From Womb to Tomb:
Disability, social policy and the life course

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Summary

This research explores an innovative framework for thinking about disability issues, policies and debates in terms of generation and the life course. This perspective is important because it highlights how disabling societies and practices affect people of different generations in different ways. It also allows for a consideration of important disability issues at the very beginning and end of the life course (i.e. at birth and death). This in turn enables us to see more clearly how societies organize generational boundaries and life course transitions in a collective way, and how this shapes our understanding of disability in the social world.

The aim of the Fellowship was to explore this complex interaction of disability and generation over the life course, with a specific focus on the role of social policy in shaping and governing social categories and transitions. The programme of work included a diverse combination of theoretical and empirical research (including conceptual development, collaborative research projects, publishing, and networking). Theoretical and methodological development focused on two complimentary approaches - an individual-biographical approach to the life course and 'life projects', examining the influence of policies and institutions on individual and collective life course pathways, and a more normative-structural approach to the social organization of life course progression and generational boundaries at the macro-level. Although indicative of an agency-structure distinction, these approaches should be viewed as complimentary rather than conflicting. Indeed, the research suggests that the most powerful and innovative approaches are likely to result from a simultaneous (or synthetic) application of individual-biographical and structural-normative models.

The research programme involved small-scale empirical projects in a local context and policy analysis in national and international contexts. The local projects focused on policy and practice in illustrative areas of generational significance (e.g. stakeholder views on school inclusion for disabled children; the transitional pathways of young disabled people leaving care; and the construction of older disabled people's needs by voluntary

sector groups). National policy analysis focused on the representation of disability rights under New Labour as 'adult-centered' generational claims. The international analysis adopted a dual approach - examining both the embodied biographical experiences of disabled people in different countries and the regulation of life course transitions and generational boundaries through social institutions, practices and culture. The published outputs of the Fellowship included a sole-authored book, an international edited collection, a number of articles, and a wide range of workshop, seminar and conference presentations to academic and non-academic audiences.

Adopting a life course approach raises a number of significant questions. Why, for example, have states gone to such lengths to prevent the birth of disabled children? Why have disabled children been so excluded from mainstream education? What is the significance of youth culture and youth transitions for young disabled people? How do expectations of 'independence' in employment or parenting affect the citizenship of disabled adults? Why are older people rarely seen as disabled in the quite the same way that younger adults often are? Why are different moral standards applied to the deaths of disabled and non-disabled people? By examining such questions in the context of theory and policy the research illustrates how our understanding of disability is framed by a particular view of life course progression in contemporary societies.

The findings suggest 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.

Existing analyses of disability and the generational system have been premised on a particular view of the social relations of production and reproduction in modern societies. Consequently, it is important to explain changes in these phenomena in the context of contemporary transformations in those societies. Processes of individuation have challenged the perceived predictability of life trajectories, and the life course has been increasingly

redefined in terms of individual risk and the pursuit of 'life projects'. Similarly, as stratification and identity becomes increasingly defined by patterns of consumption in consumer societies, so analyses of disability and generation based on the social relations of production must be re-examined.

Such developments may help to explain why the increasing claims of disabled people to full participation and equality have occurred at the same time as those from non-adult generational minorities (such as children and older people). The progress of such claims suggests that marginal groups can win concessions towards 'adult' citizenship rights. However, there is a danger that these claims also collude with an adult-centered generational system that deepens the exclusion of those more distantly displaced from traditional adult ideals (especially young disabled children and disabled people at the very end of life).

On the other hand, the progress of these social movements may suggest a significant loosening of the institutional life course and its generational system. Here the parallel claims of children, older people and disabled people may appear more radical. The task of including *all* disabled people is essentially the same task as including the very youngest and the very oldest in society. Both challenge us to reformulate our individualistic, adult-centred notions of competence and autonomy in a more relational way. If disability studies remains committed to anything more than a partial inclusion of diversity and difference in contemporary societies then the vision of an enabling society must also be conceived as a society for all ages.

Full report of research activities and results

Background

The research was based on a belief that we can learn a great deal by examining disability debates within the context of the life course. Here, the life course is understood as an organising principle in modern societies, and not simply as individual biography. Adopting a life course approach to disability means examining the ways in which disabled lives are understood, organized and governed - from the regulation of birth and reproduction to the social organisation of death and dying (and all points in between). One of the weaknesses in the existing disability literature is a tendency to focus on a narrow range of issues, affecting adults of working age. Using the life course as a conceptual framework forces us to consider a wider range of issues, affecting people at all points of life, rather than those that are relevant only to a minority.

Life course concepts and research have become increasingly important in contemporary social thinking. At the individual level, biographical evidence has been important in analysing the risk and uncertainty associated with individuation in modern societies. More broadly, life course concepts are helpful in conceptualising how 'normal' life progressions are organized and governed through social institutions, structural forces and cultural rules. Within the biographical approach, disability has been widely viewed as 'disrupting' normal life course pathways. Within the institutional view, it has been presented as a social problem of 'failure' to make successful life transitions. A more critical understanding of disability questions our assumptions about the normal life course and challenges the institutional arrangements that regulate its boundaries.

Generation has also become an important concept in social theory and research. First, there is a tradition of research examining the experience of particular generational cohorts. Second, there has been growing interest in generational location as social stratification or inequality. Both disability and generational categories (like childhood, youth, adulthood and old age) are socially produced, culturally constructed and regulated through institutions

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and policies. Relationships of power and conflict also exist between different generations. Examining how this generational system works offers a useful approach to learning more about social issues like disability.

Objectives

The aim of the Fellowship was to explore the complex interaction of disability and generation over the life course, with a specific focus on the role of social policy in shaping and governing social categories and transitions. There were four initial objectives:

1. To generate agendas for research in the context of disability, social policy and the life course.
2. To carry out applied research projects.
3. To consolidate this research activity through theoretical development and high quality publications.
4. To develop networking as a basis for future collaborative research.

These objectives were reflected in the work plan, with an emphasis on specified publication outputs (a theoretical journal paper, an international edited collection, a sole authored book, and three further papers based on empirical research projects carried out during the Fellowship). This was clearly an ambitious agenda, requiring planning and project management. Although the scope of the programme raised some concerns from referees, it proved to be achievable and all of the output targets were completed or exceeded within the lifetime of the Fellowship.

As the research developed it was necessary to refocus the objectives in the light of opportunity and circumstance. In particular, there were considerably more opportunities to develop the research in an international context than had been anticipated, and fewer opportunities to maintain collaboration with some national actors. For example, although local research partnerships with government and voluntary sector groups proved extremely productive, the intention to involve the British Council of Disabled People as a guiding partner in the initial stage proved unsustainable (due to staffing and other difficulties within that organisation). Conversely, positive responses to

the research agenda and interim outputs provided unforeseen opportunities to engage directly with disability activists and organisations in other countries.

Although the initial theoretical journal paper remained firmly grounded in British social policy debates, the edited text was refocused at an early stage (in discussion with the publisher) to highlight the differential life experiences of disabled people in minority and majority world contexts. The inclusion of 20 chapters from 13 different countries raised many new challenges and questions. Similarly, the scope of the sole authored book was extended to tackle disability debates in an international context. In retrospect, the relevance and impact of the Fellowship were considerably strengthened, rather than weakened, by this shift of emphasis from the national to the international.

Methods

The Fellowship involved a combination of empirical and theoretical research, requiring a varied and developing methodological approach. There is clearly insufficient space here to report in detail on the separate methods employed in the three projects and two books (these are reported separately in the publication outputs). Rather, it is more useful to focus on the methodological conduct of the programme as a whole. More generally then, the application of generational and life course concepts to disability issues and debates can be considered as a methodological project in its own right. This may be illustrated with reference to the two main approaches to data collection and analysis over the lifetime of the Fellowship (an individual-biographical approach and a structural-normative approach).

First, an individual-biographical approach to the life course and 'life projects' was employed methodologically to generate data about the lived impact of social relations and social policies. This approach was productive in illuminating the significance of policies and institutions in shaping individual and collective life course pathways, trajectories, and turning points. For example, the empirical project on 'Young Disabled People Leaving Care' benefited considerably from the use of life history interviews with 28 young people (examining their care pathways, transitions and future selves). Similarly, the 20 chapters for the international edited collection were

commissioned to illustrate the utility of life history research methods (including autobiography). Echoing the recent 'biographical turn' in social science, this revealed the methodological value of using data from individual life projects as an empirical lens through which to view macro-social change. In more general terms, the individual-biographical approach was useful in stimulating a grounded theory analysis, building an understanding of disability debates 'from the bottom up', based on the varied life experiences of disabled people in historically situated contexts.

During the second half of the Fellowship the methodological focus was widened, away from individual life projects and towards a more institutional or structural view of the life course. Here, the concepts of life course and generation were employed as an interrogative framework to analyze disability policies and debates in a more systematic and critical way. Normative constructions of life course progression and generational boundaries were employed, as ideal types, in order to problematise disability debates. For example, the empirical project on 'Disability and Old Age' used a categorical notion of ageing to examine why those 'made older' through policy and institutions are so rarely accorded disability identities or disability rights (in the way that younger adults are). Normative life course models were also applied to guide the data collection and analysis for the sole-authored book. Here, the aim was to test the analytical limits and power of a life course model in explaining contemporary policies and debates. The methodological rigor of this exhaustive framework analysis proved extremely productive – highlighting significant weaknesses and gaps in existing research and policy.

As methodological strategies, these two approaches offer both strengths and weaknesses. The individual-biographical approach plays to both the biographical turn in social research and to the centrality of lived experience in disability research. Within disability studies, there have been increasing claims that 'authentic' narratives are an essential component in 'renewing' the social model of disability (allowing space for diverse voices, or legitimizing embodied experiences in the psycho-emotional domain). On the other hand, the structural-normative approach plays to the materialist and social constructionist traditions that have shaped disability studies as a discipline. Indeed, the methodological power of the social model arises

precisely from its critical refocusing of attention away from disabled people and onto disabling societies.

The most powerful and innovative approaches are likely to result from the simultaneous (or synthetic) application of individual-biographical and structural-normative models. Thus, the former will yield little more than uniquely situated narratives (unless these can be reflexively analyzed within a cultural and structural context) while the latter cannot accommodate the richness and complexity of disabled people's agency or identity unless they can be informed by those diverse experiences. In pursuit of this kind of methodological synthesis it was therefore helpful to overlay an additional conceptual framework in the analysis (based on a typology developed in previous theoretical work). Thus, the Fellowship as a whole charts an innovative methodological approach to disability, generation and the life course, by interweaving narratives of the body, identity, structure and culture.

Results

The following summary highlights some of the key themes arising from the Fellowship. These are explored in more detail in the project publications.

Generation as difference

Disability studies has tended to emphasize the collective experiences of disabled people, as an oppressed group in society, and this has been a very productive approach. However, there are dangers in over-simplifying the collective experience when we know that disabling societies affect people in different ways. For example, there have been increasing claims that the disability experience is markedly different for men and women, for people with different kinds of impairment, for people from different ethnic backgrounds, and in different cultural contexts. In this context, a life course approach suggests that disability carries an additional significance for people of different ages and stages of life.

Just as gender theorists have shown how much can be gained by distinguishing between disabled women and disabled men, so a life course approach suggests that we must think more carefully about the generational experiences of 'disabled children', 'disabled adults' or 'disabled elders', for

example. When we look at the way disability is produced and regulated within modern societies there are some very important generational dimensions. Thinking about disability in terms of generation helps us to understand more clearly how disability and impairment are produced, how they are socially constructed, and how they are regulated through policy and institutions throughout the life course.

Generation, in this sense, is about more than just age. It involves thinking about the ways that important generational categories (like childhood, youth, adulthood or old age) are constructed, and how transitions between them are governed through social institutions. A good example here is the apparent lack of critical debate about disability issues in old age. The likelihood of impairment increases with age and, in Western industrialized societies, the majority of disability people are over retirement age. Yet, older people are rarely considered as 'disabled' in quite the same way that younger adults and children often are (even within more radical debates on disability rights). Understanding these anomalies is only possible if we consider the relationship between disability and generation.

Adopting a life course approach involves thinking about the way in which life course transitions are organized at a collective level within societies and about the impact of a generational system on disabled people's life chances and life projects. It adds a new dimension to our understanding of disability and offers new ways of thinking about a wide range of debates. The following sections highlight some of these themes in relation to the body, identity, culture and structure.

Generating bodies

The development of critical disability theory has seen a shift from historical concerns with the impaired body towards a more social and political view of disability. This shift of focus from the body to society has been critical in the development of a social model of disability. However, it has also attracted some criticism from those who take a more social view of the body. However, thinking about the body in its social and cultural sense is less problematic for disability studies than traditional medical views of the body

and has much relevance for the relationship between disability, generation and the life course.

For example, embodied impairment characteristics appear to carry a much greater social significance for disabled children and young people than they do in later life. In this sense, social concerns with bodily imperfection appear to play more heavily on disabled children and the unborn than on older people. Although social theorists have suggested an increasing tolerance towards bodily diversity in postmodern consumer societies there is little evidence of such tolerance about the birth of disabled children. Thus, pressures on parents and doctors to produce 'normal' children appear to have less in common with celebrations of diversity than with the more modernist concerns of uniformity and bodily normalisation.

Thinking about youth and adulthood also highlights the generational significance of the body in disability debates. Idealized constructions of youthfulness play heavily on the pursuit of bodily perfection in consumer societies, while constructions of independent adulthood emphasize autonomy in physical and cognitive function. These bodily ideals contribute to disability in two ways. First, they provide cultural scripts for decoding the body's potency as an object of beauty or sexual desire – leading to the aesthetic oppression of those whose bodily characteristics are not read in this way. Second, there is the underlying assumption that young adult bodies should be fit for production and reproduction in the interests of capital, patriarchy and the state.

The significance of a generational account of the body is also underlined in the case of old age. The impaired body has figured prominently in constructions of old age, yet rarely has this been articulated as a disability debate. Indeed, embodied experiences of impairment have been widely viewed as less 'disruptive' in old age than in childhood or young adulthood. It is tempting to conclude that the biographical normality of the impaired body in old age may explain why older people with impairments are rarely seen as disabled in the way that younger adults are.

Disability studies and disability activism poses some significant challenges to the normalisation of the body, such as resistance to the 'myth of bodily perfection'. There has also been active resistance to the elimination of

diversity through genetic technologies and eugenic practices. Similarly, disability culture has offered new representations of the body that place greater value on difference and diversity in constructions of physical beauty or sexual attractiveness. However, it is also evident that such claims remain deeply rooted in associations between beauty and youth, thereby failing to challenge the power relationships of a generational system that devalues bodies in later life.

Generating identities

Just as a consideration of the body throws up a number of generational issues, thinking about identity is also a useful approach. Encounters with disabling barriers and practices have a considerable impact on disabled people's identity. For example, the construction of disabled births as 'wrongful lives', and attempts to eradicate impairment characteristics, devalue the perceived worth of disabled people in society. Similarly, the normalisation of child development, and the segregation of children with impairments, reinforces negative associations with 'developmental delay' and abnormality. Similarly, barriers to participation in paid employment and parenting have denied many disabled people access to the social networks and citizenship rights from which adult identities are often constructed.

Institutional responses to disability have relied on definitions that tend to group disabled people together according to impairment labels or the convenience of service bureaucracies. This has been reflected in the denial of more nuanced and situated identities. For example, disabled children and young people have often been ascribed relatively static identities that privilege their impairment status above attributes of gender, class, ethnicity or sexuality. Here, age and generation are also important, since generational identities and cultures (especially youth cultures) are a significant aspect of personal biography and identity.

For example, limited access to peer networks and youth cultures may create conflicts of identity management for young disabled young people, forcing them to choose between their disability identity and their generational identity. By contrast, it has been suggested that identity management in old age may be less affected by impairment or by disabling barriers. That is not to

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say that older people with impairments are not discriminated against as disabled people – far from it. Rather, the assertion is that impairment and disability in old age might be construed as less disruptive to normal identities of ageing than say impairment in younger adulthood (because disability is more widely anticipated in old age).

The development of disability culture and disability politics has been important in promoting a more positive identity politics. However, these new identity resources remain almost exclusively adult-focused, so that disabled children, young people and elders remain conspicuous by their absence from disability culture. For both younger and older people then, choosing positive disability identities within the movement may mean losing contact with important generational networks and generational identity capital. If disability culture is to promote inclusiveness it must also resist the temptation to accept generational power relationships that place adult interests first.

Generating cultural representations

Cultural analyses illustrate a certain cultural similarity in the way that disability, childhood and old age have been constructed as 'non-adult' social categories (both marginal to and dependent upon adults). Such constructions have been important in the governance of disability through social institutions. For example, the cultural construction of disabled people as childlike (as innocent, asexual, or untamed) has been reproduced in the legitimation of adult power relationships based on custodial care and surveillance. Similarly, the infantilization and 'social death' of older people institutional settings has much in common with that experienced by both children and disabled adults.

Culturally, life course expectations in modern societies continue to be defined in relation to idealized notions of modern adulthood. Such constructions have been highly gendered, with a traditional emphasis on distinctive male and female adult roles centred on participation in productive or reproductive labour respectively (specifically, employment and parenting). By contrast, children, young people, elders and disabled people of all ages have been constructed as lacking the kind of adult attributes upon which full personhood and citizenship are premised.

However, there have been significant cultural challenges to this adult-centred construction of the life course. The recognition of generational conflict and power relationships has been mirrored in a new generational politics, in which non-adult minority groups have made new claims to adult rights and responsibilities. The emergence of movements for the rights of children and older people place an increasing strain on traditional constructions of citizenship as a uniquely adult-centred concept. Social claims from the disabled people's movement have raised similar challenges, emphasizing self-determination, reflexivity and interdependence over the adult ideals of autonomous physical functioning.

Generating social structures

The initial development of social model theory was underpinned by a structural analysis of disability, demonstrating how people with perceived impairments become disabled through processes of social transformation. In particular, materialist accounts pointed to historic changes in the social relations of production and reproduction within Western capitalist economies as a driving force for the creation of disability as a social and administrative category. Here, the changing demands of industrialization, competitive labour markets, new technologies, and the patriarchal nation state have all been important.

Structural analyses also help to explain the emergence of the generational system. For example, it could equally be argued that similar processes of social transformation created the categories of childhood, youth and old age. Thus, the increasing demands of industrialization and individuation in knowledge societies have led to an extension of the training required before young people participate effectively in productive adult labour. In this sense, the regulation of childhood and youth as dependent non-adult states has been driven by economic developments and the changing structure of adult labour markets. At the same time, increased longevity and the exemption of older workers from those same labour markets (through retirement) created a parallel category of old age. Clearly, there are considerable parallels between these processes and those that have produced the structural dependency of disabled people in modern societies.

So, a structural analysis of disability makes little sense as a 'special case', in isolation from the production of this generational system. In particular, it is important to understand the centrality of adult work and employment in producing both disability and generational boundaries. This may help to explain why the political focus of disability policies and debates still falls so heavily on adult-centred issues (particularly on issues of employment and parenting). While disability in youth and old age can be partially accommodated within an existing generational system of dependency, disability in adulthood stands out as a greater structural challenge. In this sense, social responses to disabled children have had much to do with structural concerns about their potential for participation in future adulthood. Conversely, the distinct lack of any institutional or policy focus on disability in old age reflects the fact that older people are already structurally exempt from productive or caring adult labour.

These structural analyses of both disability and the generational system have been premised on a particular view of the social relations of production and reproduction, characteristic of modernity. Given that much contemporary social theory is now concerned with explaining transitions from modern societies towards late modern or postmodern forms of social organisation, it is important to question how this affects our understanding of disability and the generational system for the future. Two themes seem important here. First, processes of individuation have undermined the apparent predictability of traditional life course pathways and expectations. As a consequence, the 'normal' life course has been increasingly redefined in terms of individually negotiated 'life projects' and risks. As these traditional expectations break down, it is perhaps unsurprising that the progress of disabled people's claims to full participation and equality have occurred at the same time as parallel claims from other 'non-adult' minorities (particularly children and older people). Second, social status is becoming increasingly defined by patterns of consumption rather than contributions to production. Since our understanding of both disability and the generational system are premised on an analysis of the social relations of production, such changes pose an additional theoretical challenge.

Conclusions

The concepts of generation and life course add an additional and revealing dimension to our understanding of disabling barriers and disability debates. Adopting a life course approach also raises a number of important generational questions. Why, for example, have states gone to such lengths to limit or prevent the birth of disabled children? Why have disabled children been so often excluded from mainstream education? What is the significance of youth culture and youth transitions for young disabled people? How does the expectation of an 'independent' adulthood contribute to the production of disability in modern societies? Why are older people with impairments rarely seen as disabled in the quite the same way that younger adults often are? Why are different moral standards applied to the death and dying of disabled and non-disabled people? Thinking about such questions suggests that the development of disability policy in contemporary societies has been framed within a very particular view of normal life course progression, based on the demand for autonomous and independent adulthoods arising from the social relations of production and reproduction within modernity. Deconstructing and decoding the operation of this generational system through policy and institutions can also inform our understanding of disabled people's resistance and social claims in the context of social transformations and a new generational politics that brings those social relations into question.

Activities and Outputs

The Fellowship activities were organized within four parallel strands, as outlined in the original proposal. These included: theoretical development, empirical research projects, publishing, and networking activities. The three-year timescale of the Fellowship, with its focus on dissemination and publication, allowed for a considerable number of tangible outputs. These included interim and developmental outputs, throughout the period, as well as summative outputs drawing together the diverse activities in the latter stages.

The **theoretical framework**, first outlined in the Fellowship proposal, was developed and elaborated through: seminar and conference papers presented within the host Department, the US Society for Disability Studies; a distinguished scholar lecture at Queen's University Belfast; an ESRC seminar

at the University of Newcastle; and an invited plenary paper to the Finnish Network on Disability Research. These developing arguments were first published as a sole authored paper in the *Journal of Social Policy*, with a focus on the policy significance of **disability and adulthood**.

The consolidation of previous ESRC funded research on **disability and childhood** focused on new outputs targeting non-academic audiences, with a view to influencing policy for the benefit of the young people involved. This included: seminar and conference events for young people, researchers and policy makers; policy guidance reports and consultancy for the local Education and Health Authorities, Save the Children and the Audit Commission; and newsletters for young people and parents. Additional research activity included co-funded projects on school inclusion, advocacy services for young people with communication impairments, and a health needs assessment for minority ethnic children. These resulted in the publication of research reports and a refereed journal paper.

The inclusion of a substantive research project on **disability and youth** transitions allowed for specific outputs in this area, focused on policy development to support disabled care leavers at the local and national level. In addition to an international refereed journal paper, these included: a major report for the National Leaving Care Advisory Service; briefings and workshops for Barnardo's, the Joseph Rowntree Foundation, regional leaving care forums and social services staff; policy briefing papers for MPs and civil servants; and a web site to provide guidance on disability issues in the new Children (Leaving Care) Act.

A second empirical project on **disability and old age** provided outputs targeting both academic and non-academic audiences, including: newsletters for local and national service providers; an international conference paper; two refereed journal papers; a book chapter; and a project web site.

The systematic development of an overall **life course approach** to disability led to some major outputs, including: a sole authored book (Polity 2003); an international edited collection (Cambridge University Press 2001); the editing of a themed journal edition of *Disability Studies Quarterly* (Spring 2003); an international seminar in Leeds; and an invitational lecture tour in

Central America (including a four-day taught course at the University of Costa Rica and speeches to national policy forums and human rights groups).

The high profile of the Fellowship activity and outputs also generated requests to present papers on more general methodological and thematic issues (for example in Belgium, Canada, Norway, Northern Ireland and the US). There were opportunities to contribute to postgraduate research training in the area of methods teaching, PhD supervision and examining (including theses relevant to the Fellowship themes from Leeds, Australia, Egypt and Finland). Finally, the Fellowship resulted in invitations to join the editorial boards of three international journals (*Disability & Society*, *Handicap-revue de sciences humaines et socials*, and the *Scandinavian Journal of Disability Research*); to referee related papers for other peer-reviewed publications; and to act as a specialist advisor to the Social Policy Panel of RAE2001.

The following publications resulted in whole or part from the Fellowship:

Sole authored books

Priestley, M. (2003) *Disability: a life course approach*, London: Polity

Edited collections

Priestley, M. (ed.) (2001) *Disability and the Life Course: global perspectives*, Cambridge, Cambridge University Press

Disability Studies Quarterly, (Spring 2003, in preparation) guest editor for special issue on 'Disability and the Life Course'

Refereed Journal articles

Priestley, M. (2000) Adults Only: disability, social policy and the life course, *Journal of Social Policy*, 29(3): 421-439

Priestley, M. (2002) Whose Voices? Representing the claims of older and disabled people under New Labour, *Policy and Politics*, 30(3): 361-372

Priestley, M. and Rabiee, P. (2002) Same difference?: older people's organisations and disability issues, *Disability & Society*, 17(6):

Priestley, M. and Rabiee, P. (2002, in press) Hopes and fears: stakeholder views on the transfer of special school resources towards inclusion, *International Journal of Inclusive Education*,

Rabiee, P., Priestley, M. and Knowles, J. (under revision) Young disabled people and the 'new arrangements' for leaving care in England and Wales, *Children and Youth Services Review*

Research Reports

Leeds City Council (2000) *Young Disabled People – Moving into Adulthood*, Leeds, Department of Social Services

Rabiee, P. Priestley, M. and Knowles, J. (2001) *Whatever Next? Young disabled people leaving care*, First Key, Leeds

Priestley, M. (2001) *Raised Voices: Do looked after children with communication impairments need an advocacy service?,* Save the Children Fund, Leeds

Rabiee, P. and Priestley, M. (2001) *What Works? Re-focussing the resources of special schools*, Education Leeds

Rabiee, P. and Priestley, M. (2002) *Building Bridges: disability and old age*, Leeds, Centre for Disability Studies

Contributions to edited collections

Priestley, M. (1999) 'Discourse and Identity: disabled children in mainstream high schools', in S. French and M. Corker (eds) *Disability Discourse*, Buckingham, Open University Press, pp. 92-102

Priestley, M. (2001) 'Disability in a global context', in M. Priestley (ed.) *Disability and the Lifecourse: global perspectives*, Cambridge, Cambridge University Press, pp. 3-14

Priestley, M. (2002, in press) '"It's like your hair going grey", or is it? Impairment, disability and the habitus of old age'. In S. Riddell and N. Watson (eds), *Disability, Culture and Identity*, London, Longman.

Knowles, J., Rabiee, P. and Priestley, M. (2003, forthcoming) 'Enabled by the Act? The reframing of aftercare services for young disabled people', (details to be confirmed).

Priestley, M. (2003, in preparation) 'Generating debates: a life course approach to disability issues'. In J. Swain et al (eds) *Disabling Barriers: Enabling Environments* (2nd edition), Buckinham, Open University Press.

Articles in periodicals and magazines

Priestley, M. (1999) Left Out in the Cold, *Community Care*, 11-17 November 1999: 29

Rabiee, P. Priestley, M. and Knowles, J. (2001) *Whatever Next? Young disabled people leaving care*, First Key, Leeds

Priestley, M. (2001) *Raised Voices: Do looked after children with communication impairments need an advocacy service?*, Save the Children Fund, Leeds

Rabiee, P. and Priestley, M. (2001) *What Works? Re-focussing the resources of special schools*, Education Leeds

Conference presentations

Priestley, M. (1999) *Disability and the Life Course: the case of British social policy*, paper presented to the Society for Disability Studies, 12th Annual Meeting, Washington DC, USA, 27-30 May 1999

Priestley, M. (1999) *In and Out of Childhood: disabled children in adult worlds*, paper presented to the 'Mind the Gap: changing boundaries of childhood in the 1990s' conference, University of Leicester, 8 September 1999.

Priestley, M. (1999) *Generating issues: disability and the life course*, paper presented to Department of Sociology and Social Policy seminar series, University of Leeds, 2 December 1999

Priestley, M. (2000) *Disability Discrimination: an historical perspective*, key note speech to National Association of Teachers in Further and Higher Education, seminar, Sheffield Hallam University, 11 February 2000.

Priestley, M. (2000) *Theorising and modelling in disability studies*, paper presented at the Flemmish Fund for the Social Integration of the Handicapped, BELGIUM, 25 April 2000

Priestley, M. (2000) *Co-participatory research and the emancipatory paradigm*, paper presented at the University of Leuvan, BELGIUM, 26 April 2000

Priestley, M. (2000) *Disability, social policy and the life course*, Distinguished Scholar Lecture, 24 October 2000, Queen's University Belfast, NORTHERN IRELAND

Priestley, M. (2000) *Understanding the emancipatory research paradigm*, invited paper presented to Norwegian Social Research (NOVA), Oslo, NORWAY, 9 November 2000

Priestley, M. (2000) *Measuring up: disability research and the emancipatory paradigm*, workshop presentation to the Society for Disability Studies, 13th Annual meeting, Chicago, USA, July 2000

Priestley, M. (2001) *Generating Debates: disability and the life course*, paper presented to the ESRC 'Social Transformations' seminar series, Department of Social Policy, University of Newcastle

Priestley, M. (2001) *Disabled children doing families*, paper presented to the Family Centre, Oxford Brookes University, 6 June 2001

Priestley, M. (2001) *Thinking Global: challenges to disability studies*, paper presented to the Society for Disability Studies, 14th Annual Meeting, Winnipeg, CANADA, 20-24 June 2001

Priestley, M. (2001) *Current Issues in Disability Studies: a European perspective*, plenary address to the Society for Disability Studies, 14th Annual Meeting, Winnipeg, CANADA, 20-24 June 2001

Priestley, M. (2001) *A Rock and a Hard Place: disabled people's organisations and the market for social care*, key note address to the Centre for Voluntary Action Studies conference on 'Citizenship or Charity? Disabled People and Voluntary Action; Northern Ireland in and International Context', University of Ulster, Belfast, NORTHERN IRELAND, 28 September 2001

Priestley, M. (2001) *Disability Across the Generations: childhood, adulthood and old age*, invited plenary address to the 10th Anniversary conference of the Foundation for Research on Disability, University of Jyväskylä, FINLAND

Priestley, M. (2002) *Participatory Evaluation and Disabled People*, workshop
presented to the LEARN Annual Conference, Policy Research Institute,
Leeds Metropolitan University, Leeds, UK, 9 April 2002

Rabiee, P. & Priestley, M (2002) *Young Disabled People Leaving Care*,
workshop presented to the Hurtling into a Void? Conference, Manchester
Conference Centre, UMIST, 2 May 2002

Priestley, M. (2002) *NewParadigms in Disability Studies*, plenary address and
lecture course to the Universidad de Costa Rica, COSTA RICA, May
2002

Priestley, M (2002) *Disability Studies and Disability Policy*, invited speech to
La Defensoria de los Habitantes (national office of human rights), San
Jose, COSTA RICA, 24 May 2002

Priestley, M. (2002) *Disability and the Generational Habitus of Old Age*, paper
presented to the Nordic Network on Disability Research, 6th Annual
Conference, 23-24 August 2002, Reykjavik, ICELAND

Impacts

The Fellowship activities and interim outputs have already had some
impact on policy and practice in local, national and international contexts and
it is to be hoped that the summative outputs will have a more extensive future
impact on theorizing and teaching within the field. There have been
substantial impacts for the host institution and the applicant in terms of
international profile, networking, subsidiary project funding and applications
for future postgraduate supervision.

At the local level, the Fellowship provided opportunities to directly
influence local planning and policy. For example, the dissemination and
development work arising from research with disabled children resulted in
changes to the Leeds Social Services Management Action Plan, to the Action
Plan of Education Leeds' Inclusion Strategy and to strategic priorities of Leeds
Children and Families Modernisation Team. More widely, inputs to the Audit
Commission reviews of inclusive education and services to disabled children
have influenced the agenda for a new national service framework.

Research with disabled young people generated a review of support for
care leavers in Bradford Social Services and contributed directly to the

training of leaving care teams in the North West region. At the national level, this research contributed directly to changes in the Children (Leaving Care) Act during its passage through Parliament and to the drafting of national guidance for its implementation. This national development work is being continued by the research partners First Key (the National Leaving Care Advisory Service). Similarly, local research with older people's groups was fed back locally, through the Leeds Community Care Forum, and nationally, through dialogue with the policy officers of campaign groups such as Help the Aged and Age Concern England. Additional influences have included training sessions for staff of the Disability Rights Commission and contributions to discussion on the framing of a UN Convention on the Rights of Disabled People.

More generally, the promotion of a life course approach and life course methods has begun to influence academic and research debates within disability studies. For example, publication of the edited collection and a panel session of contributors at Society for Disability Studies led to the allocation of a themed edition of the US journal *Disability Studies Quarterly* and a plenary presentation to the Finnish Network on Disability Research. The contribution of a novel approach to the subject has impacted on teaching (for example, with the incorporation of a life span approach in a new European Masters programme and an invitational lecture course on the same theme for postgraduate students, professionals and policy makers at the University of Costa Rica). It is envisaged that the publication of the sole-authored text in 2003 will provide substantial resources for the development of this approach in other institutions.

Future research priorities

The programme of research activity carried out during the Fellowship raises a number of general and specific priorities for future research in the area of disability and generational/life course studies:

- A life course analysis suggests that there is much to be gained from research that examines the generational boundaries and specificities of policies and institutions that impact on disabled people's lives (for example, in the way that they structure resources for identity management

or shape the collective patterns of disabling biographies in particular generational cohorts).

- Similarly, there must be concern that the recent 'biographical' turn in social science research, and the renewed interest in social policy as 'life course policy', appears to overlook or disregard disability as a significant factor for analysis. It will therefore be important to promote disability debates within the agendas for more generic life course and generational studies.

- Particular concerns are raised by the impact of policies and institutions on the life course pathways and trajectories of some young disabled people in Britain. There is a need for continuing research to examine the lack of institutional and cultural investment in young disabled people as future human capital, and to assess the impact of new policies for inclusion and equality as they develop. The life experiences, aspirations and careership of young disabled people will continue to contribute important data for such research, but there is also a need to explore negative adult influences and expectations in a more critical way.

- Similarly, there is an urgent need to develop research that problematises the influence of policies and institutions in shaping life course pathways and identities in old age. Research conducted during the Fellowship highlights many commonalities in the concerns and claims of older and disabled people but suggests that disability debates are inexcusably absent from research on ageing issues and policies. This is a matter of considerable concern when the majority of disabled people are also older and suggests that the rights-based agenda promoted in recent years may be failing to affect the lives of many by focusing on the minority of disabled working age adults.

- There is considerable scope for a more systematic approach to comparative research on the life course pathways and life projects of disabled people in different countries. For example, the diverse life experiences and influences highlighted in the edited collection suggest that a more systematic approach to individual-biographical methods, on a larger scale, may have much to offer in providing an empirical lens through which to view the impact of macro-social transformations and policy

developments in cross cultural perspective. This will be particularly important during the development and implementation of a new UN Convention on disability rights.

- The European Year of Disabled People in 2003 also highlights the need for research in an international-regional perspective. Here, there is a considerable need to promote generational analyses, since European policy has consistently privileged debates concerning disabled people of working age (at the expense of the majority of older disabled people in ageing European populations). The application of a more systematic generational analysis to European policy making would provide for more relevant and representative research. There are opportunities to pursue this, and to consolidate links made during the Fellowship, using the Networking instruments of EU Framework Six.