Five Models for Thinking About Disability:
Implications for Policy Responses

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This article advances five models for thinking about disability. Each has various degrees of relevance to policy, and each reflects various disciplines that affect policy. The article defines each model, indicates the disciplines or other sources of the model, and demonstrates the relevance of each to policy. The five models are Human Capacity, Public Studies, Cultural Studies, Ethical and Philosophical Studies, and Technology Studies

In this article, we describe a meta-cognitive approach to thinking about disability and about societal and policy responses to disability. This article connects the previous articles about core concepts and taxonomies to these discipline-based models, exemplifying how the professions that are most salient to the policy-making processes reflect societal responses to disability and thereby affect policy. It also sets the stage for the next article on possible tools to use in policy analysis. Full citations to the statutes and cases referenced in this article are contained in the Matrix article (this issue).

The Benefit of Multiple Methodologies

One of the benefits of having conducted research on core concepts by using more than one methodology and by relying on respondents from different disciplines (law, medicine, social welfare, education, psychology, political science, public administration, religious studies, and human development) is that different ways of thinking about the subject under investigation became apparent. For example, a legal and policy analysis methodology (careful study of the statutes and case law) suggested thinking about core concepts-and thus about disability-in terms of constitutional rights, statutory entitlements, and case law decision-making. On the other hand, a qualitative methodology (using focus groups and individual interviews) suggested a social science way of thinking about core concepts and thus about disability.

As a result, we began to ponder the different ways in which people think about disabilities. Two questions presented themselves:

1. Do lawyers and policy analysts think about disability in different ways than do traditionally trained social scientists? If so, do they also act differently than each other when called upon to "do something" about disability, such as identify the core concepts of disability policy? The answer seemed (and still seems) obvious: Yes.

2. What difference does it make that different people bring different disciplines and ways of thinking about disability and society to the tasks of generating and then implementing policy?

This article addresses these questions.

Confirming the Answer to Question 1

To confirm that different ways of thinking yield different approaches to policy, we needed to go no further than the data we acquired from the focus groups and individual interviews on core concepts. In these data, we found responses that clearly reflect different ways of thinking and acting. The responses of researchers reflected

their original disciplines, such as law, health policy, disability demographics, or program evaluation. Likewise, executive officials in federal and state agencies looked at their roles and at policy through the *eyes* of public administrators. In addition, because more than one of those administrators were parents of children with disabilities or were themselves people with disabilities, they also provided "extra" perspectives. Similarly, regional or local administrators approached problems with the professional perspectives of social workers, physicians, psychologists, or educators; such approaches were different from the approaches of a state executive agency director (in the same state) who was trained as a lawyer but is related to and powerfully influenced by a psychiatrist.

Thinking About How to Think About Disability

The result of this grasp of the obvious-people think about the same concept from different backgrounds and perspectives is that we began to ponder how one might think about disability. In particular, as we began to link our analyses of documents and qualitative research responses to the core concepts and then to the Professional, Constitutional, Ethical, Administrative, and Fiscal Principles, we began to develop a preliminary framework about how professionals, policy leaders, families, and individuals think about disability.

In this article, we set out five models for understanding and thinking about disability. We also indicate which core concepts seem to be most clearly associated with each model. As we have argued, the core concepts are intertwined with the Constitutional, Ethical, and Administrative Principles, but we do not identify those Principles because this has been sufficiently illustrated in Figure 2 in the Taxonomy article (this issue). These models are not complete, nor do we provide them in great detail. They do, however, seem to offer a useful preliminary framework for understanding (a) the perspectives that people bring to policy debates and (b) what underlies the policies and their core concepts. For example, if physicians think about disability from a different perspective than, say, educators, they invariably

will propose different "solutions" to the fact of disability, to the lives of people with disabilities and their families, to the ways in which professionals should interact with families and other professionals, and thus to the core concepts that should shape policies and the policies themselves (as expressed in the statutes and cases in the Matrix).

Physicians may adopt a "medical" model, educators and psychologists may adopt a "developmental" model, and rehabilitation specialists and technology developers may adopt a "technological" model. Likewise, physicians may be less apt to allow parents and children, or other professionals, to become full partners with them in decision-making, whereas educators (especially early interventionists) may be more schooled toward the concept of full partnership.

The Five Models

The following list is our proposal of five models for how people think about disability and disability policy:
1. Model of Human Capacity Studies
2. Model of Public Studies
3. Model of Cultural Studies
4. Model of Ethical and Philosophical Studies
5. Model of Technology Studies

Utility of the Five Models

Before describing the five models, it is appropriate to note why they are useful to individuals who want to create policy, implement it, or evaluate its implementation. In other words, what difference does it make that a certain model exists? The answer to this question is fairly straightforward. Persons who approach policy, whatever their model maybe, should ask two basic questions. First, does the particular policy under consideration advance one or more of the relevant core concepts? If so, how well does it do that job? The purpose of these two questions is to conform the policy to the core concepts, or in other words, to reduce the disparity between them.

For example, if an analyst is concerned with policy whose purpose is to increase the capacity of

individuals with disabilities or their families to live independently, to be economically self-sufficient, to participate in the mainstream of American life, or to have equal opportunity to achieve any of those goals (as the Individuals with Disabilities Education Act [IDEA], Part C, explicitly intends), then the analyst is putting the model of human development into play and should focus on the core concepts most closely associated with that model. If the analyst is concerned with a policy whose purpose is to increase the capacity of a service-provider system to respond to the needs of people with disabilities and their families (as Part C of IDEA does), then the analyst is putting the model of public studies into play and should focus on the core concepts most associated with that model.

Focusing on the core concepts associated with a particular model is only the first step for the analyst. The second is to track these concepts into the Matrix and use the statutes and cases associated with the particular concept as a guide for the following:

- to know how Congress has approached the policy in the past,
- to draft legislation or regulations (using the language of existing statutes as "boilerplate" or as guidelines for the draft),
- to know what other statutes exist that also may bear on the particular policy under consideration, and
- to know how the courts have interpreted the existing statutes.

Thus, the model leads to one or more core concepts. The core concepts lead to the Matrix, with its relevant statutes and cases. The relevant statutes and cases are the foundations for creating legislation, regulations, or evaluation procedures.

Model of Human Capacity Studies
The Model of Human Capacity Studies deals generally with the sciences of human development: how individuals acquire various capacities. There are at least three submodels: *medical/public health, psychological,* and *educational.* Each has played and continues to

play a large part in disability policy and services and thus in the impact that core concepts and partnerships have on family quality of life.

The medical/public health submodel generally regards the person with a disability as having a disease or condition that renders him or her "sick" and that is properly addressed through the usual means whereby physicians treat their patients. There are two aspects to the medical/public health model: physical medicine and psychiatry.

That physical medicine and psychiatry have played significant roles in disability policy and in the lives of families cannot be doubted. Initially, they were a source of the institutionalization and eugenics movements (the original "medical [or "disease"] model"); they also were the setting for the debate concerning the sanctity and the quality of life of newborns with disabilities. They have been the foundations for various interventions (such as psychopharmacy and electro-convulsive shock treatment) that have been alternatively praised, condemned, and accepted (with procedural safeguards surrounding their use).

The medical model was the bedrock for the provisions of Title XIX (Medicaid) of the Social Security Act that allot federal funds to the states so that these funds may be used to maintain acceptable standards of habilitation and treatment in institutional and community-based settings. In this respect, it has been transformed into a public health (wellness-promoting) model. There can be no doubt that medical and related health interventions are oftentimes highly effective responses to the physical, cognitive, emotional, or behavioral impairments that individuals experience. Core concepts related to the medical/public health submodel are **prevention and amelioration, privacy and confidentiality, individualized and appropriate services** (treatments), and a concept that arises from the original theory of the deinstitutionalization efforts, namely, to reform the institutions (and to prevent people from being admitted and to secure the discharge of those who are already institutionalized). This concept is **protection from harm.**

Because one of the Professional Principles in the field of medical and public health policy is **autonomy,** this core concept comes into play as well, but in historically interesting ways. In the

field of medical and public health policy, autonomy has two "edges," and they sometimes conflict. On one side is the physician's duty to respect the choices of the patient (person with disability or family), where legal rules regarding patient consent come into play. On the other side is the physician's duty to exercise his or her own judgment-to be an autonomous professional-concerning what treatment is warranted, what to tell the patient concerning the course of treatment, and whether to even secure the patient's consent to treatment (the therapeutic privilege rule; see *Natanson V. Kline* and *Canterbury v. Spence)*. Only recently has the patient-autonomy side been paramount; for many years, the "doctor-knows-best" approach prevailed.

IDEA contains at least two examples of the medical/ public health submodel: an evaluation of the student's physical and developmental characteristics and provision of health-focused related services (*ISD v. Tatro* and *Cedar Rapids CSD v. Garrett F.* [1999]). Likewise, this submodel appears in the Medicaid provisions, in the eligibility standards for Supplemental Security Income, and in the treatment standards related to "Baby Doe" children in the Child Abuse Prevention and Treatment Act (1988).

The psychological submodel regards behavior as a learned consequence to external stimuli. It holds that in order to modify behavior, it will be necessary to control the environments and the conditions within these environments that produce behavior. These conditions include relationships between the individual with a disability and others. The psychological submodel gave rise to the intervention known as applied behavior analysis and, more recently, to the intervention known as positive behavioral supports.

Just as IDEA reflects the medical/public health submodel, so too it reflects the psychological submodel in its requirements for a nondiscriminatory evaluation (including a psychological evaluation) of the student, and in the use of applied behavioral analysis and its newer version, positive behavioral supports, when a child's behavior impedes his or others' learning or when the child is subjected to discipline. Indeed, the most recent definition of the term *mental retardation* requires that the

person lack adaptive skills and behaviors in order to be classified as having the disability (American Association on Mental Retardation, 1992). The core concepts associated with this submodel are the ones associated with the medical/public health submodel, with the addition of **empowerment/participatory decision-making.**

The educational submodel holds that everyone can learn; there is no such person as one who is ineducable; and that, accordingly, all people who are of school age have a right to attend school if even one such person has the right to attend school. This submodel arose from research on language acquisition, was the foundation for the assertion in the early right-to-education cases that all children can learn *(PARC v. Commonwealth),* and currently is expressed in IDEA's zero-reject principle and in the landmark case on educability *(Timothy W. v. Rochester School District).* In this respect, this submodel is associated with the core concept of **antidiscrimination.**

The education submodel is also reflected in IDEA's principle of nondiscriminatory evaluation and especially in the requirement for an evaluation of a student's cognitive capacities. It is also inherent in IDEA'S provisions that the student with a disability should have access to the general curriculum where, it is assumed, the student will learn certain skills (with accommodations) that will lead to an independent, economically self-sufficient, productive, and fully participatory life. This submodel thus is associated with the core concepts of **integration**, **productivity and contribution**, and **autonomy** (independence). It is responsible for a variety of teaching techniques tailored to the needs and capacities of the student, which collectively are expressed as **individualized and appropriate** education and related **services**.

Model of Public Studies

The Model of Public Studies subsumes various disciplines that are linked to each other because each is basically concerned with the relationship between government and individuals. Along with the Model of Human Capacity, this was the most dominant way of thinking about disability in the United States during the 20th century,

especially during the last 30 years of it. This is not difficult to understand: The civil rights revolution that began when advocates for African American students insisted that racially segregated education is inherently unequal set the precedent for the disability-rights movement, which began in earnest in the early 1970s when advocates for people with disabilities successfully established the rights to education and habilitation in the least restrictive (most normal) settings. The core concepts associated with this model are **antidiscrimination, autonomy, liberty, privacy and confidentially, integration, cultural responsiveness, service coordination and collaboration, empowerment/participatory decisionmaking, professional and system capacity-building,** and **classification.**

The Model of Public Studies contains six submodels: *law, political science and philosophy, political economy, demographics, public administration,* and *social welfare.* None is entirely separate from the others; in fact, they tend to overlap significantly.

The law submodel is concerned with the rules of a community-particularly the rules that derive from governments and their enforcement. It regards disability as an unalterable trait that thus should not be the basis for invidious treatment by governments; this is the core concept of **antidiscrimination** and is expressed in Section 504, the Americans with Disabilities Act (ADA), and IDEAs zero-reject principle.

The law submodel also regards disability as a condition that should evoke a positive response by government. As such, its concerns are with the substantive rights and entitlements of people with disabilities and their families, and with the procedures whereby those rights and entitlements are made available and their denial is remedied. One need look no farther than IDEA, Section 504, and ADA ("reasonable accommodations"); the Social Security Act (especially the titles related to income-support and health-care, i.e., Medicaid, Supplemental Security Income, and Social Security/Disabled Individuals-Medicare); the Rehabilitation Act (vocational rehabilitation services); and the Assistive Technology Act of 1998 (access to assistive technology) to find examples of the "positive" law submodel. In the positive law provisions one finds the core concepts of **autonomy,   integration,**

empowerment/participatory decision-making, and arguably, **privacy and liberty.**

Political science is the study of how governments work (the practice of government) and of the institutions of government; political philosophy is concerned with how to deploy or limit public (governmental) power so as to maintain the sanctity and quality of life of the governed. The political science and philosophy submodel conceptualizes disability as a human condition that should be addressed through political processes and that justifies, or does not justify, various governmental responses.

Accordingly, some practitioners of this submodel are concerned with whether the majoritarian democratic processes are available to people with disabilities and their advocates, and, if so, how and with what results. Other practitioners are concerned with the nature and extent of the claims that people with disabilities legitimately may make on others and on the body politic; their issues are ones of the philosophy of government as applied to people with disabilities. Whatever the precise concern of the political scientist, the core concepts involved in this area are **antidiscrimination, autonomy, privacy and confidentially,   liberty, empowerment/participatory decisionmaking,** and **classification** (beneficiary $\rightarrow$ [i.e., eligibility] $\rightarrow$ determinations).

In disability law, all statutes that create claims (rights and entitlements), and the bases on which such claims are justified or advanced, express something about political philosophy. The same is true of concerns about many other issues:

- majoritarian decision-making and remission to majoritarian processes (see, e.g., *Parham v. J.R.* and *Olmstead v. L.*C., where certain aspects of disability policy were settled by the U.S. Supreme Court but where other aspects were left to state legislatures to address);
- the principles of federalism and separation of powers (*Alden v. Maine, Kimel v. Board of Regents,* and *University of Alabama v. Garrett*);
- the principle of judicial deference to professional judgment, also known as the doctrine of presumptive validity (*Board of Education v. Arline, Board of Education v.*

Rowley, Bragdon v. Abbott, Cedar Rapids Community School District v. Garret F., Irving ISD v. Tatro, Southeastern Community College v. Davis, and *Youngberg v. Romeo*); how the claims and interests of one group of individuals are resolved when they conflict with the claims and interests of other groups of people (as in the school-safety laws and decisions, e.g., *Honig v. Doe* and IDEA, 20 U.S.C. § 1415(k)); and

- "zones" of privacy and the relationship between private family decision-making and the public interest (as in IDEA provisions condoning parental placement of students with disabilities into or within special education or in the recent case of *Troxel v. Granville* that upheld the parental right to refuse visitation by grandparents).

Political economy is the study of the ways in which economics and government politics interact. The political economy submodel addresses disability from the bases of (a) the allocation of resources in the public and private sectors of a national or subnational economy and (b) the maximization of effectiveness, efficiency, and choice (responding to the needs and preferences of individual consumers). It comes into play in such diverse arenas as the following:

- decisions to include some people as beneficiaries of programs and thereby to exclude others,
- Congressional resolutions calling for "full funding" of IDEA,
- the arguments around "unfunded mandates" (such as Section 504 and ADA's antidiscrimination provisions),
- the debates over near-term and long-term costs and benefits of educating or providing services to people with disabilities, decisions about how to allocate education funds (e.g., the provision in § 1413 (a)(2)(C) of IDEA to allow local educational agencies to use federal funds to reduce their local contributions or to improve systems of special and general education-these being provisions that blunt local opposition to special education and that create

incentives for general education placements), and

- decisions to have federal funds for special education allotted based on U.S. Census data and poverty levels (20 U.S.C. § 1411(e)-a policy that acknowledges disproportionate placement of poor students into special education and the co-prevalence of poverty and disability).

For this submodel, **antidiscrimination** and **classification** are the most obviously involved core concepts.

Demographics is the study of human populations, including their size, growth, density, and distribution, and it relies on statistics concerning birth, marriage, age, income, disease and disability, and human life. This discipline is concerned with population trends and the distribution of people throughout the nation or parts of the nation.

The incidence and prevalence of disability and where people with disabilities and their families move and why are especially relevant factors in this discipline. When policy leaders identify certain "magnetic" school districts as attracting a disproportionately large number of students with disabilities (because the districts offer a particularly desirable level of services), or when they grapple with population projections (such as those that attend the increase in the number of students with autism or attention-deficit/hyperactivity disorder, the number of "Baby Doe" children who survive into their school-age years, or the number of persons with disabilities or elderly who claim SSI/Medicaid or Medicare benefits, respectively), they are discussing demographics. When they acknowledge that some service-provider districts (whether entire states or local/regional districts such as local educational agencies) are more or less resource-rich than others (the "zip code" factor),they are speaking in terms of geography (and of political science, as well). In this submodel, the core concepts are **antidiscrimination** and, to a lesser degree, **individualized and appropriate services** and **service coordination and collaboration.**

Public administration is the study of government organizations and their relationships to other government organizations; it is

concerned with how these organizations work and how they can be made more effective and efficient in carrying out the responsibilities assigned to them by appropriate branches of government. This submodel addresses how policies are administered, that is, how authorized services are implemented and why those *who* are charged with implementation act in various ways when providing or denying services to people with disabilities and their families. Public administration enters the policy realm in various forms, often under IDEA: School improvement grants (20 U.S.C. §§ 1451-1456), the emphasis on integrated research-training-dissemination capacities (20 U.S.C. § 1461), and the provisions for comprehensive systems of personnel development (20 U.S.C. §§ 1451-1456) reflect a concern with the administration of services. Related to public administration are the core concepts of **capacity-building** (at the system level), **service coordination and collaboration, individualized and appropriate services**, and **accountability.**

Likewise, efforts to create wrap-around programs for students with emotional disabilities and their families (under the Children's and Communities Mental Health Systems Improvement Act) or initiatives to establish intersector/agency, school-linked, or community-linked integration of services also reflect concerns about the administration of public programs. The most relevant core concept is **coordination and collaboration,** although **empowerment/ participatory decision-making** comes into play as well.

Social welfare is the field of human service that is generally aimed at enriching and enhancing individual and group development or at alleviating adverse social and economic conditions. This submodel proceeds from a purposefully "caring" or "empowering" perspective about people with disabilities and their families. Thus, the principle of human investment is reflected in IDEA and especially in its provisions for an appropriate education (one that builds on the student's capacities while it also ameliorates his or her disabilities), and the principle of empowerment (or at least of shared decision making) is reflected in IDEA's provisions for parent and student participation in decision-making (as reaffirmed by the Court's decision in *Board of Education v. Rowley)*. In this arena, the concern is with the core concepts of **autonomy, privacy and confidentially, liberty, integration, cultural responsiveness, empowerment/participatory decision-making,** and **classification.**

Model of Cultural Studies

This model approaches disability and the role of the individual and family affected by disability from the perspective of how they are viewed within their particular society. Unlike the Model of Human Capacity Studies, it is only very tangentially, if at all, concerned with understanding the causes of disability that may lie within the person and thus with the interventions that maybe addressed specifically and sometimes solely to the individual. Instead, it is more concerned with how people with and without disabilities regard the fact of disability, with how disability is conceptualized by various cultures, and with how disability is expressed or portrayed through the various modes of expression available to a culture or group of people. The core concepts associated with this model are **cultural responsiveness, classification, family integrity and unity, family centeredness, autonomy, liberty,** and **protection from harm.** There are five submodels: *cultural anthropology, sociology, literature, the performing arts,* and *history.*

None of these submodels, however, seems particularly useful to those who generate, implement, or evaluate policy. Instead, each seems much more useful to researchers (particularly those outside the disability studies field) who want to understand the nature and purpose of policy as it applies to people with disabilities and their families. Thus, these submodels are explanatory rather than directive.

Cultural anthropology is the study of human cultures and specific societies; it is concerned with their social structures, language, religion, art, and technology. In terms of disability, this submodel seeks to understand how and why a culture responds to disability. For example, in regards to language, consider how the term *retardates* has been superseded by the phrase *persons with mental retardation* and how such

words as *idiot, cretin, fool, lunatic, madman,* and *imbecile* have morphed from use in the scientific community to a general usage that carries powerful pejorative meanings. Likewise, in art, compare Velasquez' compassionate treatment of disability [dwarfism, regarded as a disability in the 17th century] in his *Las Meninas* and *The Dwarf of Don Juan Calabazas,* and Goya's latter-year paintings of the blind and deaf and arguably intellectually impaired peasants, with Picasso's disdainful treatment of the skeletal *Madman/El Loco.*

Cultural anthropology thus relates to the meanings that society gives to impairments and by extension to the structures of society. Specifically and contemporaneously, it relates to discussions about such IDEA issues as who has power in the schools to include or exclude a student from special education, attach a particular disability label to the student, make decisions about a student's program of study (the Individualized Education Program [IEP]), or determine the degree of access to the general curriculum that a student will have. It also comes to bear in the IDEA requirement that a student's IEP team must give special consideration to a student's hearing impairment and to that student's need to associate with teachers and peers who are deaf or hearing impaired (20 U.S.C. § 1414(d)(3)(B)). This is an acknowledgement that specialized modes of communication among individuals who are a deaf or have a hearing impairment is a cultural trait that is not dissimilar to other linguistic traits, and that those who use various specialized languages such as American Sign Language are members of a subculture and have every right to associate with each other rather than being required to assimilate into a speaking world. When courts defer to the judgments that professionals make about who has a disability and what the consequences of that decision are for the person and for others (see the cases cited above, under the Public Studies Model), they are affirming the power that professionals and their "guilds" have.

Sociology is the study of the origin, development, and structure of societies and the behavior of individuals and groups. Under its large umbrella fall such disciplines as "American studies" and its associated "women's studies" and "disability studies," each of which is concerned with power, status, and the role of unalterable trait in the assignment of power and status within any given society at any particular time. Accordingly, it is proper to analyze IDEA (especially its parent-and student participation provisions [20 U.S.C. § 1414(a)-(d)] and the rights that professionals have to classify a student into or out of special education and to write an IEP for a student [20 U.S.C. § 1414(a)-(d)]) as an exercise in power and an expression of power relative to the traits of an individual. Likewise, when Section 504 and ADA prohibit discrimination based solely on the unalterable (disabling) trait of an individual, they reflect the concern of sociologists with the allocation of power within society.

Literature deals with the written and oral expressions of ideas and experiences, including ideas about disability and people with disabilities, whether written from an "objective" or "outside" perspective or from a personal, subjective, and "inside" perspective. These expressions are both reflective and directive; they reflect what a culture thinks about disability and they shape that thinking as well. In shaping that thinking, they influence policy concerning people with disabilities.

To read Dalton Trumbo's antiwar polemic *Johnny Got His Gun* (1970), Carson McCullers' *The Heart Is a Lonely Hunter* (1940), David Keyes' *Flowers for Algernon* (1966), H. G. Wells' *The Country of the Blind and Other Stories* (1996), Herman Melville's *Moby Dick* (1999), John Steinbeck's *Of Mice and Men* (1937), Dylan Thomas' *The Hunchback in the Park* (1957) or even Ken Kesey's *One Flew Over the Cuckoo's Nest* (1962) is to read the thoughts of an "outsider" about physical disability, deafness, blindness, mental retardation, or even psychiatric disability because each is written by a person who does not have a disability. Indeed, to read the Court's decisions as "literature"-as the written expression of the Justices' ideas and experiences-is to have a different understanding of how they frame disability (see, for example, the "pro-feminist perspective" in *Bragdon v. Abbott* and the "pro-capitalist perspective" in *Sutton v. United Airlines).*

Moreover, to read the postmodern literature that is the direct expression of the voice of people with disabilities (Kingsley & Levitz, 1994; Rousso,

O'Malley, & Severence, 1988; Williams, 1992) or their families (such as A. P. Turnbull & Turnbull's *Parents Speak Out,* 1978; Boggs, 1976; Buck, 1950; Dybwad, 1990; Meyer, 1995,1997; Miller, 1994; Powell & Gallagher, 1993; Santelli, Poyadue, &Young, 2001; Turnbull, 1996) is to read the "insider" perspective. Neither perspective is inherently more valuable than the other in terms of how it shapes a culture's perspective about disability and the public policy response to disability. Some works may be more persuasive, but that fact does not make other writing less valuable.

The performing arts includes theatre, radio/TV/movies, painting, sculpture, music, dance, and other comparable professions and means for expressing what the artist believes, feels, and wants to communicate. As in literature and disability studies, the portrayal of disability by people who do not have disabilities and by those who do have disabilities or have personal experiences with it provides clues into and shapes how a society responds to the fact of disability. The National Theatre of the Deaf is a self-reflective cadre of performers. Such plays as *The Miracle Worker* (Gibson, 1957; about the deaf: blind Helen Keller), *Children of a Lesser God* (Medoff, 1982; also about deafness), and *The Elephant Man* (Montagu, 1971; about physical disability/facial disfigurement), and even popular movies such as *Rain Man* (Guber & Levinson, 1988; about autism), tell their viewers about disability and shape their viewers' attitudes-and perhaps their responses-to policy issues.

History has to do with the understanding of (i.e., the interpretation and "sense making" of) the past, of the events, individuals, trends, and movements that have had a significant impact on the past and will affect the future. It encompasses many different kinds of study-economics, politics, biography, and, of course, the history of ideas and of professions. History in the disability context is especially concerned with the ways in which people with disabilities and their families have been regarded and treated. Thus, such seminal works as Burton Blatt's exposes *(Christmas in Purgatory* [Blatt & Kaplan,1974], *Exodus From Pandemonium* [1970], and *The Family Album* [Blatt, McNally, & Ozolins, 1978]; Erving Goffman's *Stigma* (1986) and especially his *Asylums* (1961); David Rothman's

The Discovery of the Asylum (1971); Joseph Shapiro's *No Pity* (1993); and J. David Smith's *Minds Made Feeble* (1985) play an important role in chronicling society's treatment of people with disabilities and in shaping policy responses to disability.

Model of Ethical and Philosophical Studies

This model is concerned with the ethics and philosophies that shape the Cultural Studies and Public Studies models. Ethics is the study of moral standards and how they affect individual and group conduct. Its concerns are with the "right and wrong" of decisions about people with disabilities and their families, that is, about the morality of decisions affecting them. The core concepts associated with this model are **protection from harm, prevention and amelioration, autonomy,** and **cultural responsiveness**.

Theology is the study of religion, and religion refers to people's beliefs and opinions concerning the existence, nature, and worship of one or more deities and those deities' intervention in the universe and in people's lives. Religion is concerned with how people think about deities and how that thinking affects their behavior toward people with disabilities, their families, and the societies in which disability exists. Under this area fall debates about "wrongful life" and "wrongful birth" cases, about the quality and sanctity of life, about the essential attributes of being human, and about the rightfulness/ wrongfulness of aborting a fetus diagnosed as having a disability or at risk of being born with a disability. These debates are cast in terms of what is "morally/ethically right" or what "God" commands our personal, societal, and policy responses to be.

Like the Cultural Studies Model, this model shapes one's understanding about the existential *or* metaphysical meaning of disability. Unlike the former, however, it does apply to policymaking, *policy* implementation, and policy evaluation. It requires the policy leader, administrator, and researcher/ evaluator to ask whether the policy at issue sufficiently reflects the "right" (the ultimate right, not the legal right) that ethical precepts or religious ethics value. It should be noted that there

are varying interpretations of what is right and not right to do as a matter of religious or ethical/philosophical practice, and that there are disagreements even within the same religious tradition about what is right. A question that deals with the ultimate right/wrong invokes other questions about outcomes. If some action is ultimately right, what consequences flow from it? Such a question (in terms of disability) can be answered by referring to the core concepts: If they are the benchmarks for results, then what is right is, in part, what advances these core concepts.

Model of Technology Studies

This model is concerned with the "built" or "constructed" environment, with the physical world that people with disabilities and their families inhabit. The core concepts associated with this model are **antidiscrimination, productivity, integration, appropriate and individualized services,** and **capacity-building.** This model is similar to the Human Capacity Studies Model and the Public Studies Model in that it has been applied directly in disability policy-making and service provision. Accordingly, those who come to disability policy from the technology model background will want to ask whether the model and its application advance one or more of the core concepts. As in the other models, the effort is to identify the outcomes that result from the core concepts and to measure the policy in question according to whether it is appropriate to advance a core concept (or more than one) and whether the policy does so. (These are the questions we address in the article on tools.)

Three submodels of this model are *architecture, industrial engineering,* and *ergonomics.* Traditionally, architecture has been the discipline primarily involved in this model, with concerns related to how and why physical structures are created and whether they afford or deny access for people with disabilities. Industrial engineering is the study and practice of designing industrial operation, and ergonomics is the study and practice of how a workplace and the equipment used there can best be designed for comfort, safety, efficiency, productivity, and transportation/mobility of people with disabilities.

These sciences are concerned with access to the structures in which people carry out various activities and with the immediate "inside" environments in which people with disabilities live, work, learn, recreate, and carry out other activities with the usability of the exteriors and interiors of a structure by the person with a disability. They are manifest in the "universal design" principle and create person-friendly structures and environments, applying some of the science of space exploration (where the space capsules must be carefully designed to accommodate the astronauts and their activities) and some of the science of industrial engineering (such as how to maximize work production) so as to be accessible to and effective for a person with a disability. These aspects of this model are responsible for the accessibility and reasonable accommodations provisions of Section 504 of the amendments to the Rehabilitation Act and of ADA. This model is associated with the core concepts of **antidiscrimination** (that is, with "access") **and integration** and **productivity** (that is, with the results of access).

Technology has two facets, the first being assistive technology and the second being computer technology. Both are concerned with assisting the person with a disability and the person's caregivers (including families and others) to use or adapt off-the-shelf devices or to create customized devices and services, including computers; the purpose of the devices and services is to restore lost or impaired functions, to prevent other functions from deteriorating, and to compensate for functions that cannot be restored or preserved. In policy, the so-called "tech act" (Assistive Technology for Individuals with Disabilities Act), the related-services provisions of IDEA, and the reasonable accommodations provisions of Section 504 and ADA express this aspect of the Technology Studies Model. The concern is with the core concepts of **productivity, integration, individualized and appropriate services, capacity-building** (that is, building the capacity of the individual, through individualized services, to be productive and integrated), and **prevention** (in its secondary and tertiary meanings).

Conclusions

We have argued that there are various ways of thinking about disability; various models that reflect how any one of us conceptualizes disability as a condition, how any one of us responds to that condition in others, and how any one of us and, ultimately, how all of us, through the policy-making processes-respond to people with disabilities and the claims they assert. We have based these models in part on the perspectives that our respondents shared as they engaged in focus groups or individual interviews related to the core concepts of disability policy. We also have based these models on the statutes and cases that we set out in the Matrix.

By no means have we been comprehensive in describing the policies (statutes and cases) that attach to these models or in exemplifying the models. We have, however, suggested that the perspectives of policy leaders and of their constituents do ultimately reflect how they--and how "we the people"--think about disability and thus how we structure our public policy responses to it and to people who have disabilities (or, more accurately, to people we regard as having or not having disabilities). The thrust of our argument is simply that one cannot understand the understructures of the core concepts of disability policy without also acknowledging and beginning to understand the ways in which we and others think about disability.

Finally, we have argued that for each of the models, there is a practical issue: How does the model and its way of thinking relate to the outcomes for people with disabilities and their families? Such a question assumes that individuals who deal with policy in any aspect with these various models in mind will, deliberately or not, reach some conclusions about people with disabilities, their families, and the policies that should apply to them.

In reaching these conclusions, that is, in coming to the "so what" challenge, they can advance the interests of people with disabilities and their families by connecting to the core concepts. Is it appropriate for their thoughts about disability to relate to a core concept? We think so, because thinking implies action, and action in policy should be related to what is core about disability and family. If the answer is "Yes, it is appropriate for what I am thinking to be connected to a core concept," then the next question will be: "How well do I connect my thoughts to my actions?"