The debates about the rationale for the ADA—and in particular whether it represents some form of affirmative action (currently anathema in the US) or impermissible form of hidden taxation on business, reflect a chilling American political and landscape. Both sides of the debate are represented in this collection. Within the terms of this ideological debate the positions of the ADA’s defenders can be as troubling as those of its critics. For example, Andrew Batavia (former executive director of the National Council on Disability), having argued that the ADA has had a positive but limited impact on the lives of disabled Americans, argues that it is not politically or practically feasible to introduce greater constraints on employers’ rejecting disabled applicants and instead proposes that a ‘substantial push’ of disabled people off welfare benefits ‘may be the best thing that ever happened to them’.

The most damaging attacks on the ADA to date relate to its definition of disability. This is now looking very threadbare thanks to the recent ruling of the Supreme Court which drastically restricted the numbers of people who can claim protection under the law. This is not simply a legal issue. Fundamentally, it emerges from political concerns about acting preferentially towards minority groups. Essays in the book discuss the practical implications of differing definitions of disability: does restricting protection to a narrowly defined group mean the statute is more likely to be perceived as unfairly imposing inefficiencies on employers, or will there be a call for prohibiting practices that aid only disabled people because this is seen as discrimination in reverse?
The book also reflects the debate on the nature of entitlements under the ADA. Some disability advocates, like Anita Silvers, defend the ADA by arguing that it does not require positive rights and contrast this with previous, paternalistic forms of legislation for disabled people. This approach would in practice mean no entitlement under ADA for those who require more costly or burdensome modifications. Illingworth and Parmet critique this approach, which concedes too much to right-wing ideology: ‘By focusing so much ... on the ADA as the guarantor of self sufficiency, the needs and aspirations of those for whom self sufficiency is a quixotic goal are ignored ... Self-sufficiency is perhaps not the only goal or the highest goal of the Act.’

Bickenbach also questions the relevance of the American cult of rugged individualism, where membership of the workforce is paramount. He links the two debates by underlining the connection between arguments in favour of a restrictive definition of disability, and an approach which that positive benefits granted by the ADA are problematic and must therefore be granted sparingly. He argues that what we need to rethink is not what is a disability but rather our social and political commitment to equality.

The chapters placing the ADA in a political context (by Harlan Hahn, Richard Scotch and Andrew Batavia) were thus, for me, the heart of the book and were shorter than I would have liked. Scotch argues that progress—in terms of increased public commitment to ensuring access—has been achieved. However, it cannot be attributed purely to ADA but to broader political activism by disabled people, of which the ADA is itself a product. Achieving change requires a broadly based political mobilisation of disabled people, which can achieve integration, full participation, and non-discrimination through laws and programmes. The ADA provides crucial protection and a significant expansion of access, but social change cannot be achieved merely through passing one law. Just as with racial equality the problems of the truly disadvantaged require non-racial solutions, so promoting true inclusion for disabled people requires full employment, balanced economic growth, national health care, expanded child care and an adequate system of social support. (Many of them conspicuously absent in America.)

It is precisely these constraints of the American political and social context that made me wish that the final section of the book, which critiqued the ADA through comparison with legislative models in Canada, the United Kingdom and Australia, was longer. We need to look beyond the ADA to other models of securing equality which are less individually focussed. But this requires another book.

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