

# *One*

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## **Introduction, Background, and History**

### **Ethics, Law, and Policy: How Are They Different, How Are They Linked?**

This volume is about disability law, policy, and ethics, so the first question that needs to be addressed is, how are these three things related, what is the link between them? This is not an easy question—it is far easier to describe, as we will below, how ethics, law, and policy differ—but it is an important question. Are law, policy, and ethics on separate, but parallel tracks? Are they just different things with no reliable connection between them? Or does one of them, say ethics, inform or even determine the content of the other two? Since law, policy, and ethics are all complex social phenomena, any answer is bound to be too simplistic. But we need some guidance on it, nonetheless.

This is our proposal: Ethics is fundamental, not because it has more impact on people's day-to-day lives, or certainly not because it is simpler and univocal; rather, ethics is fundamental because it deals with underlying human issues in basic, normative terms—terms like good and bad, right and wrong. It is controversial whether law embodies a public consensus on ethical questions, or whether it should. But certainly in the case

of the issues that come up in this and the next chapter under the heading of “disability ethics,” the law—both in the form of legislation and judicial decision—most certainly tackles the same issues in more or less the same terms. Policy is complex because it is created and governed in part by law, in part by practice, in part by convention. But it too reflects and is implicitly shaped by ethics.

Saying that ethics is fundamental, and constitutes the foundations of law and policy, is dangerous because there are persistent myths about ethics that would turn this proposition into nonsense. We will address these myths below, but for the moment, all that needs to be said is that ethics is a collection of social and individual beliefs, constitutive of religious, cultural, and other forms of socialization, often unorganized and inconsistent, that form around specific practical issues and controversies that each of us faces, or will face, sometime in our lives. We may, as individuals, be able to postpone thinking about ethical questions—Should I lie to my spouse about my affair, or just hope she never finds out?—but as citizens we participate, whether we choose to or not, in social debates about very practical issues that, evidence suggests, will not go away—Should abortion be illegal? Should people be able to seek physician-assisted suicide? The intriguing thing about social ethics (as this area of ethics is called) is that *not deciding* to resolve an issue *is itself a decision* that has ethical consequences.

The plan in this chapter is therefore to assume that ethics, and so disability ethics, is foundational and always in the background, and that law and policy are in the foreground. The tough question of how ethics, law, and policy are connected or linked will not be answered, except indirectly: If we carefully describe each domain, what should be revealed is how these domains differ and how they interact. We begin then with the foreground—disability policy and law—and then go to the background—disability ethics. In each case, we briefly describe policy, law, and ethics in general, before turning to the case of disability policy, law, and ethics. With this background completed, we turn to a review of the history of disability policy and law.

## Background

### Policy and Law

#### *What Is Policy?*

“Policy,” “public policy,” or “social policy” is broadly defined as all of the actions (and inactions) of the state addressed to governance, regulation,

and organization for the public good. More concretely, policy refers to the creation and implementation of laws, regulations, entitlements and prohibitions, income generation programs, taxation strategies and spending priorities, and, finally, state actions (all of which are called “policy tools”) that respond to issues that arise in all areas of human social life, including how we interact with each other, whom we associate with, where we live, how we become educated, how we work, travel, communicate, come together in groups, or be alone.

In short, policies govern, regulate, and sometimes even define—whether successfully or not—everything done within a political organization and social structure. It is extremely difficult to describe all of the distinct areas of public and social policy for the simple reason that it is hard to know what to leave out. Moreover, it is a fundamental question of political philosophy what the proper scope of “public policy” should be, where to draw the line between the utterly personal and the social. For our purposes, and without any claim to being exhaustive, it is enough to list in no particular order the uncontroversial areas of public policy and set aside for later special, temporary, ad hoc, or borderline cases of policy. So, the clear areas of policy are:

- Health and public health
- Social or income security
- Social insurance (welfare)
- Public security and crime control
- Economic affairs
- Commerce and trade
- Communications
- Housing
- Immigration
- Transportation
- Employment (unemployment)
- Workers’ compensation
- Taxation
- Education
- Political participation
- Civil and human rights
- Science and technology

These areas of policy (and the myriad of specific policy issues that fall under each heading) constitute the subject matter or domains of governmental departments and agencies—federal, state and local. For complex reasons, some constitutional and others political, some areas of policy are within the exclusive jurisdiction of the federal government, others exclusively state, and others both federal and state. For the most part, which level of government has jurisdiction over an area of policy mirrors the legal jurisdiction of each level of government, so that a federal court or a state court has initial jurisdiction to hear cases involving the subject matter of that policy area. But legal jurisdictional questions are hugely complicated and political and need not detain us.

Some areas of policy are highly specific and concern sub-populations (policies on aging, youth in trouble with the law, and so on), and some policies are designed to address specific needs or events, such as natural emergency relief or epidemic response programs. Generally, the overall subject matter of public policy addresses basic human needs and concerns, deals with activities and life projects that people generally engage in, responds to problems people face, or want to avoid if possible, in their daily social life, and finally proposes ways of facilitating, or enhancing, the small and large plans that each of us has, day to day, and across a life span. In a word, there are no hard and fast boundaries to what can or cannot be the subject matter of public policy, other than the obvious one: Policy is about human needs, wants, desires, and plans.

### *Making and Analyzing Policy*

Policy scientists agree that there are four stages in the life of any policy, big or small. First, there is a recognition—by some combination of the public at large, bureaucrats, or politicians—that some social or human *goal* is worth achieving (and can be feasibly achieved or at least furthered in some manner), and that there is a mandate for trying to achieve the goal. Next, in light of this goal and an understanding of actual social conditions, *specific objectives* for planning policy are identified. Then, *mechanisms* for reaching these objectives, subject to specified milestones, are proposed and existing *policy tools* are used, or new ones created, to implement the mechanisms. Finally, *implementation is monitored* for effectiveness and, if necessary, the objectives are refined, the mechanisms modified, and the tools recrafted accordingly. (Usually, though, the underlying social goals are so fundamental that they are never wholly abandoned except in emergencies or other rare circumstances.)

Of course, this sequence of steps—social goals, objectives, mechanisms and tools, and monitoring—is an idealized scheme, rarely followed so logically. Many policies are proposed without much thought or planning, and without a clear idea of what they should achieve. Sometimes policy solutions are so effective that they are implemented without a clear understanding of whether there is a genuine problem that needs solving. And sometimes goals are subtly shifted when bureaucrats or politicians realize that the public is not at all happy with how their lives are directly affected when the policy tools are implemented.

Nonetheless, although unrealistically logical and abstract, the scheme does underscore the fact that policy is the outcome of a political, social, and organizational process that depends entirely on the existence, and operation, of basic social institutions. When societies and governments break down, policy slowly disappears. We might even say that the existence of public policy is one indication of the existence of a viable government. Since policy is both a matter of content (what the policy is about, i.e., security, employment, taxation) and process (how the policy is created, developed, and implemented), the institutions that make policy possible have to directly address the ways and the means of policy.

Lastly, this idealized scheme defines the scope of what is usually called “policy analysis.” Hence, policy analysis is a matter of (a) *interpreting and clarifying* policy goals in light of basic social values such as liberty, equality, and dignity; (b) *exploring the relationship or connection* between these goals and proposed objectives; (c) *evaluating the effectiveness* of the policy mechanisms—regulation, entitlement, guidance, prohibition, coercion, public education, or whatever; (d) *describing* the policy tools that are involved—laws, regulations, guidelines, programs, or other state actions; and (e) *monitoring the outcomes* once all of these are implemented. This will be our framework for scrutinizing disability policy in what follows.

### *Law as a Toolbox for Policy; Ethics as Its Foundation*

It should be noticed that the law of the land, on this broad understanding of policy, is merely a collection of tools that facilitate or implement public policy. Lawyers might object (as they tend to do) that the law is far more than this, but it is enough to say that the law is at least this much: a toolbox for policy implementation. Legal policy tools range from the punitive and coercive to the merely persuasive and recommendatory. Since policies are the products of either executive or legislative branches of government, legal tools tend to be the most common. But they are not

the only tools available, nor are they always the most effective ones. As a rule, people like to be free to do the right thing rather than to be forced, and people like to know the reasons for following social rules rather than to be treated like children and told what to do, on threat of punishment. So, information and public education campaigns are common techniques that can have a substantial impact on changing attitudes and behaviors in pursuit of policy objectives. Finally, the state and its bureaucratic agencies—federal, state, and local—have at their disposal a bewilderingly wide range of inducements, tax incentives, and other forms of persuasion that can directly or indirectly affect public behavior.

These tools implement policy even when it seems as if no explicit policy is in evidence. For example, there is no explicit policy for the law that prohibits murder, rape, or theft and empowers the state to enforce criminal law and punish offenders. In criminal law, the goals are so obvious that the law and legal organizations are a social expression of fundamental moral values that are no longer up for political discussion. There will always be debate and movement around the edges, of course, since social values are themselves dynamic. But although it is popular to say that social values are always changing, in fact the fundamentals of these values are really not all that dynamic. The moral evil of being cruel or intentionally causing harm or death is not a matter of debate, and so laws against assault, rape, and homicide are unlikely to become controversial (although, needless to say, whether abortion constitutes murder, or whether racial slurs constitute harm, will remain so).

At the other extreme from criminal law is the law regulating and enabling commercial activities, including the operation of corporations, and the law relating to taxation. Here laws and regulations are highly dynamic, technical, and subject to unceasing fine-tuning in light of changing economic circumstances and shifts in political will and ideology. This kind of law is nothing more than a regulatory toolbox for putting into effect, or implementing, commercial, business, and trade policies, or state revenue-generating policies.

At the same time, even this technical law reflects implicit social values that are ultimately moral in nature, as well as goals and explicitly chosen policy objectives.

Underlying the Uniform Commercial Code, for example, are the values of freedom and reasonable expectation of security of contract, both ultimately moral values. The law that is generated from this and related codes will be closely monitored and evaluated for its effectiveness in

achieving the stated objectives. Laws protecting freedom of contract express a social consensus that, generally speaking, people should be free to arrange their lives and financial interactions with others as they wish. Laws prohibiting predatory business strategies, monopolization, and unfair practices (including laws regulating the safety of drugs, foods, and other potentially dangerous products) reflect the social concern that people should not be taken advantage of, especially when they have no way to protect themselves.

As a general matter, policies always point in the direction of underlying social values and goals (even when they are actually results of shameless political expediency and the expressed values are more image than reality). The reason for this is very simple: Without some linkage to fundamental social values such as liberty, equality, security, dignity, and so on, policies would be (and would quickly be seen to be) mere exercises of arbitrary power and would be very unpopular. It is important not to be naïve about this—the history of policy in the United States, like everywhere else, is replete with mischief and calumny, deceit and treachery. But, even the worse offenses were effective only as long as the image of ethical justifiability in light of agreement with social values could be plausibly maintained.

## Disability Policy and Law

It might not seem controversial to say that disability policy and law is just policy and law that addresses the needs and issues of a person with disabilities. After all, some laws explicitly use the word (the most obvious example being the Americans with Disabilities Act, 1990), and there is much policy and law that is, in the jargon, “targeted” to this population, such as the disability benefit programs of Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI). There is also education policy for children with learning problems, workers’ compensation for people injured on the job, and policies encouraging the development, marketing, and accessibility of assistive technologies, such as wheelchairs, orthotics, or Kurzweil readers. All of these would be called “disability policy.”

So understood, disability policy, from the beginning of the 20th century onward, has been a permanent feature of the U.S. policy landscape, as it has been around the world. It is difficult to estimate the overall cost of disability programming—even if we set aside general or mainstream health

care, which people with disabilities need like everyone else—but one estimate of cash and in-kind programming at the federal level suggests that disability policy constituted in 2002 somewhere in the area of 12% of all federal outlays (roughly 2.2% of gross domestic product), and that states contributed an additional \$50 billion under federal–state disability programs. Most of this money is spent on income support and the specific health care needs of working-age people with disabilities who are either unemployed or underemployed (Goodman & Stapleton, 2007).

It would not be difficult to defend targeted disability policy since, however a “person with a severe disability” is defined (which is not a simple matter, as we shall see), there is no lack of evidence that this population falls behind the nondisabled U.S. population in nearly every social and economic indicator standardly used in policy: The unemployment rate for people with severe disabilities is roughly three times that of the nondisabled population; salaries for those who are employed are roughly 60% of the nondisabled average; education rates are far lower; the poverty rate is far higher; and only one in ten people with a severe disability own their own home (see Chapter 5 for further details). Disability policy is thus policy for a sub-population that clearly needs targeted and programmatic relief.

### *What’s Wrong With Calling It “Disability Law and Policy”?*

Yet, there are two problems with approaching disability policy and law in this way. The first problem is obvious: People with disabilities are people, so arguably all policy and law applies to them. Conversely, anyone can become a person with disabilities, so disability policy and law applies, potentially, to everyone. In this sense, criminal law is disability law, and environmental protection policy is disability policy. Similarly, all foreseen or unforeseen phenomena that affect public policy—from demographic changes in aging patterns to wars, climate change, and economic downturns—affect people with disabilities as well (though often in different ways).

The second problem is more subtle and rooted in history. As we shall see below, much of what we now understand to be targeted disability law and policy arose as ad hoc, “special” add-ons to “normal” law and policy. From the early Middle Ages onward, disability was conceptualized either as a personal misfortune of no concern to the community, or a “special problem” that needed to be dealt with, often by making people with



disabilities invisible or objects of charity. Given this history, even to use the label “disability” for a species of policy and law is to perpetuate an ancient injustice, namely the view that society first must devise policy for normal people, and then, if it absolutely must, it can turn to policy for special populations with special needs.

This aspect of the historical emergence of disability law and policy remains the source of ongoing controversies to this day. Sociologists and political theorists have puzzled over the strange dynamics of disability policy in which people with disabilities, because of the best of intentions, are sometimes included and sometimes excluded from policy on the basis of being “different,” sometimes equal and sometimes not. At its most generic, this phenomena is called the “dilemma of difference” (Minow, 1990): In order to seek and achieve social equality, people are tempted to deny their differences (“we are just like you”); but sometimes doing that creates barriers, even insurmountable ones, to actually achieving meaningful equality, because the differences are genuine and may require adjustments, modifications, and additional resources. As we will explore in detail in the next chapter, the dilemma of difference is reflected in policy terms as the debate between universal and targeted policy options. In legal terms, the dilemma is expressed as the difference between conceptions of legal equality: formal equality versus substantive equality that includes reasonable accommodation.

Although we will continue to speak of disability law and policy, it is important to appreciate that the historical roots of this policy and law are significant for another reason. It is impossible to describe, let alone understand, the nature of disability policy and law without seeing the role that conceptions or models of disability have played in its evolution, and continue to play in current debates. These models not only affect how disability is defined for programs and laws, but also the fundamental epidemiological questions of prevalence (how many people with disabilities are there?) and incidence (now that the population is aging more rapidly, how many new persons of disability are there?). Knowing these numbers is essential for resource allocation decisions for present policy and planning for future policy needs. But beyond statistics, models of disability are influential in all aspects of policy and law. The historical details of these models we will canvass below, but first we need to look briefly at the broad contours of the central models of disability that have shaped, and continue to shape, disability law and policy.

## Disability Policy and the Models of Disability

First a word about models. No topic in disability studies has been more extensively discussed than “models of disability,” and it is easy to become lost in the terminological and ideological tangle. A model of disability is a general theory that tells us what a disability is, what it means to have a disability, who a person with a disability is, and what it means to be a person with a disability (Altman, 2001). There are many models, variants of models, and sub-models, but in the history of public policy there have only been four dominant conceptions of disability that have left their marks on disability policy and law.

In the late Middle Ages, disability policy took the form of state charity. This first model arose primarily as an enlightened and compassionate response to the perception of disability as punishment from God, a personal misfortune or tragedy, or some combination. Though for individuals charity is a moral virtue, once institutionalized it shows a darker side by reinforcing a stark division between normality and deviancy, between the virtuous alms giver and the pitiable and wholly dependent alms receiver. In the model of charity, moreover, policy for those with disability is inherently exceptional, not mainstreamed, and always vulnerable to changing social circumstances—charity is a luxury.

The second dominant approach to disability, and in some ways the original theme of disability policy, was economic in nature. The explicitly legislated distinction between the unworthy and the worthy poor in 15th century English Poor Laws was the first indication of the division between those who were not expected to work or be part of the economy because they were physically incapable of doing so, and therefore were proper objects of pity and charity, and those who were essentially criminals or outcasts. It was certainly an advantage to be in the first group, but there was a catch. To qualify as worthy poor, one had to be a victim of an incapacity, not a willing participant in it. If incapacity was voluntary, then it was blameworthy laziness, malingering, or immorality. Being without talent or trade was one’s own fault; being injured, diseased, or born with a defect was not. For not dissimilar reasons, as we shall see, much of the disability policy of the last two centuries has resulted from the felt need to compensate injured veterans for their service. Not only were they not to blame for their incapacities, they became incapacitated in the service of their country and deserve compensation and tribute for this service. On the other hand, being an alcoholic, drug abuser, or pedophile is voluntary and immoral, so not worthy of being classified as having a disability.

Sometime around the late 19th century, however, an abrupt change in the public conception of disability arose, clearly in response to the growing influence of physical sciences and the emergence of the economic and policy sciences. This was the creation of the medical model of disability, the no-nonsense, scientific view that disability was not a matter of guilt or innocence, possession by demons or god's wrath, or the object of pity and charity, but a perfectly understandable biological or psychological defect, infirmity, or injury. Disability was a medical problem calling for a medical solution. More or less at the same time, scientific public policy depicted disability—along with disease, poverty, crime, and other social ills—as a matter for social engineering, a problem of redistribution of public resources so that, to the greatest extent possible, those with physical or psychological defects were to be treated humanely, outside of the economy, and protected by the largess of the community. The social policies that were created in response to this view built and reinforced what has been called the welfare conception of disability.

Although the medical and the welfare models of disability diverged in their implications for policy—one insisting on access to appropriate medical care and rehabilitation, the other on income support from public coffers—they shared the view that disability was a problem that, so to speak, resided exclusively in the body and mind of the inflected individual (Drake, 2001). Sharing this premise, however, the two approaches went off in different directions, and were sometimes in conflict. Medical sociologists have argued that the policy grounded in the medical model served to colonize people with disabilities by insisting that medical expertise alone was the solution to their “problem,” and then abandoned and stigmatized them when they were incurable and beyond fixing (Hahn, 1985; Zola, 1989). The medical ghettoization of disability left a distinct stamp on disability policy. On the other hand, political theorists have argued that the welfare approach, at least in some cultures, was the antithesis of the charity approach, as it was rooted in a sense of community solidarity in which disability was not at all a personal misfortune but a universal risk to which everyone was vulnerable (Hahn, 1986). This view, too, left its distinctive stamp on disability policy: Welfare or social assistance was not a matter of charity but of entitlement.

### *The Social Model of Disability*

In the 1960s and 1970s, the conceptualization of disability went through a profound, revolutionary change, leading to what is now known as the social

model of disability. The historical development of the social model—which we will outline below—was a complex product of academic social theorizing across disciplines, insights from the practice of rehabilitation therapeutics, and grassroots political movements. Like all powerful ideas, at the heart of the social model was a clear and simple insight: The actual impact on a person's life of a problem of physical or mental functioning is as much a matter of his or her physical, social, political, and attitudinal environment as it is a matter of the functional problem itself. Indeed, as early as 1917 an English physician, arranging rehabilitation services for soldiers returning from World War I, remarked that it was foolish to plan therapy in terms of the nature of the injury, since two soldiers with the same injury would require different therapies depending on what job they wanted to go back to (Fox, 1917). A disability does not reside in a person's body; it is a relationship between the person's body and the world in which he or she lives and acts.

The insight found its expression in many ways. At one extreme, disability was said to have nothing at all to do with the body but was purely a "socially constructed disadvantage" (Oliver, 1990). Society disables, people are "just different." Although good political rhetoric, this view dangerously underestimated the impact that the underlying functional problem had on a person's life. The limitations that a person who is blind since birth will face may be greatly influenced by the absence of supports and the presence of fear, stigma, and stereotypes; but the impact of a spinal cord injury on a person's life has much less to do with the social environment. The radical version of the social model was roundly criticized, by both the disability community and the feminist community, for "making the body disappear" and ignoring the lived experience of most people with disabilities (Hughes & Paterson, 1997; Shakespeare & Watson, 1997; Swain & French, 2000). To do justice to disability, especially for policy purposes, they argued, it makes good sense to acknowledge the realities both of the person's environment and the underlying functional condition.

Although terminological debates continue to rage, for our purposes it will be helpful to follow the well-established practice of using the term "disability" for the complex, multidimensional phenomenon that results from interactions between features of human bodies and minds and features of the physical, human-built, social environment in which people live, while using the term "impairment" to name the essentially biomedical, underlying functional condition that is intrinsic to the person. Impairment constitutes the essential health component of disability; but disability itself is more complex and variable across environments.

There are further refinements of the social model that have been suggested and argued for, most notably those found in models proposed by Saad Z. Nagi (1969) and, much later, the model in the World Health Organization's *International Classification of Functioning, Disability, and Health* (ICF) (World Health Organization, 2001). We will return to these models later, but for now the simplistic disability–impairment distinction will serve us well enough.

Stripped to its essentials, then, the social model views disability as the overall lived experience of a person with disabilities, shaped both by external features of the person's environment—physical and social—and by internal or intrinsic features of a person. Calling these intrinsic features “medical,” though common, is not entirely adequate since they are problems in functioning—moving across the room, seeing trees, driving cars, and so on. It is better we call these health problems in functioning (the sort of problems that rehabilitation therapists of various sorts work on, for example). That said, whether, and the degree to which, disability is disadvantageous to the person depends not merely on the extent and severity of these functional problems—impairment and its consequences—but also on features of the external world the person lives in.

Impairments may be sensory (difficulty in hearing or visual impairment) or physical (difficulties in moving or standing up) or psychological (difficulty in coping with stress, depression, or memory loss); but, in any case, they are best described in biological or psychological terms. Impairments may be congenital or caused later in life by diseases, injuries, or disorders. They may be trivial differences or major disruptions, temporary or permanent. Importantly, impairments enter into the discussion—and are distinguishable from mere differences, like hair color—because they may create specific needs that if not responded to, will undermine independence and participation in major life areas. These basic facts about impairments are essential to keep in mind since disability policy must, at the very least, address the realities of impairments. (Needless to say, mere differences, such as most racial or sexual characteristics, though obviously not impairments, have historically been the basis for discriminatory treatment as well.)

Environmental factors, on the other hand, can be barriers for people when they deny them access to needed resources or opportunities, discriminate against them, or otherwise undermine their dignity, equality, or autonomy. Alternatively, environmental factors may be facilitators, by responding to impairment needs, providing people with disabilities with support and

assistance required to participate in all areas of life, or empowering them to be independent and in charge of their own fates. As barriers, these factors may be overt and obvious: curbs or other roadblocks that prevent wheelchair use, inaccessible rooms or public buildings, or people's attitudes and discriminatory behaviors. And barriers may be hidden or systematic: bureaucratic decisions about how scarce health resources are to be distributed, economic policies that directly or indirectly prevent people with disabilities from entering the work force, or cultural assumptions about the social value of people with mental health problems. Facilitators in the environment cover a similarly extensive realm, from wheelchairs and other assistive technology to personal assistants, accessible public buildings, anti-discriminatory employment policies, and positive cultural representations. Knowing the range of what hinders or helps in a person's environment is equally essential for policy purposes.

Although we normally think of disabilities as permanent or chronic, and usually serious, it is important not to be stuck in the stereotypical examples of mobility problems, blindness, deafness, and cognitive impairment or mental disorder. Many disabilities have natural histories or trajectories, changing as we age, sometimes getting more severe as the underlying health condition or impairment gets worse, sometimes becoming less severe. And many of us will move in and out of disabled states, either as the health condition changes (e.g., postpartum depression, arthritis, episodic schizophrenia) or as our environment changes (e.g., climate change, job change, policy or legal change). Although some people with disabilities are hesitant to acknowledge this, there is no reason why a disability cannot be temporary or curable: If one is fired from one's job because of the flu or a broken arm, there is no reason to deny that this is discrimination on the basis of a disability.

In summary, the social model of disability that stands the best chance of being workable, realistic, and true to the lived experience of disability—and so a good basis for understanding and evaluating disability policy and law—has the following characteristics:

1. Disability is a *multidimensional phenomenon* that includes: intrinsic features of the human body and mind (impairments described in biological, physiological, psychological language); the impact of impairments on the way people perform or execute actions as whole persons (sometimes called "functional limitations" or "activity limitations"); and finally the overall lived experience in the person's actual physical, social, attitudinal, and political environment ("participation restrictions"). As a global concept, disability is all of these things.

2. Disability is the outcome of an interaction—the complex nature of which we are only beginning to understand empirically—between features of the person (impairments and functional limitations) and features of the overall physical, human-built, social, attitudinal, and political environment. The same impairment in different environments will affect the person’s life in different ways, so it is invalid to infer from impairment anything at all about how disability is actually experienced. People who are blind are blind everywhere on earth; but what blindness means to their life, what their opportunities, challenges, benefits, or ways of living will be, depend on environmental factors (Fougeyrollas & Beauregard, 2001).
3. Disability is a continuous, not dichotomous phenomenon. All dimensions of disability are matters of “more or less,” not “yes or no.” For policy purposes—the distribution of resources, the allocation of opportunities, and the eligibility for programming—we must draw a line between those who are disabled for the purposes of the policy or law, and those who are not. But, importantly, this line is negotiable: It is not a scientific fact where the cutoff along the continuum should be drawn; it is a political decision that depends, among other things, on available resources.
4. Disability is a universal human condition, a feature of what it means to be a human being and vulnerable to impairments and other limitations of functioning; it is not a mark of a distinct and insular, permanent minority group. Anyone can become a person with disabilities through diseases, disorders, accidents, or even just living long enough (Shakespeare, 2006; World Health Organization, 2001).

The social model, so construed, helps us ask the questions that set the stage for the entire policy agenda: Should policy be designed to respond to impairments—by preventing them, when possible, or ensuring that their impact on a person’s life is limited or accommodated—or should policy be designed to remove environmental barriers and make provision for environmental facilitators? Since the disability policy agenda undoubtedly requires both kinds of responses, the challenging issue is choosing where the focus should be, or in social model terms, what policy produces an environment that is the most facilitative and constitutes the least barrier for persons with disabilities?

### *The Social Model and the Rights Approach*

The impact of the social model of disability on disability policy has been profound, mostly because the disability movement expressed its demands in social terms, specifically in terms of civil and human rights. These two varieties of basic rights are similar, but also importantly different.

The standard distinction between civil and human rights is that the former, but not necessarily the latter, are inextricably bound to the role of the citizen. It is sometimes said that the civil rights approach extends the social model of disability by adding that persons with disabilities are a minority group who are entitled to equal citizenship—a view usually credited to the political scientist Harlan Hahn (see Hahn, 1985, 1986). Hahn was greatly impressed by the parallels he saw between the civil rights movement, and in particular the political dynamics of an oppressed “insular and discrete” minority group, and the disability rights movement. Others, however, remarked that as people with disabilities are an amazingly diverse group, it is difficult both in theory and in practice to view them as a minority group (Zola, 1989).

Still, the demand for equal citizenship was politically strategic and effective as the rallying cry of the disability movement during the 1970s in its fight for substantial legal change (Anspach, 1979; Driedger, 1989; Scotch, 1984). Somewhat later, and influenced by European voices, U.S. disability rights activists made the case for human rights—rights owed to all human beings, regardless of national affiliation and independent of cultural or political context. Rights such as those enumerated in the 1948 United Nations Universal Declaration of Human Rights, it was argued, were so utterly basic that their denial amounted to a travesty of justice. This approach has continued and culminated in the 2006 United Nations Convention on the Rights of Persons with Disabilities, which the United States signed in 2009.

In the United States and many other high-resource, industrialized countries, the disability rights movement—grounded upon one or another version of the social model of disability—has played itself out against a background of civil or human rights and has strived to incorporate these rights into specific policies, primarily in the areas of health, rehabilitation, transportation, education, and employment. As we shall see below, moreover, nearly all disability policy in the United States can be traced to the demands of disabled veterans: The very first attempt to shape disability policy at the federal level was the 1918 Veterans Rehabilitation Act. This has left its mark. Disability policy and law, despite the rights revolution, tends to be reactive and piecemeal (Bickenbach, 1993; Leichowitz 1988; Stone 1984). Often, too, disability policies have seemed to be more responsive to the professional needs of service providers and bureaucrats than to people with disabilities themselves (Albrecht, 1992).



Disability policy has always been incoherent and highly vulnerable to shifts in political attention. Programs for disabled veterans have been created and financed, it is true, but once they were put in place, it was assumed that “the disability problem” had been solved, and policy makers turned to other issues. The disability rights movement, being essentially a consumer protest, has long been aware of the inherent inadequacies of disability policy, its incoherence, its reactive and ad hoc nature. As we shall see, one of the central and ongoing challenges of disability policy is discovering how to mainstream it so that it is fully integrated with public policy, rather than added on after other policy decisions have been made.

### *The Anti-Discrimination Strategy in Disability Law*

How have the social model and human rights approach shaped disability law? In some ways that is an easy question since law is the primary vehicle for human rights. Philosophically, the civil and human rights approach rests on a demand for equality for persons with disabilities. But translating that abstract political demand into specific laws has always been challenging (and not just for people with disabilities; the same has been true for African Americans and women). The most natural approach, as mentioned, was to follow the pattern of the civil rights movement and secure enforceable protections against discrimination on the grounds of disability.

In retrospect, the social model and rights approach can be credited with nearly every change in attitude and treatment of people with disabilities in the last three decades, from the provision of curb cuts and accessible bathrooms, to the creation of programs to integrate developmentally disabled children into the public schools, to the implementation of anti-discriminatory employment policies. As it has matured, the social model and rights approach has adopted some of the theoretical developments introduced by feminists and Black theorists, including identity politics. Yet, through it all, faith has been retained in the legal representation of disability rights in anti-discrimination legislation in general and the Americans with Disabilities Act of 1990 (ADA) in particular.

Reading through the academic and popular literature of the disability rights movement in the United States from the 1960s through to the 1990s, one theme that keeps recurring is that while the “equality agenda” is first and foremost, the “cultural agenda” is not far behind. The U.S. disability movement has always reacted strongly against the cultural

view of disability expressed in stereotypes of people with disabilities as infirm, inferior, and childlike in their dependency on the good will (or charity) of the majority, “normal” population. Although some disabled feminists argued that dependency is universal and part of the human condition (Morris, 1992) while fully sharing the goal of equal opportunity, the disability movement often aligned itself with the very different goals of independence, unfettered autonomy, and self-sufficiency.

Few disability theorists have more clearly expressed the prominent role that anti-discrimination protection must play in disability policy and law than Harlan Hahn:

All facets of the environment are moulded by public policy and . . . government policies reflect widespread social attitudes or values; as a result, existing features of architectural design, job requirements, and daily life that have a discriminatory impact on disabled citizens cannot be viewed merely as happenstance or coincidence. On the contrary, they seem to signify conscious or unconscious sentiments supporting a hierarchy of dominance and subordination between nondisabled and disabled segments of the population that is fundamentally incompatible with legal principles of freedom and equality. (Hahn, 1993, pp. 46–47)

Here Hahn ably identifies the core rationale for putting anti-discrimination at the heart of disability law and policy. Because of their minority group status, people with disabilities are denied the full enjoyment of their rights, principally through entrenched discrimination created by prevailing attitudes that are part of the very fabric of our culture and suffuse all social institutions. For Hahn, “the primary problems confronting citizens with disabilities are bias, prejudice, segregation, and discrimination that can be eradicated thorough policies designed to guarantee them equal rights” (Hahn, 1987, p. 182). Although Hahn was well aware that courts and judges are not immune from prevailing “disabling images” and attitudes, he argued that legally enforceable prohibitions against discrimination based on disability stand the best chance of guaranteeing civil and human rights to all people with disabilities.

In its pure form, anti-discrimination, either as a policy or as an explicit legal tool, has an internal logic that requires us to, first, identify a *group characteristic* that defines the oppressed minority group; second, identify an action or behavior that is *discriminatory* against a person or group identified by that characteristic; and finally, provide a compensatory *remedy* for the discriminatory action or behavior. Each of these three

requirements has created problems of judicial interpretation for the ADA. Saving the details for later, these problems focus on (a) disability as a group characteristic, (b) discrimination as an action or behavior, and (c) the appropriateness of the remedy in light of the background objective of full participation and equality.

## Enduring Themes of Disability Policy and Law

As we shall see in Chapter 2, controversies that hearken back to the question of whether the anti-discrimination strategy, however extended or modified, is sufficient for the rights approach and the equality aims of persons with disabilities are an enduring theme of disability policy and law. Although no commentator has argued that discrimination against people with disabilities does not exist—indeed, recognition of discrimination is a consensus that crosses the U.S. political spectrum—there are certainly those who argue that the ADA is either counterproductive to the interests of persons with disabilities (e.g., Epstein, 1992), or essential to their interests but not sufficient to the task of protecting rights, achieving meaningful equality, or fulfilling the policy aspirations of persons with disabilities (e.g., Bagenstos, 2009; Bickenbach, 1993; Schriener, 2001). Moreover, the responsibilities incurred once the United States ratifies the UN Convention on the Rights of Persons with Disabilities have the potential to profoundly affect how the rights agenda is developed in the United States.

Suffused through these debates is a classic controversy about the proper role of the law, or more precisely of the rule of judges, in policy development. Legislatures at all levels of government pass laws and regulations that implement policy; but in common-law countries like the United States, lawyers and judges interpret these laws and policy is affected by these interpretations. It is an open question whether it is appropriate, beneficial, or indeed unavoidable that judges contribute to the shaping of policy through their decisions. Most scholars argue that this interplay is potentially beneficial to secure clarity and general applicability of laws as policy tools. In part as a response to this interplay between legislatures and the judiciary, agencies of the executive branch of government may be established to provide guidance in the interpretation of laws in the hope that courts will abide by interpretations that preserve the spirit of the policy. The Equal Employment Opportunity Commission (EEOC) is such an agency, responsible for enforcing and interpreting several pieces of anti-discrimination legislation in the

employment sector, including the ADA (see further discussion of the EEOC's role in Chapter 5).

The following sections introduce other enduring themes or debates, some of which have already been hinted at, that will also set the agenda for Chapter 2.

### *What Is Disability?*

A report prepared for the Interagency Committee on Disability Research (2003) found 67 different legal and policy definitions of “disability” (or “handicap”) in federal statutes, from civil rights, education, and internal revenue to Social Security.

And this is only the tip of the iceberg. In the hundreds of distinct programs for persons with disabilities administrated by the federal government, there are many other definitions of who is disabled and qualifies for the program; across state programs, there are countless more. With effort, one might be able to reduce this number to a handful of model definitions, but one thing is clear: At all levels of government, disability policy is governed by many different definitions of disability that identify different groups of people.

The enduring debate is whether this is a sign of incoherence that should be remedied, inevitable and something we just have to live with, or, finally, appropriate and perfectly acceptable. Would anything be gained by having a single definition of disability that would be used across policy sectors and for all objectives? Would a single definition undermine the effectiveness of different kinds of disability policy that aim to achieve very different goals? We return to this complex issue in Chapter 2.

### *Universal or Targeted*

Another pervasive concern is whether policy should be universal, in the sense of being designed to fulfill policy objectives for everyone, or specifically targeted to people with disabilities. Universal policy, while not singling out sub-populations by name or description, when properly designed can accommodate differences between and among sub-populations, so that the overall policy objectives are achieved fairly and equally by all. Targeted policies focus on the needs and objectives of a defined population, often in response to historical inequalities of treatment or abuse. Targeted policies require “eligibility determination” that qualifies an individual to benefit from the targeted program.

Universal policies also need a characterization of sub-populations, but only in order to identify the differences that need to be accommodated in order to universally achieve the overall policy objectives.

In part, the contrast between targeted and universal policies reflects another contrast already mentioned: that between Harlan Hahn's minority group approach and Irving Zola's universal approach. The impact of this contrast on policy is quite far-reaching, as it affects how the political and economic argument for the need for disability policy is constructed. All policy is driven by demographic information, and in particular prevalence statistics (Stone, 2002): The greater the number of people affected, the bigger the social problem and the more likely policy will have a higher political profile and economic impact. Hahn's call to focus on a minority group status, created as a deviation from culturally defined standards of the normal and operationalized in terms of explicit indicators of social visibility (wheelchair use, blindness, aberrant behavior, difficulty communicating), suggests that the prevalence of disability should be relatively low, since to be socially noticeable as an "insular and discrete" minority group, the disability will tend to be severe. Zola's universalism, which clearly reflects a longitudinal and continuous understanding of disability, points to far higher prevalence—potentially everyone may be covered. (In Chapter 5 we look in more detail at the issue of prevalence.)

### *Inclusive or Separate*

A similar theme has a greater application to areas of life, such as education, in which differences impact centrally on how the program is constructed and delivered. The issue is whether the program should aim for separate but equal services, for inclusion, or for full integration. Each option has its consequences, both positive and negative, and debates continue about both the effectiveness and the fairness of different policy strategies. Is mainstreaming always the best solution, or is more good than harm done by retaining "special" services tailored to specific, and potentially unique, needs (Scotch, 2000)?

### *Impairment Focus or Environment Focus*

A theme with many manifestations across policy areas is whether our objective should be to address, prevent, or mitigate the impairment aspect of disability—to change the person, so to speak—or to invest our resources in accommodations and other modifications to the physical, human-built,

and social world so that the impairment does not unduly or unfairly affect a fair range of opportunities. If, as seems sensible, the answer is that both approaches should be adopted, the issue then becomes, given limitations of social resources, how should the balance be achieved?

Underlying the previous three themes, and to some degree cutting across them, is a partly empirical, partly political controversy that takes us back to competing models of disabilities. The issue is whether impairments matter, and if they do, how and how much do they matter (Wasserman, 1998)? Advocates of the medical model insist that impairments and functional limitations are the entire story: If we deal with those, then disability will disappear. On the other side, radical social model advocates insist that impairments, functional limitations, and other “differences” are not relevant to disability at all, as this is purely a matter of socially constructed disadvantage (Oliver, 1990; Roth, 1983). One underlying challenge for disability policy, therefore, is to find a way between these extremes, or in the words of the U.S. Commission on Civil Rights report in 1983, “The goal is neither to exaggerate and stereotype nor to ignore . . . functional limitations” (USCCR, 1983).

### *Sword or Shield*

Another theme in disability law involves a common legal metaphor: Should disability law be a sword or a shield? That is, should the law enable and empower an individual or a group of persons with disabilities to take on barriers, whether physical or social, and where successful alter social, cultural, economic, or political institutions to dismantle these barriers? Or should the legal tools we create function primarily to protect the interests of people with disabilities that might otherwise not be taken into account in the pursuit of other policy objectives? Again, if we adopt a balanced approach using the law in both ways, how can we identify the proper and most effective balance?

### *Reactive, Piecemeal Policy or Unified and Coherent Policy*

Although not unique in this regard, disability policy has long been reactive and ad hoc rather than unified and coherent. Ed Berkowitz (1987) notoriously described employment policy for people with disabilities as consisting of “layers of outdated programs” piled one on the other in an incoherent attempt at reform or response to new political pressures or economic conditions. The hundreds of federal and state programs that come and go, relying on an equal number of definitions of disability for

eligibility, often have different, if not conflicting, objectives and use policy tools that create an administrative nightmare for those who could benefit from them. On the other hand, it might be argued that this incoherence is not only unavoidable, it has the virtue of being flexible and individualized, and a “one size fits all” disability policy might be coherent, but unfair and ineffectual.

### *Equality of Opportunities or Results*

A theme that calls forth more fundamental political values is whether the desired outcome of all of our policy and law for people with disabilities should be to achieve a “level playing field” of equal opportunities (acknowledging the fact that some people with disabilities will not be able to translate opportunity into a successful, or even viable, life), or whether we should adopt the far more radical approach of seeking equality of results (acknowledging that, in the face of unavoidable human differences in talent and ability, our policy and law must be tailored to make continual adjustments and responses to unequal results over time)?

### *Intersectionality*

Another theme that needs to be dealt with in legal and policy terms involves the recently labeled notion of “intersectionality,” which recognizes that people may hold more than one social identity at a time—people are disabled and women, disabled and aging, disabled and African American (Silvers, 1999). This is a challenge for targeted policy and anti-discrimination law, or indeed for any response to disability that ignores other, potentially influential affiliations with other groups who have an equality agenda that may or may not align with that of disability.

### *Public or Private*

A debate that rages across all areas of policy is whether the state and its agencies—the public sphere—is the best, or the only, institutional structure for responding to the needs and interests of persons with disabilities, or whether it would be more effective and efficient to allow the private sector, in particular the free market, to deal with these concerns. Although disability policy of the past century rejected the private, charity approach in favor of some form of public response, it remains a policy question whether the best policy tools might be private, either for the delivery of services or remedial response to discriminatory practices. Although often

a technical economic question beyond the scope of this volume, the public–private debate is indeed an enduring theme of disability policy.

A related issue of great importance to persons in need of personal assistance services for the basic activities of daily life is whether these services should to any degree be within the scope of public regulation (for example, by means of a state-funded and monitored service brokerage arrangement), or whether they should be left entirely to the open market in a consumer-run and directly funded approach following the so-called “independent living” model. Similarly, the assistive technology market might arguably be best created and managed by the state, regulating the development, production, and safety of wheelchairs and other mobility aids; transportation, communication, and other impairment-related aids; and durable medical equipment such as orthotics and prosthetics. Alternatively, it might be suggested that the free market is best for both development and distribution of these technologies and aids.

Finally, there is one remaining public–private issue that arises most clearly in disability ethics. The question is whether there are some aspects of life that are unquestionably outside the proper purview of public policy and law, some areas of privacy in which nothing is achieved, and much potentially sacrificed, by bringing them into public scrutiny. Are there, for example, areas of life that are so private—involving the decision to have or keep a child, to continue living or seek a painless end of life, or to maintain the life of another where there is no prospect of recovery and only continued pain—that our policy and our law should not interfere with them, even if decisions made are potentially detrimental to the interests of persons with disabilities?

All nine of these enduring policy debates have consequences on the lives of people with disabilities: They are neither abstract nor academic concerns. It would be impossible in a single volume to deal adequately with all of them, so in Chapter 2 we will return in more detail only to the issue of definition, the public–private balance, and the debate between universal and targeted policy. At this point, however, and before we turn to the history of disability policy, we need to complete our introduction by looking at disability ethics.

## What Is Disability Ethics?

### *Ethics in General*

Ethics is a branch of philosophy concerned with issues of right and wrong, good and bad, virtue and vice. Although often used interchangeably,



the term “ethics” is occasionally used for specific moral codes of professions and other groups, while the term “morality” (or mores) is restricted to the actual ethical beliefs and customs of particular cultures. But this is mostly a verbal distinction. The important difference is between morality as a matter of personal beliefs or cultural customs that can be empirically discovered, and the systemic and analytic treatment of moral issues, which is called ethics.

There are common misconceptions about morality which, were they true, would make ethics of little relevance to policy and law, of no interest to disability studies, and indeed of little interest to anyone. The first is that morality is purely subjective or just a matter of taste or opinion. The evidence for this is supposed to be that ethical controversies seem unending and that people sometimes get very emotional about the positions they hold. But this is compatible with moral issues being very difficult to resolve (which they often are) and people caring about them (which they often do). If moral issues were really subjective, no one would waste time arguing over them. (Truly subjective topics, like preferences in flavor of ice cream or other likes and dislikes, are neither debated—no one can show that you are wrong about your preferences—nor of much lasting interest to others.)

The other misconception is that morality is so completely culturally determined that there is no scope for reasoning or theorizing about it. But this view as well is inconsistent with the facts. People from vastly different cultures share many basic moral beliefs (that it is generally better to live a full and active life than not, that people matter, that one should take care of one’s children, and so on), and we debate moral issues both earnestly and rationally. A related misconception is that morality may be all well and good, but sometimes it is too expensive to be moral, or other considerations are more important. But this too mistakes moral beliefs for mere preferences: Moral problems require practical solutions, not impossibly impractical and idealistic solutions. Moral solutions are “all things considered” solutions that take into account everything relevant to the situation. If an option to solve a problem is too expensive in time, resources, or human energy, then it is impractical and ethically unsound since it unduly sacrifices other important interests.

Usually when these or other skeptical views about morality are expressed, the speaker is not thinking of real, concrete moral dilemmas that she or he has had to face, or could face, in his or her life. If your parent is dying but has not yet been told, should you tell him or her? If your

spouse wants children but you do not, should you change your mind to make your spouse happy? Should you risk your life to save a stranger from drowning? Should you to save someone else's child from drowning? To save your own child? If four people need a liver transplant to live and there is only one available liver, do you give it to a young child who has cognitive impairments, to someone who is very old, but rich, to someone who is an alcoholic, but a marvelous musician, or to your good friend who will spend the next 20 years in prison for murder? These are not easy questions. But they are neither trivial, unimportant, nor just a matter of irrational personal preference. These are the kinds of questions that ethics in general, and disability ethics in particular, is about.

There is some point, however, in distinguishing between personal morality (the basis for how one lives one's life and the decisions one makes about oneself) and social ethics (the basic moral principles, values, or ethical theories about which there is sufficient agreement to form an important input into our public policies and laws). Social ethical values inform and underwrite our civil and human rights, and, at least for viable and relatively stable cultures, there is not much dispute or controversy about what those principles and values are. The disputes that make the newspapers and academic journals typically involve more concrete and particular questions where values conflict, or when the issue is just too complicated or novel for an easy answer. Social ethics (or "practical ethics") is the ethics of real, concrete, practical social issues, and typically these are dilemmas in the true sense of that word: problems about which reasonable people, in good faith, and sharing common values, can disagree, since there is no perfect answer and more than one solution seems ethically justifiable.

### *Bioethics and Disability*

Bioethics, or health care ethics, is a particularly volatile and high profile example of practical ethics. There are others, such as business ethics, the ethics of legal and other professions, or journalistic ethics, and these too raise troubling issues. But since bioethics deals with life and death issues, involving basic values like autonomy, dignity, and respect for persons, it is an ethical domain of considerable interest and controversy. It is also the primary source of moral issues that involve the concept of disability, as well as the lives, rights, and interests of persons with disabilities. As with disability policy and law, since people with disabilities are people, all areas of practical