Symposium on Disability and the Life Course

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Introduction to the Symposium

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A Life Course Approach

The theoretical frame of a life course approach offers two perspectives that have great relevance to the study of disability within a social model approach. On the one hand, we can conceptualize the life course in terms of individual biography and unique life experiences. In this sense, a life course approach allows us to examine how individual life projects are forged and how they unfold in different historical moments and social contexts. From a social model perspective, the value of this approach lies in the opportunity to learn how disabling barriers are manifested and challenged via a direct connection with the lived experience of disabled people. Alternatively, we can think of the life course more generally, as a kind of generational system operating at the macro-level in societies, grounded in the shared cultural rules and structural boundaries that define what a 'normal life' should be. In this sense, a life course approach helps us to understand how societies organize life transitions in an institutionalized or structural way. From a social model perspective, the value of this approach lies in the opportunity to learn about the differing impact of disabling barriers, and the different social meanings attributed to disability, in different generational locations (e.g. in childhood, youth, adulthood or old age).

Like disability, generational location is both socially produced and culturally constructed. Generational identities and transitions may be manifested in the subjective reflexivity and agency of individuals but they are also regulated through powerful discourses of 'normal' life progression, and governed through social policies and institutions (such as the family, schools, work, and welfare). Exploring these ideas in my own research, and that of others, has led me to the view that generational location should be viewed as a significant dimension of difference within the analysis of disability. Just as gender theorists have shown what may be gained by adopting a gendered perspective, so a

life course approach suggests that we must think more carefully about the impact of generational systems and politics. This helps us to understand more clearly how disability is produced, how it is socially constructed, and how it is regulated through policies and social institutions.

As I have argued elsewhere (Priestley 2000), our gendered expectations of 'independent adulthood' lie at the heart of this generational system in modern Western societies, and other generational categories (such as childhood and old age) have been constructed as 'non-adult' because of their historical exemption from, and structural dependence on, adult labor (both productive and reproductive labor). In this sense, there are important relationships of power and conflict between different generations, and the 'generational system' is, in many ways, analogous to systems of gender and class domination. Within this context, disability has been produced in very similar ways to childhood and old age - as a 'non adult' social category of people excluded from adult labor markets and subject to enforced dependency on non-disabled adult labor. Moreover, without 'adult' responsibilities there are rarely 'adult' rights, and this may help to explain why children, older people and disabled people (of all ages) have been subject to very similar forms of institutional discipline and control in modern societies (Hockey and James 1993).

Finally, it is important to note that the adoption of a life course, or generational, approach in disability studies is not simply a means to understand oppression in a static way (at the individual or structural level). It also offers a means to uncover, to understand and to share the strategies and forces that contribute to positive change. Taking the individual-biographical approach, there is much to be gained in the transformative potential of individual life histories as they reveal the kinds of agency and opportunities that contribute to real and positive change in people's lives (Kasnitz 2001).

Stories of resilience and resistance make a movement stronger and contribute to the building of disability culture. Likewise, in terms of a structural-normative analysis, there is much to be gained from marking the progress of change in disabling societies over time, through the analysis of different generational cohorts for example.

So, to summarize, 'a life course approach' could be considered as encompassing two strands that are very relevant to disability studies - what we might call the individual-biographical approach and the structural-normative approach. Thus, the individual-biographical approach draws on the importance attached to lived experience in disability culture and research while the structural-normative approach draws on the materialist and social constructionist traditions that have shaped disability studies as a discipline. The theme for this symposium arose from a personal interest, developed during a three-year research Fellowship funded by the UK Economic and Social Research Council (number R000271078). This, in turn, provided an opportunity to explore the

implications of a life course approach in two recently published books, *Disability and the Life Course: Global Perspectives* (Priestley 2001) and *Disability: a Life Course Approach* (Priestley 2003). The contributions to this symposium illustrate some of the ways in which such an approach can be applied to disability studies and disability research in an international context.

The Contributions

The eight papers in this symposium offer some diverse perspectives on disability, generation and the life course from a number of different countries. Some are driven by a methodological interest in life course research or theory, while others are motivated by more substantive issue-based concerns, to which a life course analysis has subsequently been applied.

The opening paper by Johans Sandvin combines both theoretical and empirical interests. In this sense, it demonstrates how researchers can maintain a genuine connection with the lived experience of disabled people whilst also maintaining a focus on disabling social arrangements and institutions. Drawing on data from life history interviews with disabled people in Norway, Sandvin shows how the historical development of social attitudes and welfare regimes, over time, creates different opportunity structures for disabled people of different generational cohorts, and how this impacts upon the kinds of disability identity resources they are able to draw upon. In this kind of approach we can see how life course methods and generational concepts can be employed to create an analytical lens through which to view macro social change in disabling societies.

The paper by Nina Slota and Daniela Martin also examines how life course theory and methods can benefit disability studies (and vice versa). In this context, they reflect on the lessons learned from research into the lives of survivors of traumatic brain injury in the USA. In addition to providing some useful theoretical links between disciplines, and reflections on methodological design, their conclusions suggest that a life course approach can help us to avoid an unnecessary fragmentation of disability experience by maintaining a focus on 'whole lives'.

Beth Ritchie and colleagues move the focus from a retrospective or prospective focus on individual lives towards a more categorical analysis of generational significance. Taking as their starting point, the stories of resilience amongst land mine survivors in different countries, they examine the differing generational impact of traumatic limb loss and adjustment at different life stages. Here, the emphasis is on illustrating how generational location emerges as a significant variable that interacts with the psycho-emotional, economic and social context of disability.

Similarly, Elaine Gerber and Corrine Kirchner's paper

begins not from a grounding in life course research but from a particular empirical research problem, that of defining and creating 'livable communities' for people with visual impairments in the USA. In their reflexive account of research practice and analysis, they show how generational location became a key factor in explaining the interaction between disabled people and disabling environments across the life course.

Justin Powell's paper returns to a more general commentary on the importance combining life course theory and methods with disability research (highlighting again the apparent lack of cross-fertilization between these disciplines). In this contribution, Powell uses a secondary analysis of special educational policies and research in Germany and the USA to show how systems of 'special needs' categorization separate disabled and non-disabled children into different opportunity structures at an early stage of life. This in turn steers them into divergent life course trajectories, affecting future life ambitions and life chances in terms of individual psycho-emotional effects, the shaping of collective biographies and the creation of disabling barriers in adult life. Early educational dis/advantage is thus shown to have a multitude of cumulative effects in adult life.

Hilde Haualand, Arne Gr°nningsµter and Inger Hansen pursue a related argument in their research with Deaf and hard of hearing young people in Norway. Here they compare some of the generational cohort factors affecting the language and identity formation of young Deaf people growing up today with those of earlier generations. This analysis reveals how macro-social and policy changes at the level of culture and the state can provide very different opportunity structures for young disabled people. In particular, they draw attention to the significance of changes in oral and language policy for Deaf young people and how this positively influences their sense of identity, culture and life choices.

Tim Epp explores generational concepts in a more conceptual and categorical way, by highlighting the barriers to recognition of adult status for people labeled as having learning disabilities in Canada. Drawing on observation, and the accounts of self-advocates in Ontario, the paper examines the denial of appropriate generational status during a period of reorganization in provincial policy and services. This raises some fundamental questions about the central value attributed to the achievement of 'adulthood' in modern societies, and the intense sense of marginalisation that results from the perceived denial of adult social status.

The final paper, by Yasmin Hussain, develops this theme, by examining the processes and meanings of transition to adulthood for young disabled people and their families. In this paper, she emphasizes the importance of a multidimensional approach to understanding life transitions and generational identities. Drawing on the life experiences

and accounts of young people, their siblings and parents in British South Asian families, she shows how gender and ethnicity interact with disability and generation to introduce significant dimensions of complexity and cultural hybridity in young people's lives. In this way, the paper illustrates how the adoption of a generational or life course approach in disability studies must be incorporated alongside other dimensions of difference and diversity.

References

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