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CONCEPTS

This opening chapter provides an introduction to some of the key concepts used in the book – disability, generation and the life course. A distinction is drawn between individual and social models of disability, and the discussion draws attention to the complexity required in explaining disability as a social phenomenon. Four key themes are identified as significant in dealing with disability issues: the body, identity, culture and social structure. The concept of generation is introduced, as an important dimension of social stratification, with reference to different theoretical approaches. The argument suggests that it may be useful to think about relationships of power between different generations as a kind of 'generational system', analogous to gender or class relationships. Finally, the concept of the life course is reviewed, highlighting its importance in contemporary social thinking. This discussion examines the life course in terms of both individual biography and collective social organization. The argument shows how societies and social institutions regulate gendered patterns of life progression, based on shared cultural rules. However, social changes resulting from greater individuation and a more critical understanding of disability challenge these traditional views of what a 'normal' life might be.

Disability

Since disability is the main focus throughout this book, it is not necessary to provide more than a brief introduction here. The emergence of disability studies as an academic discipline has been both rapid

and extensive, but has its roots in the activism and experiences of disabled people. It is therefore no coincidence that developments in disability theory have taken place alongside the emergence of an international disabled people's movement, campaigning for equality and full participation in all spheres of social life and human rights. Indeed, the kinds of models and thinking that have allowed academics and researchers to engage in a new and radical reappraisal of disability issues over the past twenty or so years spring directly from ideas developed within disability activism (Driedger 1989; Campbell and Oliver 1996; Fleischer and Zames 2001).

Undoubtedly, the most significant achievements (both academically and politically) have arisen from the development of a social interpretation, or 'social model', of disability that highlights the shortcomings of more traditional and individualistic approaches. Thus, social scientists have increasingly come to view disability as the product of complex social structures and processes, rather than as the simple and inevitable result of individual differences or biology. This historic shift of emphasis, from the individual to the social, has allowed both activists and academics to promote a fundamental and far-reaching critique of the way in which societies disable people with perceived impairments, and to envisage the possibility of more enabling social alternatives. Grasping the underlying distinction between individual and social models of disability is therefore key to understanding contemporary disability debates.

One way to understand this distinction is to think about the life experiences of disabled people. There is now a great deal of evidence to show how people with impairments are often excluded or disadvantaged in important areas of social life, such as education, employment, family life, political participation and cultural representation; or in access to goods and services, like transport, housing, information and so on (e.g. Barnes 1991). One of the big challenges for disability researchers and theorists is to explain how and why this happens. The traditional view within social science and medicine was to assume that someone with an impairment would inevitably find it difficult to perform various 'normal' activities and, as a consequence, would also have difficulty in fulfilling normal social roles (e.g. Parsons 1951). Thus the kind of social disadvantage commonly associated with disability in modern societies was viewed largely as *an individual problem caused by impairment*. From this perspective, the most appropriate social response was either to correct the impairment or to help the person 'come to terms' with it, by negotiating different (less valued) social roles (e.g. Nirje 1969).

By contrast, a social interpretation of disability turns this whole idea on its head, questioning the assumption that there is any necessary causal relationship between having an impairment and becoming disabled. For example, it is clear that the experience of disability varies for different people, in different cultures, and in different periods of history (e.g. Ingstad and Reynolds Whyte 1995). Thus, people with apparently similar biological characteristics might become more or less disabled depending on social circumstance. This implies that the disadvantage often associated with disability might be a social rather than an individual phenomenon, something that is not biologically determined but produced by particular social processes. Crucially, this view suggests that it is not physical, cognitive or sensory impairments that cause disability, but rather the way in which societies fail to accommodate natural aspects of difference between people (e.g. Zola 1989). Consequently, a social interpretation of disability tends to relocate the 'problem' from the individual to society. Disability can then be viewed as *a social problem caused by social processes*.

Individual and social models

These contrasting ways of thinking about disability have been developed more formally in the disability literature as two competing models, commonly known as the 'individual model' and the 'social model'. Traditionally, individual approaches dominated academic understandings of disability, especially in the medical and therapeutic literature. However, it is now social interpretations that largely define the boundaries of contemporary 'disability studies' (Albrecht, Seelman and Bury 2001; Davis 1997; Linton 1998). This distinction between individual and social models of disability was first articulated in an academic context by Oliver (1983) and has been developed at length since then. However, the original impetus came from ideas developed within the disabled people's movement. In particular, Oliver drew directly on a distinction made in the 1970s by activists within a British organization called the Union of Physically Impaired Against Segregation (UPIAS). In an exchange of ideas with other, more mainstream lobby groups, UPIAS argued that 'Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society' (Union of Physically Impaired against Segregation/Disability Alliance, 1976: 3).

Although the original members of UPIAS were building on their experiences as adults with physical impairments in an industrial society, they were also aware of the wider social significance of their claims. Yet, they could scarcely have been aware of the impact that these ideas would have on disability politics in the following twenty-five years. The UPIAS interpretation of disability influenced not only disabled academics like Oliver, but also the definitions adopted by the international disabled people's movement in the 1980s and, through this activism, the formulation of a radical policy agenda for full participation and equality in the twenty-first century.

From the UPIAS definition flows much of what we now under-stand as the social model of disability. Looking at the wording in more detail, there are four important points. First, the interpretation offered by UPIAS acknowledges that some people do have impair-ments, but points out that disability is something different, 'imposed on top'. Second, it suggests that disability is about exclusion from full participation in society. Third, and most important, this exclu-sion is neither necessary nor inevitable (by implication, we could imagine a society in which people with impairments were not dis-abled). Fourth, it makes sense to think of disabled people as an oppressed social group, and not simply as the victims of individual and tragic circumstance (for a discussion of the UPIAS document, see Oliver 1996).

Social model approaches to disability focus on explaining the social processes and forces that cause people with perceived impair-ments to become disabled, as a minority group in society. There have been different approaches to this task. For example, some writers have argued for a political economy of disability that explains the oppression of people with physical impairments or learning difficul-ties as a product of industrial capitalism (Finkelstein 1980; Ryan and Thomas 1980). Here, the emphasis is on identifying structural forces and material relationships of power arising from the division of labour and the factory-based waged economy that excluded many people from participation in paid labour. This was also an argu-ment developed more formally by Oliver (1990). Other writers have emphasized the role of culture and ideas in shaping disability labels and social roles (e.g. Ingstad and Reynolds Whyte 1995; Shakespeare 1994; Ustun et al. 2001). Such approaches often emphasize tradi-tional beliefs and folklore or the continuing reproduction of disabling images in the mass media. However, the differences between cultural and structural approaches tend to be a matter of emphasis, and most social model writers accept that both material and cultural forces play

a part in creating the collective social experience of disability (Barnes 1996; Finkelstein 1991; Oliver 1990).

> Hence disability, according to the social model, is all the things that impose restrictions on disabled people; ranging from individual prejudice to institutional discrimination, from inaccessible buildings to unusable transport systems, from segregated education to excluding work arrangements, and so on. Further, the consequences of this failure do not simply and randomly fall on individuals but systematically upon disabled people as a group who experience this failure as discrimination institutionalised throughout society. (Oliver 1996: 33)

A complex phenomenon

For my part, I have found it helpful to distinguish different approaches to disability under four broad headings, using the distinction between individual and social models and also a distinction between materialist and idealist explanations. Broadly speaking, individual model approaches tend to focus on either biological or psychological explanations of disability, while social model approaches tend to focus on either cultural or structural explanations. This typology was originally developed in some detail in an earlier published paper (Priestley 1998b), but it may be helpful to review the framework briefly here.

Within the individual model we can identify two parallel themes of enquiry: one focused on the measurable characteristics of the body and its physical or cognitive functioning (a biological model of disability) and one focused on the negotiated aspects of individual identity and adjustment (a psychological model of disability). Similarly, social model accounts tend to cluster around two types of explanation: one focused on the role of cultural values and representations (a cultural model of disability) and one focused on political economy and disabling environments (a structural model of disability). A simplified form of this typology is shown in figure 1.

It is not necessary to review these distinctions in detail here; suffice it to say that each of the four themes is evident in contemporary writing about disability. In this book, I have not taken a rigid stance on the kinds of writing used to illustrate the various chapters. The overall approach is grounded in social model explanations, both structural and cultural, but I have sought to include a good deal of reference to studies that are more individualistic (including many from the medical or therapeutic literature). For those unfamiliar with

	Materialist explanations	Idealist explanations
Individual models	biology	psychology
Social models	structure	culture

Figure 1. Four approaches to disability.

this diverse theoretical terrain it may be worth consulting the original article (Priestley 1998b) together with some of the reading materials identified at the end of this chapter.

It is important to understand that there is room for a considerable amount of overlap between the basic types outlined above. To take an example, it would be quite wrong to consider all approaches to disability based on the body or impairment as simply biological in their orientation. Indeed, social models of disability have been criticized for ignoring the embodied experiences of disabled people (e.g. Crow 1996) and for 'abandoning' the body to medical science (Hughes and Paterson 1997). Biology is relevant to understanding the body, but environments and social processes play a big part too. Indeed, even the physical characteristics of bodies are shaped by social factors, such as access to nutrition, patterns of work, accidents and cultural practices (see Abberley 1987). Beyond the merely physical dimension, the experience and representation of disabled bodies is also mediated through negotiations of identity, through language and through cultural representation (Corker and French 1999).

Likewise, it would be wrong to think of all approaches to disability based on identity as simply individual. The personal life experiences and identities of disabled people are not simply the product of individual cognitive psychology, but are deeply embedded in the
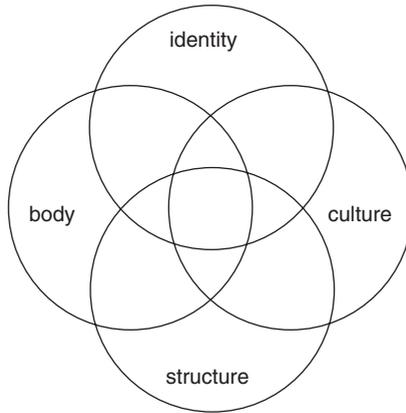
Figure 2. The complexity of disability.

social. Individual identities are negotiated with others in a social context, in response to cultural values and structural forces. They are narrated through language, and situated in social spaces and historical moments (Corker 2001). Consequently, explanations of disability that draw heavily on individually narrated experience or identities are often much more than simply psychological.

These kinds of examples suggest that it might be more appropriate to view the four theoretical approaches outlined earlier as overlapping areas of concern rather than as discreet conceptual 'boxes' fitting neatly into either individual or social models of disability. With this in mind, figure 2 provides a more useful framework for thinking about disability and its various representations in social science.

Looking at disability in this way, the complexities become more apparent. Many of the important questions we want to ask about disability deal with areas of overlap between different kinds of explanation or approach. For example, how do structural changes in the mode of production affect our collective cultural understandings of what it means to be disabled in a particular society? Thus, Burch (2000) illustrates how the unique socio-economic context of pre- and post-revolutionary Russia produced a different kind of 'Deaf identity' to that emerging in the USA and the UK, leading to alternative forms of 'subversive activity' to sustain Deaf culture. Similarly, taking another area of significant overlap, we might ask how far the adoption of disabled identities is influenced by embodied experience and

how far by cultural or historical context (e.g. Kalekin-Fishman 2001). And so on.

This framework of multiple approaches is also useful when we think about disability in terms of generation and the life course (the primary focus of this book). For example, we could think about the way that a body and a sense of identity develop over the course of a life, within a particular structural or cultural context. This would involve quite a complex explanation of how biology and psychology interact with objective social positioning, power, language and culture. Keeping all of these factors in view at the same time is a significant intellectual challenge, but offers the potential for a more comprehensive account than could be gained by remaining within a single paradigm of enquiry (for a more detailed discussion of ontological pluralism in social-scientific thought, see Giddens 1984; Miller 1992; Rohrlich 2001). The interaction of different models, both individual and social models, has yet to yield a more general 'social theory' of disability; but such a theory would clearly need to explain the dynamic relationships between all of these contributory factors – biology, psychology, culture and structure.

Returning to the material in this book, it is relevant to note that we could also think about important generational categories (like childhood, adulthood or old age) within the same framework. For example, we could simply substitute the concept of childhood for disability in the model above, since theoretical approaches to childhood have also drawn on the diverse contributions of biology, psychology, culture and political economy (see chapter 3). A similar argument could be made about the generational category of old age (chapter 6), and so on. Indeed, these are recurrent themes throughout the book, drawing parallels between our understanding of disability and generation (the latter is explored further in the following section).

Key points and ideas for learning

To summarize, disability studies is a diverse and vibrant field arising from new and critical understandings of what it means to be disabled in modern societies. It owes its origins to the experiences and activism of disabled people, and has been developed within academia on the basis of a distinction between individual and social models of disability. However, it is important to look beyond this simple dichotomy and to note how different

approaches emphasize different causal factors. Although there are many different approaches, it may be helpful to think of four overlapping themes, focusing on the body, identity, culture and social structure. This typology also offers some interesting possibilities for examining the relationship between disability, generation and the life course.

QUESTIONS
- What is disability?
- What is the difference between individual and social model approaches?
- How do the body, identity, culture and social structure interact in shaping the experience of disability?

EXERCISE: A useful exercise is to examine a piece of writing or research about disability and determine how it might 'fit' within the typology outlined earlier. Does the author's position draw heavily on one of the four basic approaches, or does it contain aspects of two or more positions? How useful is the typology in highlighting the differences between particular authors or pieces of writing?

Generation

A second key concept used in this book is that of 'generation'. This concept is explored in some detail later with reference to childhood, youth, adulthood and old age, and it is not necessary to repeat those arguments here (see chapters 3–6). However, it is important to provide a brief introduction and to explain more clearly how the concept of generation is to be used, since this differs in some respects from the way it is often employed in life course studies and research.

Actual generations and cohort studies

The concept of generation was introduced into sociological theory by the German writer Karl Mannheim (1952). Mannheim noted that although people of the same generation were 'bound together' in some way, they could not automatically be considered as members of a concrete social group. Rather, he argued that generational location

may be more similar to social class. Thus, although people are positioned within a particular generation (by virtue of their birth), they may or may not experience any sense of shared generational consciousness or identity. So, while generational location has a biological basis, it is more than this. Generation is also a social location, situated within a social structure and a historical time (i.e. different generations are exposed to different social influences and possibilities). However, Mannheim argued that 'actual' identifiable generations do emerge when there is some conscious bond between them. The identification of a generation in this sense involves a collective sense of identity in relation to other generations.

In this way, generations are often conceived as historical cohorts of similarly aged people who share significant formative experiences that have a lasting effect on their lives and identities, compared with those that went before or go after them. This approach has been widely used in life course research, particularly in explaining how different biographies and generational identities have been shaped by significant historical events (such as wars, economic depression and so on). Thus, Corsten (1999: 249) illustrates how the 'collective cognitive background or horizon of a generation' arises from a combination of biographical, historical and generational perspectives on time. As a consequence, people born into similar societies or families but in different historical epochs may develop divergent world-views and social values. These collective value differences may, in turn, exacerbate existing intergenerational differences and conflict (e.g. Scott 2000).

This kind of approach has been widely used to explain the apparently differing political values and actions of different generational cohorts. Here, a sense of generational consciousness is often seen as important for cohesion or social action at moments of historical importance. For example, Dunham (1998) draws on the experience of the anti-Vietnam War movement in California to demonstrate how younger people with the greatest 'generational consciousness' were also the most likely to participate in peace protest. Similarly, Cherrington (1997) uses Mannheim's approach to examine the distinctive political self-confidence of the 'reform generation' of young intellectuals in the democracy movement of 1980s China, while Misztal (1998) uses a cohort approach to explain the emergence of critical social theory amongst academics in the 1960s. From a disability perspective, Kasnitz (2001) applies a similar line of thought to explain some of the cohort factors involved in the emergence of political leadership within the US independent living movement.

However, political values and participation are by no means the only areas of concern for generational cohort studies, and there has also been a great deal of work examining changing patterns of education, employment, birth rates and family life over successive generations (for some examples, see Giele and Elder 1998; Hareven 1994). Drawing on intergenerational studies in the Netherlands, Diepstraten, Ester and Vinken (1999) conclude that values associated with personal relationships, such as upbringing, family life and sexuality, are actually more indicative of generational location than those associated with the public areas of politics or employment. Thus, the explanations offered by generational cohort studies, arising from Mannheim's approach, have been extremely useful in uncovering shifting patterns of social change, participation and the transmission of culture in contemporary societies. There is a great deal of scope for this kind of approach in disability studies too, examining the changing life experiences of disabled people and generational cohorts in different societies (for an application of some of these ideas, see Priestley 2001).

Generational categories and conflict

An alternative way of thinking about generation is to consider generational location in terms of broad, age-related categories in a society (such as childhood, youth, adulthood or old age). Looking at generation in this way, individuals and cohorts do not remain in the 'same' generation throughout their lives, but instead move through a series of transitions from one generational category to the next (e.g. from childhood to adulthood). This view of generation opens up a whole range of new questions – about the meaning of these categories, and about who is included or excluded from them. For example, when does 'childhood' begin and end? What does it mean to be an 'adult' in society? Has 'old age' changed?

This more categorical approach has been bolstered in recent years by a dramatic resurgence of interest in generational studies. For example, we have seen the development of a 'new sociology of childhood' (Brannen and O'Brien 1995), a renaissance in 'youth studies' (Coles 1986), and a critical reappraisal of approaches to social gerontology (Bengtson, Burgess and Parrott 1997). Such developments have shown how generational categories shift over time, how they are embedded within culture and shaped by structural processes of social change (e.g. changes in the mode of production and labour supply). Thus the social study of generation now provides the

focus for a number of distinct sub-disciplines within the social sciences.

Thinking about the meaning of generational categories and the relationships between them also raises questions about generational inequalities, in terms of power and access to physical or cultural resources. In particular, studies of childhood and old age have high-lighted the existence of significant intergenerational conflicts, con-tracts and bargaining (e.g. Caillaud and Cohen 2000; Collard 2001; Johnson 1995; Turner 1998). These debates have been mirrored in the widespread attention paid recently to generational rights and duties (e.g. in the United Nations Convention on the Rights of the Child). In some ways, the current preoccupation with generational inequalities in social science mirrors more traditional discussions of social stratification, linked to social class or gender, for example. It also raises questions about the way in which societies organize and regulate the boundaries of different generational categories and the transitions between them. Irwin (1999) reviews the development of such arguments, summarizing the general approach:

> In these perspectives life course differences are treated as an expres-sion of inequality. Independent adulthood is the key to inclusion and relative advantage, whilst childhood, youth and later life are charac-terised as socially disadvantaged or marginalised positions. The young and the old are seen to experience exclusion from various forms of meaningful social participation and their voices are unlikely to be heard in contemporary society. In all these approaches life course stages, in particular as they cleave around the tripartite division between childhood (and youth), 'independent adulthood' and later life, appear to have a new significance as dimensions of inequality. (Irwin 1999: 692)

Foner (1988: 176) argues that, although generational inequalities cannot be understood solely in class terms, different age groups are stratified with 'different rights, duties, status, roles, privileges, disen-franchisements'. Age, she argues, is a particularly useful approach, because it alerts us to consider inequalities across the whole life span and not simply in particular age groups (such as those of working age). The purpose in this book is to do just that, with reference to inequalities arising from disability. This is important for two reasons. On the one hand, the similarities of inequality between disabled people of different generations have not always been recognized (e.g. there has been much more attention paid to disability rights for younger people with impairments than for older people). On the

other hand, there are important distinctions to be made between the kinds of disability inequality experienced by people in different generations.

In a discussion of childhood sociology Alanen (1994) argues that the adoption of a generational analysis has much in common with developments in gender studies. In particular, she notes the analytical power that was gained by introducing gender as a relational and generalizable concept, one that offers a systematic approach to the examination of all aspects of the social world. Similarly, she suggests that generational concepts (such as childhood) are also relational, because they cannot exist except in relation to one another, and that they offer an important dimension for thinking about social relations more generally. Likewise, McDaniel (2001) argues that there are similarities in the way that generation and gender have emerged as 'social categories and identity signifiers', shaping public debates and public policy. Alanen concludes that it may be useful to think about a 'generational system', analogous to the gender system, at work in all aspects of the everyday social world and social relations. Thus:

> The assumption of the pervasiveness of the gender system implies that all social relations are 'gendered' – so feminists claim, and have substantiated the claim by producing much research. To acknowledge this has the effect of changing the focus from one turned exclusively on women to examining how gender shapes and is implicated in all kinds of social phenomena. . . . Can we accept that all kinds of social phenomena are not only 'gendered' but 'generationed' as well? (Alanen 1994: 37)

The analogy is a useful one, and it is precisely this question that influences the analysis of disability in chapters 3–6 of this book. When we look in detail at the way in which disability is produced and regulated within modern societies, it becomes clear that there are some very important generational dimensions, and that there is indeed a generational system at work. Thinking about disability in terms of generational categories (such as childhood, youth, adulthood or old age) helps us to understand more clearly how disability and impairment are produced, how they are socially constructed, and how they are regulated in significantly different ways across the life course.

Thinking back to the typology of disability theory introduced earlier, some of the same concepts can be applied to thinking about generation. Indeed, there are some striking similarities. Both disability and generation are important social categories. Both rely heavily on the application of labelling based on biological characteristics (e.g.

chronological age, physical and cognitive development, or bodily differences). Both disability and generation involve significant aspects of negotiated identity and accepted social roles. Both can be viewed as categories that are socially constructed through culture, and socially produced through structural changes in society. In this way, the typology used earlier – body, identity, culture, structure – works well in thinking simultaneously about the category of 'disabled' and about generational categories (such as childhood or old age). That is not to suggest that disability and generation are the same thing, simply that they are produced and regulated as social categories in very similar ways.

Key points and ideas for learning

To summarize, generation has become an increasingly important concept in social theory and research. This has been reflected in two areas of concern. First, there is a strong tradition of research examining the changing patterns of experience for particular generational cohorts. Second, there has been a growth of interest in studying generational location in terms of social stratification and inequality. Both disability and generational categories (such as childhood, youth, adulthood and old age) are socially produced, culturally constructed, and regulated through institutions and policies within societies. Relationships of power and conflict also exist between different generations and these play an important part in social stratification. Examining how this generational system works, and applying a generational analysis, offers a useful approach to learning more about social issues like disability.

QUESTIONS
- What are the main differences between people of different generations (e.g. children, adults and older people), and how do we know which generation we are in?
- Which generational groups are more or less dominant in modern societies and why?
- Does it make sense to talk about a 'generational system' within societies?

EXERCISE: It may be helpful to think more about these ideas before tackling the chapters on disability and generational location. One way to do this is by exploring an example in more detail (adult-

hood is a good example). Think about the way in which adulthood is defined and understood in society. How do we know that someone is an adult, rather than a child, for instance? What can adults do that children cannot? When does adulthood begin and end? Using the four headings of body, identity, culture and structure, try to identify which aspects of these differences are attributable to (a) chronological age or biology, (b) an individual's own sense of generational identity, (c) shared cultural traditions, (d) economic and structural influences. It may also be useful to list some examples of state policies and statutes that define who is regarded as an adult (are these related to a person's age, or to their competence in certain activities?).

The life course

The third key concept underpinning this book is that of the life course. The idea of a life course can be interpreted or understood in a number of different ways. In empirical research, it is often used to describe the life progress of individuals or cohorts over time. Many studies adopt quantitative methods, based on records of life events, although more qualitative and narrative methods have become increasingly popular. Life course methods are quite diverse, involving longitudinal or cross-sectional studies, retrospective or prospective accounts, and focusing on individuals or cohorts (for a fuller discussion of different approaches, see Giele and Elder 1998). For example, Mayer and Tuba (1990) advocate the use of 'life event histories' in chronologically mapping significant life events to explain changing roles and 'transformations of status' over the life course. A similar approach can be useful in identifying the significance of life events and social change for disabled people (e.g. Kasnitz 2001). More qualitative approaches have found increasing favour with researchers seeking to assert the value of 'authentic' narratives in the life histories of disabled people (e.g. Goodley 1996). Looking at individual lives over time is, I believe, a very useful way of expanding our understanding of disability and social change (Priestley 2001). However, the emphasis in this book is on thinking about life course concepts in a rather more general way, as a framework for assisting our understanding of contemporary disability debates.

Regulating the 'normal' life course

Traditional approaches to the life cycle tended to assume a fairly predictable progression through a sequence of life stages broadly linked to biological and chronological ageing (i.e. from birth to death via childhood, adulthood and old age). Consequently, the role of social institutions was seen largely as managing and supporting successful transitions from one stage to the next. For example, we could view historical changes in the social organization of the family, schooling, the labour market or welfare as institutional responses to the challenge of reproducing new generations and ensuring their successful passage through life (or in managing and containing those who 'fail' to make 'proper' life course transitions). Underlying this view, however, is an implicit understanding of the 'normal' life course, an idealized version of life patterns based on cultural norms and rules.

A useful approach is to critically examine some of our commonly held assumptions about progression through life and about the social institutions that regulate this. What, then, is an ideal life course, and what role do social policies and institutions play in policing it? In this ideal world, we are born healthy, we develop naturally as children and progress through education, we become independent young adults, we find work and partners to share our lives with, we establish our own homes and may have children of our own, develop a career, become old, and die a 'good death' (no doubt knowing that we would happily have done it all over again). Such idealized notions of the normal life are also highly gendered, with different expectations of proper work and family roles for women and men. Of course, 'real' life is not so straightforward, and such stereotypes have been brought into question by the emergence of a more contextual and socially constructed view of the life cycle (see Bryman et al. 1987).

However, social institutions continue to shape our understanding of a normal life and the 'problems' that arise when individuals or groups 'fail' to make proper progress through it. For example, from a social model perspective, we might view the history of public institutions and professions dealing with older and disabled people as a social response to these groups' perceived 'failure' to achieve or maintain the adult-centred life course ideals of independence and autonomy (Albrecht 1992; Finkelstein 1991; Oliver 1989). Similarly, Meyer (1988) argues that important social institutions arise in response to the transgression of shared 'cultural rules' associated with normal life course progression:

> Individual life course problems are a matter of deep *collective* concern and much of the life course is explicitly and purposefully organized at the collective level in modern society. Improper or inarticulate sequencing, or unjust transitions or inattention to individual development rights, become major problems and institutions arise to manage them properly. The cultural rules of the life course are central elements of these and other major institutions. (Meyer 1988: 58, original emphasis)

Thus, Walker and Leisering (1998) argue that the 'quasi-biological' view of the life cycle has become increasingly outdated, and that the concept of 'life course' helps us to gain a better understanding of the ordering of our lives – driven by individual decision making, yet shaped by public institutions and policies. They argue that regimes of policy and practice play a significant role in structuring life course transitions and the relationships between different generational groups (e.g. through policies for education, social security, employment and pensions). Thus, they perceive a continuing connection between social policies and the construction or maintenance of normal life course progression. Indeed, Brückner (1995) argues that social policy has become 'life course policy', dealing as it does with the negotiation and management of risk over a lifetime (see also Falkingham and Hills 1995).

This is an important observation in the context of this book, since a critical understanding of disability challenges both life course institutions and the cultural rules that define what a 'normal' life means. This argument is then central to understanding the chapters that follow, which are primarily concerned with charting the social organization of life course transitions and their impact in producing and reproducing disability. For example, by understanding more about the social regulation of 'normal' birth, it is easier to appreciate why eugenic debates about who should be born are so hotly contested. Understanding our assumptions about 'normal' child development makes it easier to see why the education and care of disabled children is regarded as such a problem in modern societies. Similarly, understanding more about our idealized expectations of an autonomous adulthood (in relation to work or parenting, for example) helps to explain why disability debates so often focus on dependence and independence. Likewise, understanding more about 'normal' ageing helps to explain why older people with impairments are often overlooked in discussions of disability. These and related issues are discussed in the subsequent chapters. Here, the significant

point is simply that we need to understand more about the social regulation of the normal life course in order to appreciate the significance of contemporary disability debates.

Uncertainty and biographical disruption

As mentioned earlier, it is important to distinguish between the apparent certainties of idealized life course models and the comparative uncertainties of 'real' lives. This, in turn, brings into question traditional assumptions about the predictability of 'normal' life course progression, and highlights the increasing fragmentation, uncertainty and biographical risk associated with more postmodern theories of society (e.g. Bauman 1995). Such accounts tend to stress the breakup of traditional life course pathways, based on class, gender or national stereotypes, for example, and the rise of individuation and choice in negotiating the risks of contemporary life (Beck 1992). Put simply: 'Where earlier agrarian and industrial societies provided social scripts, of deferential or collectivised kinds, which most individuals were expected to follow, contemporary societies throw more responsibility on individuals to choose their own identities' (Rustin 2000: 33).

Thus, Giddens (1991) sees the changing patterns of consumption in late modernity as indicative of a shift away from predictable life course trajectories and towards more individual biographical views of chosen 'life styles' or 'life projects'. Given the multiple narrative options and 'props' available to us in a consumerist society, from which we might construct and perform our individual life projects, there are seemingly unlimited possibilities for reflexive biography and 'choosing' our own lives. However, as Giddens (1991: 54) admits, this kind of reflexive self-identity remains contingent upon 'the capacity to keep a particular narrative going'. In this sense, we need to look beyond the individual to the kinds of resources that people are able to draw upon, and the kind of barriers they face in negotiating their lives.

Theoretical interests in biography and risk negotiation have been mirrored in life course research, and this has given rise to a growing stream of biographical writing in the social sciences (Chamberlayne, Bornat and Wengraf 2000; Luken and Vaughan 1999; D. Morgan 1998). Within this approach, much attention has been paid to the role of impairment and disability during life. For example, within medical sociology, particular emphasis has been given to the idea of impairment and chronic illness as 'biographical disruption' (see

Brown and Harris 1989; Bury 1982) requiring 'narrative reconstruc-
tion' (G. Williams 1984). In this sense, medical sociology has tended
to view impairment as disrupting or subverting our assumptions and
explanatory frameworks of the 'normal' life course.

S. Williams (2000) reviews this tradition, and asks whether the
idea of biographical disruption remains useful in the context of late
modernity. For example, where traditional life course assumptions
become blurred through reflexivity, diversity and risk, so our assump-
tions about 'normal' biography are widened. More specifically,
Williams argues that the use of biographical disruption in explaining
disability and the life course relies on an 'adult-centred model of
illness'. Thus:

> Biographical disruption . . . rests on problematic foundations concern-
> ing the 'shattering' of our taken-for-granted assumptions about our
> bodies, our selves and the world in which we live. In doing so, it fails
> to account for a range of other possibilities in which illness may
> already be a central part of one's biography, either from birth, early
> childhood or in later life. (S. Williams 2000: 60)

It also fails, he argues, to take adequate account of lay under-
standings about 'normal' illness and impairment during the life
course (see Kelly and Dickinson 1997; Pound, Gompertz and
Ebrahim 1998). In this sense, generational location and generational
identity are very important (e.g. in the case of impairments accepted
by many as 'normal' in old age). Consequently, Williams argues that
age, timing and context are critical factors, and that we should seek
to liberate biographical sociology from adult-centric preoccupations
by extending its use to 'both ends of the life course'. This concern
mirrors some of the arguments presented later in this book.

The limits of individual biography

Current interest in the individual aspects of identity and biography
has contributed greatly to disability studies, by highlighting 'authen-
tic' accounts of disabled people's life experiences. However, there is
also a danger that biography on its own, or interpreted within an
entirely post-structuralist framework, may lead us back full circle to
thinking about disability simply as a life course risk to be negotiated
by individuals. Such a move would clearly negate many of the theo-
retical and political advances gained by viewing disability as a social
or collective phenomenon. So it is important to think carefully about

the limits of biography in adopting a life course approach to disability issues.

As much feminist writing has consistently reminded us, individuals live relational and interdependent lives with others, together producing intertwined and reciprocally constructed biographies. For example, individual life stories are embedded within the ongoing dialogue of historically situated family histories (Vierzigmann and Kreher 1998). Similarly, numerous other people in circles and networks of interdependence contribute intimately to the construction and reconstruction of an individual biography – parents, peers, partners, carers, colleagues and so on. The use of biographical methods in studying the life course therefore requires a relational, rather than an individualist, view of the way that life course pathways and narratives are constructed.

Meyer (1988) goes further, arguing that the level of explanation offered by individual approaches is inadequate, demanding much more social context. For Meyer, preoccupation with individual models of the life course reflects the dominance of individualist values in Western societies, rather than any 'real' individuation within society. Thus, he expresses concern that individual approaches risk reproducing the cultural values of individualist societies in a rather unquestioning way:

> the modern institutionalized life course structured around the rights and development of the individual may be less a consequence of political and economic changes than a deliberate and grounded reflection of the collective cultural authority given the perspective of the individual. That is, in individualist societies, the elaboration of the structured life course may reflect the culture of individualism more than the efforts of natural individuals or the functioning of an individuating social organization. (Meyer 1988: 50)

The key point here is Meyer's recognition that the life course is not simply an individual matter, but something that is heavily institutionalized and organized within societies (through culture, policy and governance). A great deal of collective effort is invested in the social institutions and cultural processes that shape our progression through life – for example, in the way we manage education, work and care. This is what Meyer is implying when he talks about the 'institutionalized' life course. Within these institutional practices there is still plenty of room for the kind of reflexivity and resistance that biographical methods often reveal. However, that should not hide the fact that the available options for life course transitions

and choices are also mapped out within societies at a collective level.

This kind of approach is particularly important if we want to understand disability issues from a social model perspective. Disability studies have been greatly enriched by disabled people's biographical writings and life experiences. None the less, these accounts have become politically meaningful and powerful because they have helped us to understand and challenge disabling barriers. They have been helpful because they enable us to understand more about the way in which disabling societies work, and how people have challenged disabling social relations in real world situations. Finding the connections between individual biography and social barriers is therefore an important task, if sometimes a difficult one. In this sense, biography becomes more than simply individual when it provides us with a window on the social world, or when it provides 'traces' of wider social relations and macro social change (e.g. Chamberlayne and Rustin 1999; Priestley 2001; Ulrich 2000).

Key points and ideas for learning

To summarize, life course concepts and life course research have played an increasingly important role in contemporary social thinking. At the individual level, the life course has been a useful tool in analysing biographical evidence of the risk and uncertainty associated with individuation in modern societies. More broadly, it has been helpful in conceptualizing the way in which 'normal' life progressions are organized and governed through social institutions, in response to structural forces and shared cultural rules. Within the biographical approach, impairment and disability have been widely viewed as disrupting normal life course pathways. Within the institutional view, disability has been presented as a social problem of 'failure' to make successful life transitions. A more critical understanding of disability offers the opportunity to question assumptions about the normal life course and to challenge the institutional arrangements that regulate its boundaries.

QUESTIONS
- Is there such a thing as 'a normal life', and what would it be like?
- How do social institutions (like the family, schools, the media and welfare) shape our expectations of a normal life?

- In what ways may disabled people's life experiences differ from the gendered 'cultural rules' of normal life course progression?
- Should disability be seen as a form of 'biographical disruption' or as part of the normal life course?

EXERCISE: It may be useful to think more about the relationship between individual biography and social institutions in shaping life course pathways. One way to introduce this idea is to critically examine biographical accounts of disabled people's lives. Using two or more pieces of autobiographical or biographical writing, identify the key turning points that had a significant impact on the person's life (both positive and negative). How many of these are presented as personal choices, and how many as external influences? How might life have been different in another time or another cultural context?

Summary

The preceding discussion provides an introduction to ways of thinking about disability, generation and the life course, and illustrates how these have been operationalized in social research. This review suggests that disability should be viewed as a social phenomenon caused by social processes, rather than an individual phenomenon caused by biological processes. However, disability is also a complex concept that can be interpreted on many levels, and it is therefore important to consider a number of possible approaches – for example, in relation to the relative significance of the body, identity, culture and social structure.

Similarly, the concept of generation is open to different interpretations. Here, it is used to define important social categories or life course stages (such as childhood, youth, adulthood or old age). Like the category of disability, these generational locations have been socially produced and culturally constructed. Generational boundaries and transitions are therefore partly about people's subjective perceptions of where they stand in relation to others, and partly about collective frameworks and expectations negotiated through policy and governance. Since there is also a generational system of

conflict and power relationships, applying a generational analysis to important social divisions like disability can be a useful approach to studying inequality.

Thinking about the life course as a whole forces us to consider social issues as they affect people of all generations and throughout the life cycle (including birth and death). This is important when we consider disability issues, since it avoids an over-simplification of disabled people's collective experiences and the marginalization of issues affecting underrepresented groups (e.g. disabled children and older people). The life course can be considered as both an individual and a social construct. But the social approach is particularly useful in highlighting how societies and social institutions reproduce idealized notions of what it means to live a 'normal' life. In this context, critical disability studies and disability politics pose some significant challenges to our assumptions about normal life course transitions, and raise important questions about the policies and institutions that regulate them.

SUGGESTIONS FOR FURTHER READING

There is a wealth of literature within the field of disability studies, much of it dealing with the distinction between individual and social models of disability. For an introduction to these concepts it would be useful to read Oliver's (1996) *Understanding Disability*, especially chapter 2. This volume also contains a partial reproduction of the historically significant UPIAS discussion document *Fundamental Principles of Disability*. For an excellent introduction to the development of social thinking about disability, see *Disability: A Sociological Introduction* (Barnes, Mercer and Shakespeare 1999) or *Disability Studies Today* (Barnes, Barton and Oliver 2002). It would also be useful to look in more detail at the article discussed earlier in relation to theoretical typologies (Priestley 1998b). Linton's (1998) book *Claiming Disability* deals with some of the issues in defining disability and disability studies, while a more comprehensive overview of the discipline is provided in *The Handbook of Disability* (Albrecht, Seelman and Bury 2001).

Similarly, there is a considerable literature dealing with concepts of generation and the life course. For an introduction, it may be worth consulting *Methods of Life Course Research: Qualitative and Quantitative Approaches* (Giele and Elder 1998) or *Social Structures*

and Human Lives (Riley 1988b), particularly the chapters by Meyer and Riley. A more directly relevant discussion may be found in Arber and Evandrou's (1993) *Ageing, Independence and the Life Course* or Hockey and James's (1993) *Growing Up and Growing Older*. For an application of these ideas to disability, there are a variety of useful contributions in the edited collection *Disability and the Life Course* (Priestley 2001).