

A Taxonomy for Organizing the Core Concepts According to Their Underlying Principles

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This article organizes and classifies the 18 core concepts. There are nine overarching principles into which the concepts fit: life, liberty, equality, dignity, family as foundation, community, capacity, individualization, and accountability. These in turn reflect three approaches to policy: the Constitutional approach, consisting of the principles of life, liberty, and equality; the Ethical approach, consisting of the principles of dignity, family as foundation, and community; and the Administrative approach, consisting of the principles of capacity, individualization, and accountability. There is also a set of Professional principles, which the article illustrates with examples from the field of medicine/health care. Finally, the article demonstrates how the organization and classification of the core concepts create a wholistic, unified approach to policy.

Taxonomies in General

To date, the most ambitious recent attempts to organize the core concepts of disability policy have been conducted by a researcher (Braddock, 1987) and a policy analyst (Silverstein, 2000). In his article on the federal statutory disability policy framework, Silverstein placed the approach embedded in the Americans with Disabilities Act of 1990 (ADA) as the core precept: Disability is a natural part of human experience that in no way diminishes a person's right to participate fully in all aspects of life. He then argued that there are four overarching goals of federal policy:

1. equality of opportunity,
2. full participation,
3. independent living, and
4. economic self-sufficiency.

Silverstein also identified various methods of administration for implementing the four goals, including monitoring; procedural safeguards; accountability; representation; coordination; privacy; and racial, ethnic, and linguistic diversity.

Our researcher respondents suggested various other ways to organize the core concepts. (See the article in this issue on the core concepts for a description of our methodology and our reliance on researchers as respondents.) Some respondents suggested that we distinguish between what a person has or seeks (e.g., civil rights or liberty) and how a person receives

that which he or she seeks (e.g., empowerment, individual services). Others suggested that we group the core concepts according to legal rights (e.g., civil rights, liberty, and accountability), independence (e.g., empowerment), privacy and services (e.g., individualized services), and family interests (e.g., family centeredness). Still others suggested that we categorize the concepts by natural or constitutional law (e.g., liberty and independence), entitlements (e.g., individualized services and inclusion), and hortatory admonitions (e.g., cultural responsiveness). Some respondents suggested grouping by generic or universal concepts applicable to all individuals (e.g., civil rights and independence) and those that apply to only people with disabilities (e.g., individualized services). Finally, others suggested that we add management concepts (e.g., accountability and resource allocation/rationing) to some of the categories.

A New Taxonomy

After considering the benefits of all these approaches, we have identified nine principles as the basis for our taxonomy. We have also grouped the principles into three larger categories. The nine principles are as follows:

1. Life
2. Liberty
3. Equality

4. Dignity
5. Family as Foundation
6. Community
7. Professional and System Capacity-Building
8. Individualization
9. Accountability

The categories are as follows:

- **Constitutional Principles** (Principles 1-3)
- **Ethical Principles** (Principles 4-6)
- **Administrative Principles** (Principles 7-9)

Several reasons support our decisions and our taxonomy. First, in its own way, each category of principles is important to the development of good domestic policy in the United States. Three of the nine principles--Life, Liberty, and Equality (the Constitutional Principles)--are foundations of democratic government. Accordingly, they are reflected in various provisions and doctrines of the Constitution of the United States. This is important for at least two reasons: First, the Constitution is the nation's fundamental law, the benchmark by which all other laws are judged. Second, it also expresses our cultural, political, philosophical, and legal traditions.

Three other principles--Dignity, Family as Foundation, and Community (the Ethical Principles)--reflect widely held societal ethics, values, beliefs, and ideals. In order for a policy to last, it must conform, or at least not conflict, with the values of the society in which it is administered. In the end, real change is created through people, not policy. If a law or program conflicts with the values and beliefs of the people, it will not engender long-term change; similarly, change is most easily accomplished when policy speaks to the hearts and minds of the people it will govern. The last three principles--Capacity, Individualization, and Accountability (the Administrative Principles)--reflect the qualities (capacity), foci (the individual beneficiaries), and procedures (legal and other accountability standards) that must be included in any policy to support its successful implementation.

Our second reason is that our approach synthesizes the literature, the statutes and case law, our respondents' suggestions, and our own judgment on how best to connect the core concepts with the Beach Center's analytical framework. As Figure 1 illustrates, this framework connects the core concepts to family quality-of-life outcomes through the mediating effects of partnerships. Particularly because family quality of life seems to relate powerfully to six of these principles (Life, Liberty, Equality, Dignity, Family as Foundation, and Community) and also because partnership seems to relate strongly to the three others (Capacity-Building, Individualization, and Accountability), we believe these principles are especially appropriate to use as a taxonomy for understanding family-focused disability policy.

Third, the Constitutional and Ethical Principles are generic and universalistic, as distinguished from being specialized and exceptionalistic. That is to say, they apply to all citizens, not just

those with disabilities and their families. Through these principles, our approach emphasizes the essential sameness of families and individuals, whether or not they experience disability. For example, when we assert that Dignity is a principle affecting people with disabilities, we also regard it as a principle affecting people without disabilities; the same applies to Life, Liberty, Equality, Family as Foundation, and Community.

The Administrative Principles are also generic and apply to persons with and without disabilities, but disability makes a difference in the ways in which these principles are operationalized. For example, Individualization clearly is a principle applicable to the education of students with disabilities, yet it is not nearly so applicable to students without disabilities. Special education is the individualized education of a few (or even one); general education arguably is education of the masses. Individualization, however, does apply when students in general education are themselves sorted into categories such as "Title I" children (economically disadvantaged) or "gifted and talented" students. Similarly, individualization is indispensable when providing mental health services or physical health services to a child with a disability, but it also applies when those same services are provided to children who do not have disabilities. By the same token, the principles of Capacity-Building and Accountability apply to children with disabilities and their families and to children who do not have disabilities and their families: All service systems must have the capacity to deliver appropriate services and all are held to account for delivering (or not) the services to which their beneficiaries are entitled. Thus, although the Administrative Principles are universalistic, they apply differently to different (disabled and nondisabled) populations.

Accordingly, our approach allows family policy analysts to illustrate how disability policy fits within the framework of generic policy and how generic policy may be tailored to benefit both families and individuals affected by disability. For example, the extent to which individuals without disabilities and their families are affected by policies and services that enlarge or diminish their interests under the principles of Life, Liberty, Equality, Dignity, Family as Foundation, and Community sets the standard for the provision of services to individuals with disabilities and their families. If the policy or service delivery norm is inadequate for individuals without disabilities and their families, it presumptively will also be inadequate for individuals with disabilities and their families. Indeed, it can be inadequate for them even if they have access to the nondisabled norm, for, as we point out below, equal opportunity does not always result from exactly equal treatment. Moreover, by incorporating these generic principles in our taxonomy, we make it possible for policy analysts primarily interested in disability matters to use the taxonomy framework to evaluate both disability policy and a generic family; we provide them with more powerful armamenta for analysis and advocacy.

Fourth, our approach is wholistic and therefore functional in that it can be used to focus on any of the

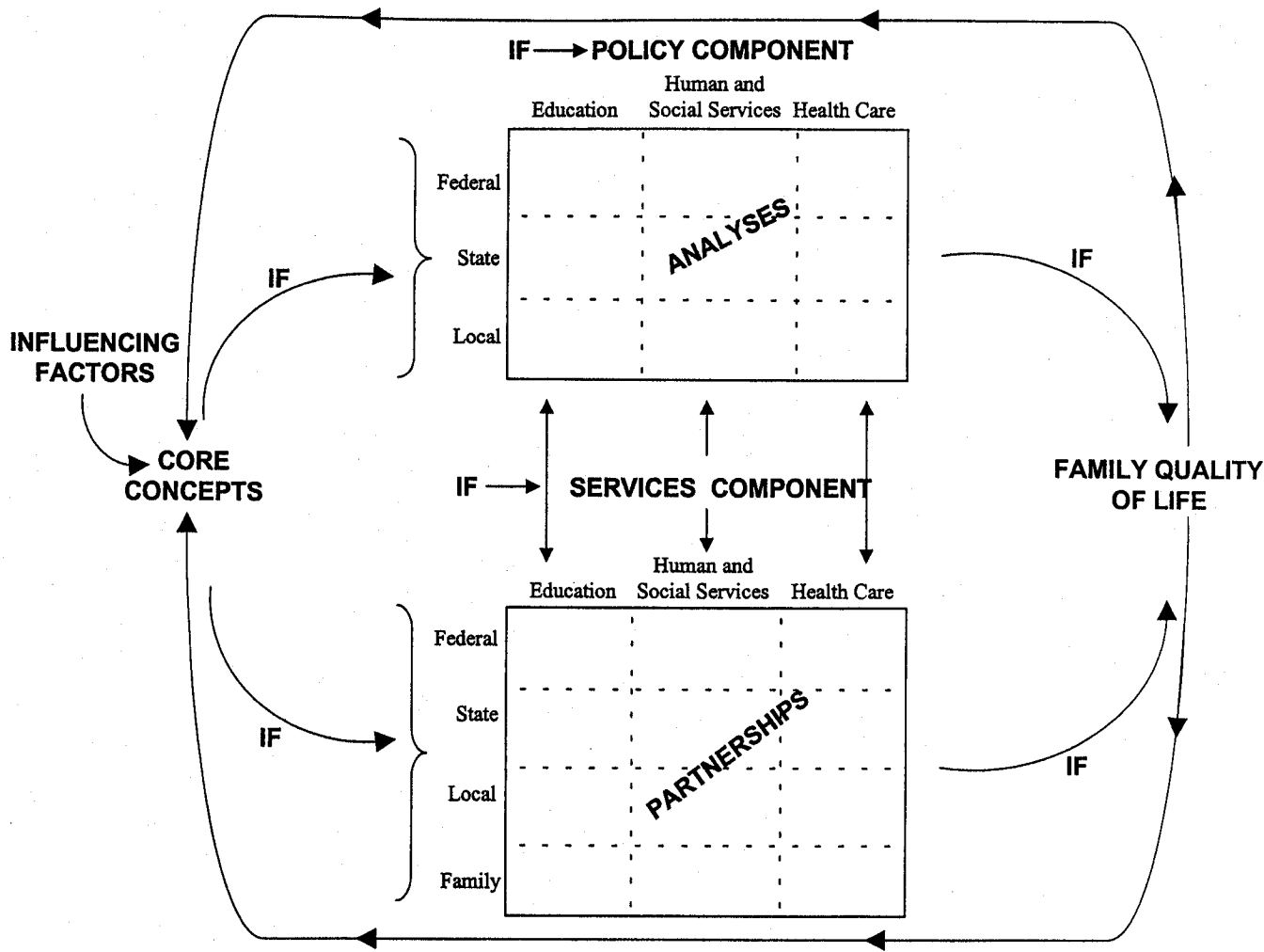


FIGURE 1. Analytical framework for the research endeavor.

components of the other taxonomies suggested by our respondents or in the literature on disability policy's core concepts. Further, our approach is not discipline-specific; it is equally applicable in the fields of health care, social service, and education and in the provision of services in those fields to people without disabilities and their families.

Fifth, our taxonomy allows us to illustrate how the Constitutional Principles, Ethical Principles, and Administrative Principles relate to certain principles we call the Professional Principles. In our analysis, we used the Professional Principles that derive from research on health policy that was carried out at the Beach Center as part of its grant to study the effects of policy on families (Umbarger, 2000). These health-care principles are Beneficence ("do good"), Nonmaleficence ("do no harm"), justice (access, accountability, equity, and dignity), and Autonomy (patient and physician consent). We probably could have made a similar point by connecting the Constitutional and Ethical Principles to principles that guide the fields of social welfare and education, but we have not yet engaged in that kind of research and analysis.

Sixth, the Constitutional, Ethical, and Administrative Principles can be used in decision-making about who benefits from public policy and to what degree the beneficiaries reap rights or entitlements as a matter of public policy. In turn, decisions about who is or is not a worthy beneficiary of certain degrees of public support always translates into resource-allocation decisions, and these then become fiscal-resource allocation decisions. Fiscal Principles invariably affect public policy. We take that into account in our taxonomy by allocating a role to the Fiscal Principles, just as we allocate a role to the Professional Principles.

Frankly, we have not yet explicated all of the components of the Fiscal Principles; however, several come readily to mind. Money plays two obvious roles:

1. It influences the decision as to whether a policy is affordable, and here it plays a role in policy generation.
2. Its availability or lack thereof affects how generously and well, or how scantily and barely, policy is implemented; here, it plays a role in policy implementation.

But there is more to money than these roles. Cost-benefit and cost-efficacy calculations are made when policies are developed, implemented, and evaluated. It is inevitable that the claims of some constituencies will clash with the claims of other constituencies. In balancing these competing equities, money is a determinant: Who gets what and how much they get sometimes depends on how much they spend to advance their claims and how fundable their claims seem; the legal and moral worth of their claims is often measured by how much money is allocated to them in the policy-making process. These, then, are some of the fiscal factors that constitute the Fiscal Principles.

Finally, our taxonomy is useful as a guide for developing or reforming any policy and for ensuring that the policy will (a) be acceptable on majoritarian-democratic grounds (appealing to the majority of a legislature and to the legislators' constituents), (b) produce outcomes for designated beneficiaries (such as individuals with disabilities or their families), and (c) be implemented by service-delivery systems.

A Heuristic Model

To illustrate our framework of Professional, Constitutional, Ethical, Administrative, and Fiscal Principles, we have provided a figure—a "ramp" (an apt metaphor for disability policy)—to illustrate our text; as we elaborate on our explanations in the text, we will build "the ramp" (using subsequent figures) so that it continues to illustrate the principles, their relationships to each other, and their relationships to the core concepts.

This ramp (see Figure 2) fully illustrates our argument that the principles and the core concepts are indivisible from each other. It is too much to expect at this point that a careful reader will be able fully to appreciate the ramp, for it contains so much that we have not yet explained. We ask the reader to bear with us, however, as we deconstruct the ramp, justify its component parts, and then explain the ways in which we created it as we gradually and step-by-step reconstruct it (as will be shown in Figures 3 through 9.)

It is worth noting that although each core concept and each principle can be separated from the others for the purpose of identification, definition, exemplification, and utility in policy analysis, there is undeniable connectivity among each and every one of them. They constitute a whole theory of disability policy.

As we discuss the Constitutional, Ethical, and Administrative Principles, we will also discuss each subsumed principle (e.g., the Constitutional Principle of Life). We will start by identifying the core concepts that are primarily related to each principle and pointing out how they are related to it: for example, how the core concept of **prevention and amelioration** is related to the principle of Life. (The core concepts will be in boldface throughout this article.)

Next, we will examine the relationships between the Constitutional and the Ethical Principles. This relationship will

be illustrated in our ramp as the places where the core concepts related to the Constitutional Principles and the core concepts related to the Ethical Principles converge. For example, the core concept of **protection from harm** is related to the Constitutional Principle of Life but is also related to the Ethical Principles of Community, Family as Foundation, and Dignity as those principles relate to Life. Finally, we will discuss the Administrative Principles, the Professional Principles, and their relationship to the core concepts and to the Constitutional and Ethical Principles. We do not discuss the Fiscal Principles here because we have not sufficiently related them to the Analytical Framework and the core concepts.

The Constitutional Principles

As Figure 3 shows and as we asserted previously, some of the core concepts reflect the three Constitutional Principles of Life, Liberty, and Equality. These principles are central to understanding the legal foundation that the core concepts share with generic policy.

A word or two is in order about the Constitutional Principles. What the Constitution "says" or "means" depends on how the U.S. Supreme Court interprets it, and therein lies the challenge for our work: reconciling the Constitutional Principles as they have been expressed in federal statutes and relatively "old" decisions of the Court with the most recent decisions of the Court. As we conducted our early research, we focused on cases decided prior to 2000, as did most of our research respondents. In 1999 and again in 2000 and 2001, however, the Court began to reinterpret the Constitution; kindly put, it asserted the "old" (pre-1935 or so) or "original intent" doctrines of *federalism* and *separation of powers* to strike down provisions of important federal antidiscrimination statutes (see, for example, *Alden v. Maine*, *Alexander v. Sandoval*, *FPPEEB v. College Savings Bank*, *Kimel v. Board of Regents*, *Sutton v. United Air Lines*, and *University of Alabama v. Garrett*).

Accordingly, our statements about the Constitutional Principles are intended to capture the meaning and impact of those principles as the Court has interpreted them traditionally; our statements are not intended to be a precise statement of how the Court currently interprets them. After all, many years have had to pass between the times a core concept is advanced, advocated, and finally adopted. The truly unfortunate aspect of the Court's present decisions is that they signal a retreat from the core concepts. That these decisions also signal a major change in the federal government's role in protecting up-to-now well-settled constitutional rights and in the power of Congress relative to the power of the Court and the states is itself deplorable. That these recent decisions may be the beginning of the end of the liberal welfare state is frightening.

As a result of the Court's decisions of the past 2 ½ years, advocates for people with disabilities and their families have been obliged to seek redress in the state legislatures and state courts. However, we will not address state law and its relation-

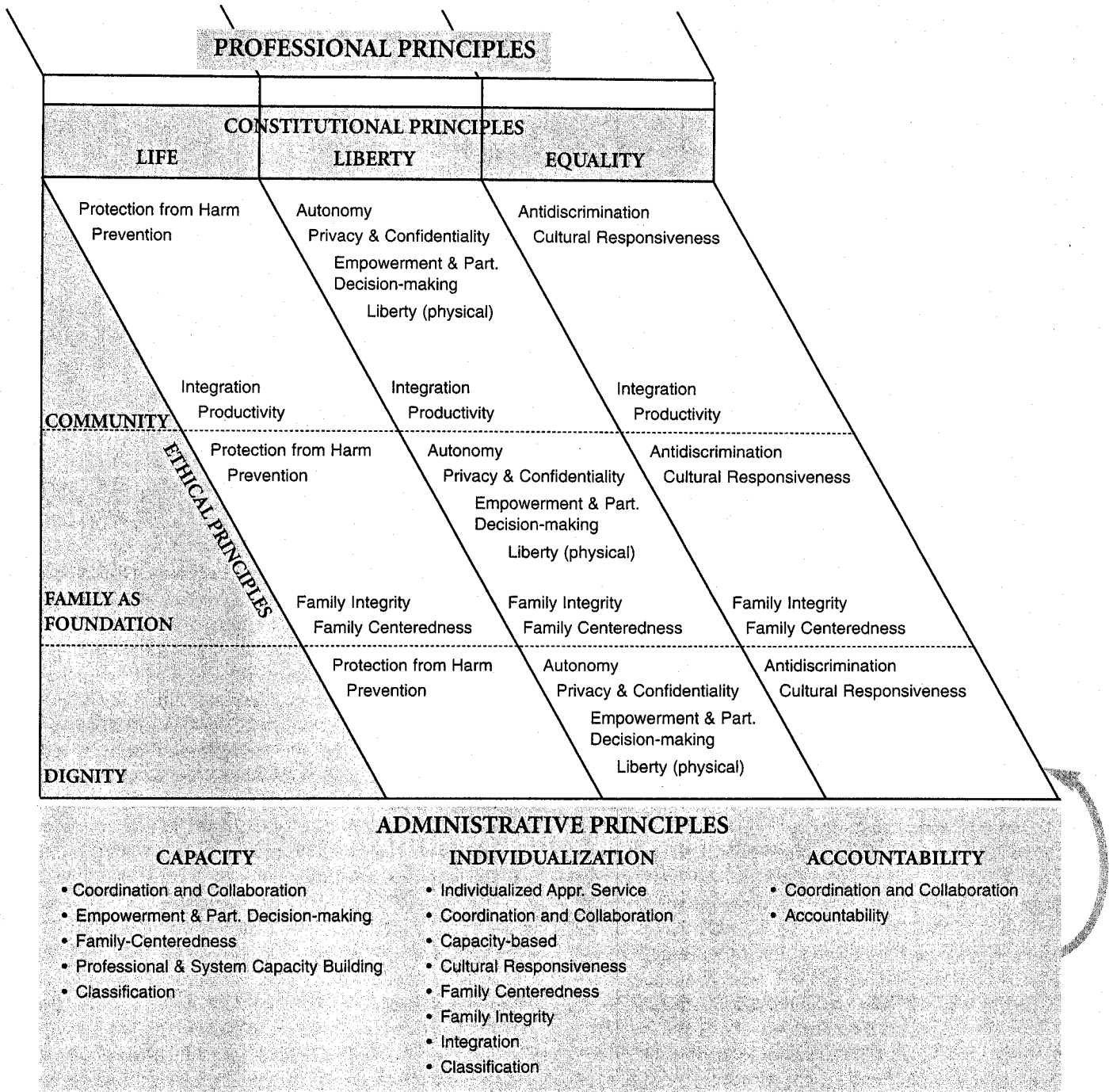


FIGURE 2.

ship to core concepts in the articles in this series. Such a discussion must be reserved for another time.

Life. The Constitutional Principle of Life values human existence. It refers to both the sanctity, or inherent worth, of a person's or family's life and to the individual's or family's quality of life; yet it does so in distinctive ways.

On the one hand, the Constitutional Principle of Life includes the legally enforceable claim against government action that deprives a person of life (liberty or property) without cause (substantive due process) and without a fair process (procedural due process). Inasmuch as life itself is ultimately valuable, the Constitution prohibits the state from taking action to deprive a person of life without cause (arguably, capital crimes

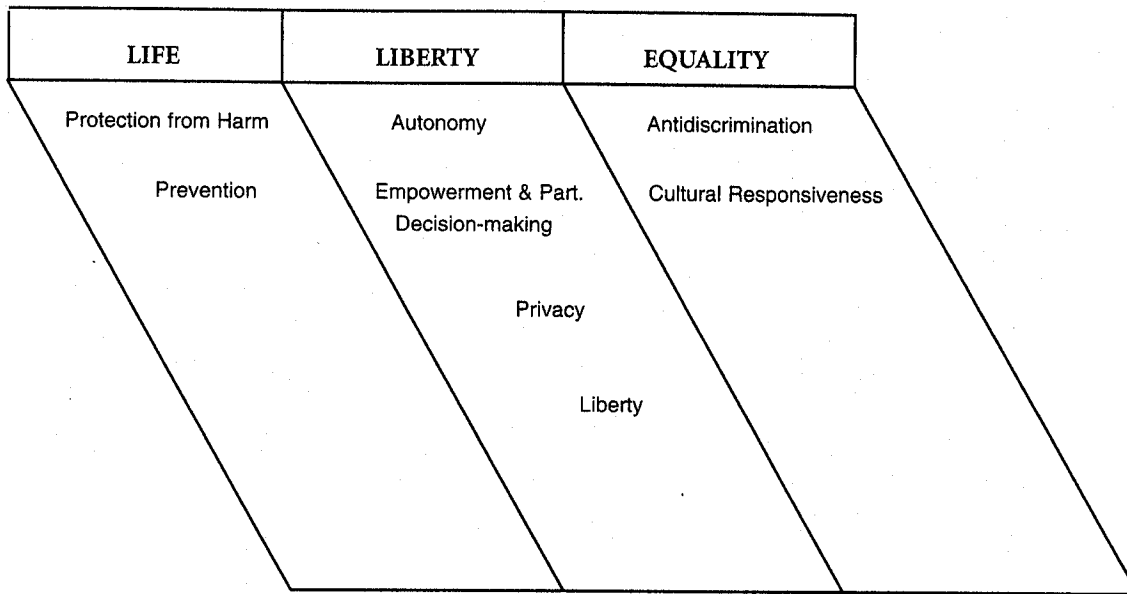


FIGURE 3.

justify capital punishment). Thus, the core concept of **protection from harm** exemplifies this legalistic approach. And the Professional Principle of Nonmaleficence (do no harm) supports it.

On the other hand, there is no explicit constitutional right to a certain quality of life. True, there are claims to certain kinds of treatment at the hands of the state (see the core concept of **protection from harm** and the Court's decisions in *Youngberg v. Romeo* and *DeShaney v. Winnebago*). Because these are enforceable legal claims, they advance the theory that government should not take action that adversely affects an individual's quality of life. Notice the difference: The constitutional claim (substantive due process) is that the government "may not" (in the legal sense that it is generally prohibited from) take certain action. By contrast, the claim to a certain quality of life appears to be based in ethical and political philosophy and asserts that the government "should not" take certain action; indeed, that it "should" take certain kinds of affirmative or positive action to enhance families' quality of life. Here, the claim is to a positive good, to beneficence (to do good): Government has a duty to those citizens who are in need of protection to offer services (including medical intervention) or other reasonable assistance to preserve their lives, prevent the creation or continuance of unacceptable burdens upon the quality of their lives, and take positive action to enhance their quality of life. This is a claim to "the good life" through government action in pursuit of the common welfare. It is a claim that government should protect its citizens from harm, whether at the hands of the government itself or at the hands of private actors. But it is also more than that. It is a claim to a certain governmentally underwritten quality of life. At the very center of the Principle of Life are the core concepts of

protection from harm and **prevention and amelioration**.

Liberty. The Constitutional Principle of Liberty states that everyone within our society is entitled to certain freedoms: freedom of speech and worship, physical freedom (i.e., from unreasonable search and seizure), and the freedom generally to carry on the pursuits of life without undue interference from others--to choose the paths he or she takes in pursuit of life's goals. With whom we associate, where and how we live, what we value, and what we do are all fundamental decisions that the principle of Liberty allows us to make. The government has a duty to refrain from encroaching upon these freedoms and to remedy encroachments from whatever source when they do occur. This kind of liberty is a "negative" liberty: It is freedom from something.

The principle of Liberty also makes these kinds of choices meaningfully available to individuals with a limited capacity to make and carry out their choices; it assists these individuals and their families in pursuing the lives they want to live, without unwarranted interference from others, to be as "free" as individuals who do not have disabilities. This is a "positive" liberty that consists of two elements: *freedom to access resources* and *resources that support freedom*. The goals of both positive and negative liberty are the same: to preserve and promote the core concepts that form the heart of the principle of Liberty: **liberty, autonomy, empowerment/participatory decision-making, and privacy and confidentiality.**

Equality. The Constitutional Principle of Equality stands for the right of each individual to the same access, opportunities, and benefits that other citizens enjoy and can usually take for granted. Equality includes the individual's right to be free of discrimination based on unalterable traits (such as race, gender, or disability) or on protected values (such as one's religion). This principle includes the individual's right to legal

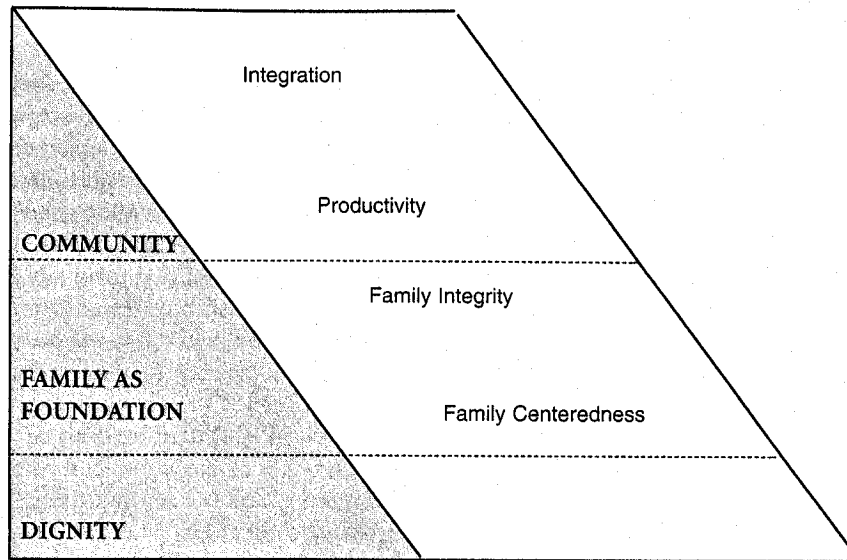


FIGURE 4.

remedies for illegal discrimination. The principle applies to governments and private entities (e.g., public accommodations) that are closely connected to a public interest. Equality reflects a founding principle of democratic government—that all people are created equal in the eyes of the law. This is not to say that everyone is the same or to deny differences between individuals but rather to establish legal equality of opportunity and treatment in spite of individual differences.

In the disability field, this principle has formed the most commonly used and effective strategy for advocating for increased statutory protections and entitlements for individuals with disabilities. Even society's failure to extend the principles of Life and Liberty to individuals with disabilities has been most successfully attacked not solely as a violation of those principles but also as unequal treatment, on the basis that individuals with disabilities were treated differently and less favorably than individuals without disabilities in their pursuit of life and liberty. The antidiscrimination laws such as the ADA, the constitutional challenges such as in the *City of Cleburne v. Cleburne Living Center* case, and many of the goals and outcomes of social programs for individuals with disabilities are couched in the language of civil rights. So, too, are statutes that require agencies to accommodate to people from culturally, ethnically, and linguistically diverse backgrounds. The core concepts that reflect the principle of Equality most intensely are **antidiscrimination** and **cultural responsiveness**.

Interaction of the Three Constitutional Principles. Each of the Constitutional Principles—Life, Liberty, and Equality—interacts with the other two; there is triangular connectivity. For an individual with disabilities to have life (as that term is used in a quality-of-life sense) largely depends on the person having liberty (freedom to pursue the kind of quality of life that the person wants) and equality (the opportunity to pursue). To have liberty, a person must

also have life (be alive and have certain capabilities, even minimal ones) and equality (opportunity), because one cannot be free unless one has the opportunity to be as free as other citizens to pursue the quality of life that one wants. Likewise, to have equality (in the sense of equal treatment and equal opportunity), a person must have life (be alive and have certain capabilities) and liberty (to act, to pursue equal opportunity), and one's liberty indeed has to be comparable to (that is, roughly equal to) the liberty of others.

Each concept thus supports and advances the others; they are mutually reinforcing. Sometimes, of course, they are mutually conflicting; tension can exist among them, requiring trade-offs. Simultaneously maximizing each is desirable but rarely feasible.

Yet, for the purposes of policy analysis, each principle also can be treated as distinct from the others. For example, some policies will be based on equality (for example, antidiscrimination laws) more than on liberty; however, antidiscrimination laws also advance the liberty of people with disabilities to pursue the lives they want to live. Likewise, some policies will be based more on life (for example, protection from harm) than on liberty or equality, yet laws protecting individuals and their families from harm also advance the equal opportunity of those people to pursue the lives they want to lead, that is, to pursue their liberty. Similarly, some laws will be based more on liberty (for example, privacy and confidentiality laws) than on equality or life; yet liberty, in the sense of privacy and confidentiality, is no less valuable to people with disabilities and their families than to people who do not have disabilities and their families.

The Ethical Principles

Our taxonomy also includes three Ethical Principles—Dignity, Family as Foundation, and Community. The Ethical Principles and the core concepts that reflect those principles are set out in Figure 4. We use the term *ethical principles* because

they have to do with what is good and bad, right and wrong, and because they involve an analysis of moral principles and values. Indeed, ethics itself is a discipline concerned with the study of right and wrong and with moral duty and obligation. The word *ethic(s)* refers to a set of moral principles or values and to a theory or system of moral values.

Admittedly, public policy is not always consistent with everyone's ethics or sense of right and wrong. That is not to say, however, that the analysis of policy, especially of disability policy (where so many ethical/moral issues arise—for example, should "Baby Doe," the newborn with obvious birth anomalies, be kept alive, or should physician-assisted suicide be legalized) should ignore ethics and values. Indeed, it is a proud tradition to analyze policy precisely from a value-based perspective, that is to say, from an ethical-moral one (Moroney, 1981; Singer & Gent, 1999; H. R. Turnbull et al., 1986).

Moreover, our data are replete with respondents' references to "right" and "wrong" as measures of policy. Indeed, respondents who are from different disciplines and respondents who have different roles from each other often distinguished the legal/Constitutional Principles from what some of them called (and that we ourselves came to call) the Ethical Principles. For example, as one senior federal official and mother of a son with severe impairments put it, "Policy fails to distinguish between the mechanics of care and the ethics of care." She went on to explain that programs fail to be ethical when they attempt to increase productivity while they overlook an individual's self-determination. Here, the claim is to the principle of Dignity based on the right of self-determination, and the contrast is between the mechanics of care and the ethics of care.

Some respondents also claimed that policymakers fail to ask themselves what policies and practices fragment the families who are so central to the well-being of policy "clients" (people with disabilities). According to these respondents, policymakers fail to understand that support for the family of an individual with a disability translates into better outcomes for that individual and that weakening or burdening the family impedes the achievement of service outcomes.

Other respondents believed policymakers should advocate for normalization, and some asserted that the moral value of the core concept of **integration** compels professionals in the field of disability policy to have a larger vision for the future of the field. "We need to move from a civil rights perspective to a 'welcoming community' perspective," one respondent said, reflecting on both her role as an administrator in a federal agency and her role as the mother of a young adult with a disability. For example, this woman and other mother/administrator respondents in the same focus group said that the disability community needs to be more welcoming of culturally diverse families into its sphere of influence. Here, the respondents' emphasis was on cultural responsiveness within the context of the principle of Community (an Ethical Principle). The various respondents' statements concerning

values led us to conclude that Ethical Principles are crucial to a complete understanding of policy and its analysis.

Still other respondents argued that although the Constitution (as interpreted, see *Youngberg v. Romeo* and *DeShaney v. Winnebago*) creates a right to be protected from harm (and thus involves the core concept of **protection from harm**), it does not sufficiently express the value of regarding the person with a disability with dignity and respect. Likewise, although a statute (Child Abuse Treatment and Protection Act) protects newborns with disabilities from unwarranted denial or withdrawal of medically effective interventions, it does not sufficiently express the sense that the newborn is inherently worthy of being treated with dignity. Again, although the core concepts of **antidiscrimination**, **liberty**, and **integration** all advance the right of the family and person to be members "in" a community and to participate in it, to be "of" the community, they do not clearly assert that there are many grounds on which the "in" and "of" can be advocated.

One ground is that just because the person has a disability and the family is affected by it, there is no basis for segregation and exclusion: Something is inherently and instinctively wrong about trait-based segregation, about condoning the stigma it creates, and about allowing that stigma to attach not just to the person but also to the person's family (see, for example, *Brown v. Topeka Board of Education [1954]* and compare it with ADA: Trait is not a reason for segregation). Another ground is that individuals who have disabilities and their families benefit from being included in communities; their presence advances their opportunities to be productive, to contribute, to be protected from harm, and so on. **Antidiscrimination**, **liberty**, and **integration** thus become not only ends in themselves but also means; they have both ultimate and instrumental value.

Yet another ground is that individuals without disabilities benefit from their association with people who have disabilities. The "benefit to the nondisabled" is, of course, one of the foundations for integration by trait and for the principle of the least restrictive environment (LRE; see, for example, Individuals with Disabilities Education Act of 1990 [IDEA] and H. R. Turnbull, Turnbull, Stowe, and Wilcox, 2000, regarding the values underlying IDEA's LRE principle). Moreover, the benefit-to-others ground is justified on the purely utilitarian points proposed in Bentham's theory of the greatest good to the greatest number: People with disabilities and their families "enrich" those who do not have disabilities. It also is justified on purely Judeo-Christian grounds and on Kant's categorical imperative: To be a member of a community affirms the inherent worth of a person with a disability and the person's family, just as to deny community membership because of disability diminishes the very "human-ness" of the person and the family.

Very simply put, the point is that although the Constitutional Principles or various core concepts express certain moral duties, there are other and equally accurate ways of stating what

is clear about the core concepts, namely, that they reflect a sense of what is right/good and wrong/bad to do for and with families and children with disabilities. To disentangle the legal/Constitutional from the moral/Ethical reflects the data and creates a different, and just-as-valid, way of understanding what is core to the concepts of disability.

There is still another benefit to bringing the three Ethical Principles to bear as tools for policy analysis, and it relates to the insufficiency of the other principles. Constitutional Principles are necessary, valid, and useful, but they carry the analyst only so far. They do not sufficiently express

- a sense that each individual and each family, whether or not affected by disability, is entitled to some measure of respect, worthiness, and dignity;
- the fact that family is the initial and most fundamental social unit; or
- the sense that individuals and families are social beings, that we human beings derive our existence, and the meaning of our lives, from our relationships with others.

Dignity. Dignity is the state of being worthy, honored, or esteemed. The principle of Dignity holds that individuals should not be regarded as expendable, disposable, or inconvenient. Less able does not mean less worthy (H. R. Turnbull, 1976; Turbiville, Turnbull, & Turnbull, 1995). Dignity supports the right of each person to be valued not merely as a life in being but as an individual and member of our society.

Dignity recognizes that every individual asserts a claim to and, simply as a member of the human race and of our society, is in some way or another entitled to respect and justice (however defined). It is a claim to the perception and presentation of each person's worth, recognition of his or her strengths, accommodation for his or her needs, belief in his or her potential, and esteem for his or her efforts (even when those efforts are simply efforts to live).

No protection of the sanctity of an individual's life or improvement of the quality of that life needs to result from an action in order to justify a claim to the dignity that the action affords (i.e., an individual in a coma still has a right to clean sheets). The right to dignity is not conditioned upon any outcome, classification, or contribution and is due to everyone without regard to the existence, cause, extent, or nature of the disability.

Furthermore, dignity requires that we acknowledge the historical stigma behind disability (as exemplified by the historical use of the terms *idiots*, *imbeciles*, *lunatics*, and *morons*); that we recognize the mythologies about people with disabilities (that they are mad, bad, sad, hyper-sexual, or all of these together); that we confront society's propensity toward deviance juxtaposition (simultaneously placing people with disabilities and those convicted of a crime in the same categories for various purposes); and that we understand that stigma,

mythologies, and deviance juxtaposition assault the dignity of persons with disabilities.

There is no single core concept that best exemplifies Dignity, nor indeed does any combination of them or all of them together necessarily and sufficiently express Dignity. Dignity overarches, transects, and undergirds the other principles and the core concepts. It is what we ourselves want from others and what we must therefore offer to others, especially (given their history) to individuals with disabilities.

Family as Foundation. The family is the core unit of society. Most of us are born into and raised within a family. Our family's values often become our own, and in this way we transmit across the generations the ethical and cultural characteristics of our families. Of course, there are exceptions to this generalization, but they do not invalidate this simple proposition: Within this country, the family is an inherently valued social unit (*Troxel v. Granville*) that more than any other factor shapes and influences the lives of people with and without disabilities. The family is the very first, often the most enduring, and arguably the most important entity to which people with disabilities relate, especially when they are children. For this reason, the family should be the foundation of our policies and "first" in our policy priorities, and its preservation and integrity should be a policy goal (A. P. Turnbull & Turnbull, 1978; H. R. Turnbull, Turnbull, Bronicki, Summers, & Roerder-Gordon, 1989).

The principle of Family as Foundation recognizes that the strengths, needs, and decisions related to children with and without disabilities are normally managed within the context of a family; that issues involving children are therefore properly regarded as family concerns; and that by addressing the strengths, needs, and autonomy of families, we better support and honor their members. Family as Foundation recognizes that disability affects more than the individual: It affects every member of the family and the function of the family as a social unit (A. P. Turnbull & Turnbull, 1986; A. P. Turnbull et al., 2000). Thus, at the crux of the Family as Foundation principle lie the core concepts of **family centeredness** and **family integrity and unity**.

Community. The ethical principle of Community is closely related to one of the Constitutional Principles--Equality. An individual must have equal access, equal opportunity, and equal benefit before he or she can truly become a member of the community. Community invokes more than fairness in allocation of resources and in governmental "treatment," however, and Equality does not always speak to the minds and hearts of the people who make up any particular community. The principle of Community stands for membership in, ownership of, and ownership by the cooperative spirit of the people within "the community." It encompasses the relationships of individuals to each other and the necessary and real interdependence of people upon one another as families, friends, co-workers, and advocates.

It speaks to autonomy and the right to choose those with whom you associate, where you live, and what you do and to the claim that families and individuals affected by disability make to be "in" and "of" their communities. Community also embraces the right to speak, be heard, and be given consideration on issues that affect the day-to-day world in which the family and individual actually live. It is the entitlement to, and the benefit of possessing, the rights and responsibilities of membership and participation in the community, of contributing to the whole.

In the simplest sense, a community is a group of people whose actions affect each other. Ideally, these members work together, cooperate, and help one another, thereby benefiting each member and the group as a whole. The principle of Community holds that the right to be part of a greater social whole is a natural right of every member of society and is to be fostered for each individual member with a disability to the maximum extent possible. The Ethical Principle of Community will be fully achieved only when individuals with disabilities are regarded and respected as full members of society. At the very center of community are the core concepts of **integration and productivity and contribution**.

Relationships Among the Three Ethical Principles. The relationships among the Ethical Principles of Dignity, Family as Foundation, and Community are also illustrated in Figure 4. Like the Constitutional Principles, the Ethical Principles are connected to each other, but they are also discrete in that each one has its own definition and can be considered separately. The relationships among the Ethical Principles can be best understood and functionally represented in a tiered structure.

The principle of Dignity is the underpinning of the tiered structure because the basic aspiration of the Family as Foundation principle is to give Dignity to the individual as a member of a family and to give Dignity to the family itself; moreover, the central theme of the Community principle is to give Dignity to the individual and to the family as members of a community. Alternatively stated, the first tier gives Dignity to the individual through respectful treatment of the person. The second tier dignifies the family and its role; it also dignifies the individual by valuing the family as the initial and normal unit for performance of family functions that support the individual. The third tier yields Dignity to the individual, family, and community by including the individual and family within the Community. Dignity, Family, and Community thus are nested principles.

Convergences of the Constitutional and Ethical Principles

Together, the Constitutional and Ethical Principles form the basis of disability policy; each is necessary to understanding and advancing policy, but neither alone suffices for understanding and advancing policy. This is so because the Constitutional Principles are limited in that they create only legal claims by individuals and families as legal entities.

No doubt these legal claims are invaluable, but are they sufficient and do they fully express the respondents' views about policy, families, and individuals with disabilities? We think not. By contrast, the Ethical Principles focus on the personhood of the individual and of the members of the family, but they fail to acknowledge that the realities of membership in a discriminating and arguably devaluing society require enforceable legal rights in order to have equal access to and to benefit from community resources. It is only when the Constitutional and Ethical Principles converge that benefits for and social acceptance of individuals with disabilities and their families actually occur.

The Constitutional and Ethical Principles converge in two ways. First, the principles themselves interact to form nine combined principles: Life/Dignity, Life/Family as Foundation, Life/Community, Liberty/Dignity, Liberty/Family as Foundation, Liberty/Community, Equality/Dignity, Equality/Family as Foundation, and Equality/Community. These nine combination principles, which we call convergences, form the parallelograms shown in Figure 5 and represent how law and service delivery incorporate the Ethical and Constitutional Principles into generic policies. We use the term convergences because each parallelogram is formed by the convergence of one Ethical Principle and one Constitutional Principle.

The second way in which the Constitutional and Ethical Principles converge is through the core concepts that are common to each principle. To illustrate these connections, we return to the ramp and place the connecting core concepts inside the nine parallelograms or convergences. As Figure 6 shows, each core concept associated with one of the Ethical or Constitutional Principles is reflected in three of the convergences. For example, the core concept of protection from harm is contained in the three convergences of Life/Dignity, Life/Family as Foundation, and Life/Community.

How the core concepts group when reflecting the interaction of the Constitutional and Ethical Principles actually defines the convergences. For example, the Constitutional Principle of Life contains *six* core concepts: **protection from harm, prevention and amelioration, family centeredness, family integrity, integration, and productivity and contribution**. The Ethical Principle of Community contains the core concepts of **protection from harm, prevention and amelioration, integration, productivity, autonomy, empowerment/ participatory decision-making, privacy and confidentiality, liberty, antidiscrimination, and cultural responsiveness**. Considered together, the Principles of Life and Community share the four core concepts of **protection from harm, prevention and amelioration, integration, and productivity and contribution**. The result is that these four core concepts work together to form a convergence where the Constitutional Principle of Life meets, overlaps, and interacts with the Ethical Principle of Community.

By placing **protection from harm, prevention and amelioration, integration, and productivity and contribution** inside the parallelogram where Life converges with Community, we indicate that these four core concepts

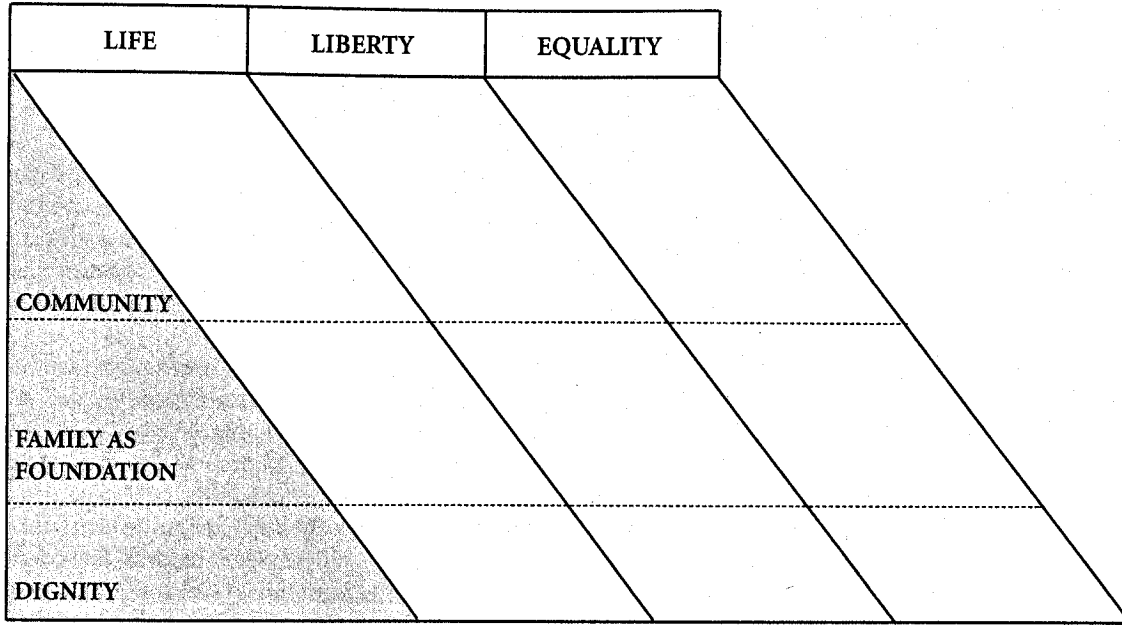


FIGURE 5.

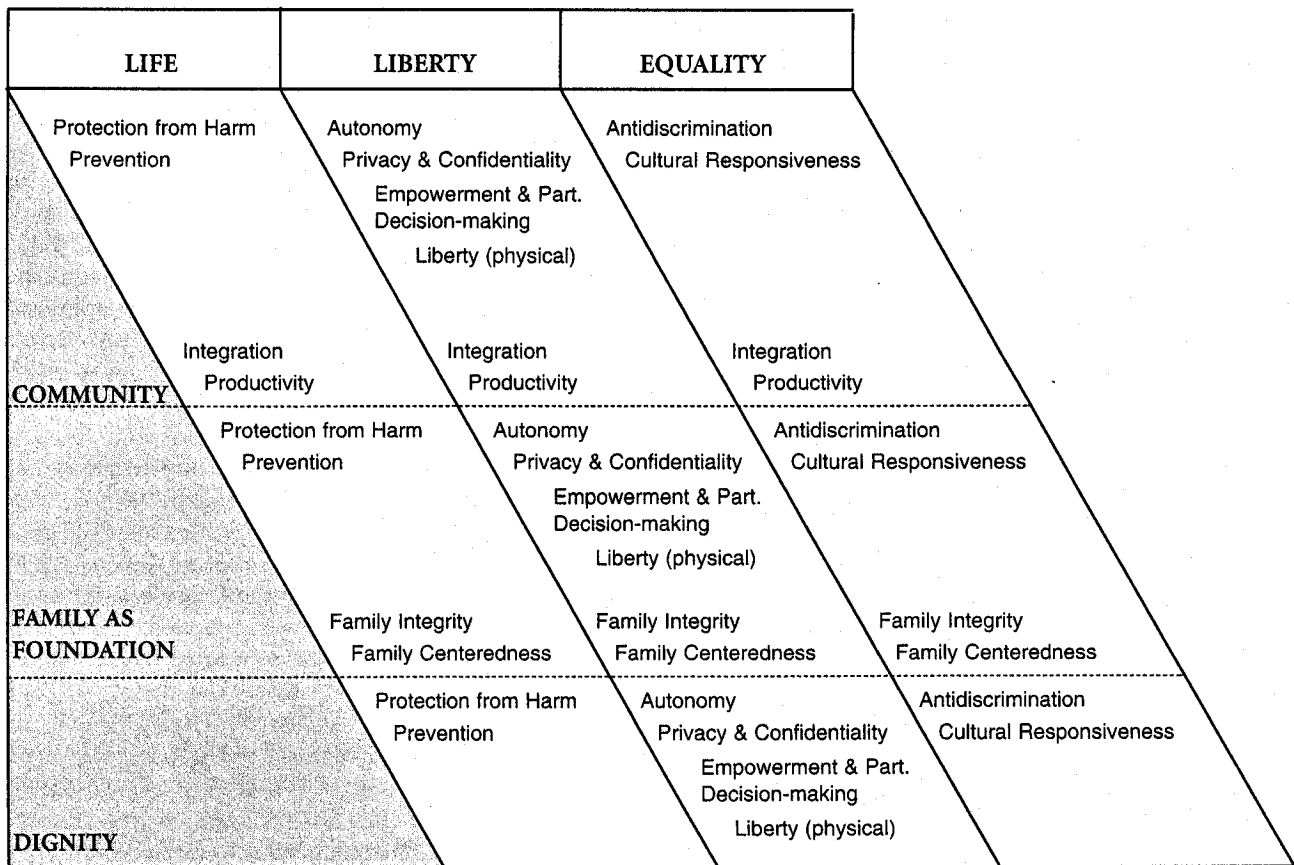


FIGURE 6.

are related to each other and jointly advance the Life and Community principles. Similarly, each of the Constitutional Principles (Life, Liberty, and Equality) converges with each of the Ethical Principles (Dignity, Family as Foundation, and Community) through shared core concepts that simultaneously support both principles. The result is that the nine parallelograms show the interactions of the Constitutional and Ethical Principles in the context of disability-specific policy (represented by the core concepts) as well as in generic policy.

At this point it is necessary to explain why we placed a core concept within a particular parallelogram within the ramp; in explaining that placement, we continue to explain the relationships among the core concepts and the principles. In this explanation, we briefly describe the convergence in terms of generic policy, that is, universalistic policy that applies to all people--with and without disabilities--and their families. We then describe the convergence in terms of disability policy only, that is, exceptionalistic policy that applies only to people with disabilities and their families.

Life/Dignity. Life and Dignity converge as each addresses two fundamental questions: "What is life?" and "Which lives are to be valued?" These arguably are the most important questions in disability policy because they address defining the essence of being human, the rights of people with profound disabilities to life-sustaining medical treatment or to food and water, and the claims of other individuals to determine what defines life and if and when life-sustaining services should be discontinued.

Policies that value dignity at the edges of life and death create a presumption in favor of life-sustaining treatments and services, but they also take into account the efficacy or futility of medical treatment, the providers' obligation to not harm the person as a result of providing such services, and the person's irreversibly comatose state (Child Abuse Prevention and Treatment Act of 1988). (It should be noted that the Professional Principles of Beneficence, Nonmaleficence, Justice, and Autonomy come into play here.) More than this, however, these policies attempt to strike an acceptable balance between two sometimes competing tensions: the sanctity of life and the quality of life, the latter of which includes the claim to die with dignity.

In generic policy, statutory authorizations of living wills, durable powers of attorney, and other advance-directive instruments recognize that incompetence-causing disability or disease can strike anyone at any time; that disability is often the result of circumstances over which one has little (if any) control; and that a person, while still competent, should have the right to direct what happens to him or her, what kind of life and dignity he or she wants, if rendered incompetent. Likewise, for individuals who need emergency services but are unable to consent to treatment, the principles of Life and Dignity advance policies such as implied consent that allow healthcare providers to apply effective medical treatment to preserve the patients' lives or to stabilize their conditions.

Life/Dignity is also recognized in the policy and

professional requirement that services be effective and that standards of care demonstrate respect for patients as fellow human beings regardless of their ability to derive (or to know they derive) a benefit from the service. For example, a caregiver bathe, a patient who is temporarily disabled and a comatose patient because each one is entitled to be treated with dignity and respect, that is, to be kept clean. A dignified life is a sufficient outcome by itself; no other reason is needed to justify the provision of services in a manner that shows respect for the individual.

In the disability field, these are issues addressed in the "Baby Doe" case (*Bowen v. American Hospital Association*), where the main question could be phrased as "When, if ever, should life-sustaining medical treatment or nutrition or hydration be withheld or withdrawn from newborns or other persons who are at the edges of life?" For individuals with disabilities, such as Baby Doe, the analysis involves their claim to Dignity. This includes a claim to be valued as human beings: The fact that one or more Baby Does have significant disabilities and may lack most of the capacities of children without disabilities does not negate their value as humans. The infants' sanctity of life supports the claim to Dignity.

Moreover, Baby Doe's claim to Dignity includes a claim to have effective life-saving or life-enhancing services rendered. In this regard, the presumption is that the claim to effective services almost always will trump any assertions that the child's life will lack quality. These kinds of predictions were at the root of the treat/do-not-treat debates of the early and mid-1980s. The policy resolution expressed in the Child Abuse Prevention and Treatment Act is that predictions about "poor" or "unacceptable" quality of life presumptively should be set aside in favor of treatment that can enhance that quality. After all, predictions made during the earliest days of a baby's life about his or her future quality of life often are inaccurate because they do not take into account future developments in technology, interventions, family and societal responses, and policy that singly and jointly may add to the quality of the baby's life and then later to his or her life as a child and an adult.

Thus, the claim to Dignity involves consideration of and respect for Baby Doe's potential capacities. His or her present condition and its probable future trajectory may, and perhaps must, be considered, but that kind of prediction-of-diagnosed or forecasted limitations-is not controlling, nor should it be, for it is often unduly pessimistic. The claim to Dignity also involves the right to medical treatments and other services that prevent further disability and that mitigate the effects of an "incurable" primary disability.

Neither Baby Doe nor "Granny Doe" (an elderly, infirm individual with a very brief life expectancy) can speak for him- or herself (although Granny Doe may have given prior instructions and warrants for action); both usually must rely on legal and ethical principles to protect them from harms motivated by a discriminatory animus or a misguided vision

of mercy. The core concepts of **protection from harm** and **prevention and amelioration** (secondary and tertiary) come to bear at the convergence of Life and Dignity to preserve and promote the dignity of the individual.

Life/Family as Foundation. The challenge represented at this convergence is to protect the stability of the family as a means for protecting the individual's sanctity and quality of life. Protecting the integrity of the family includes (a) adopting policies and procedures that are not harmful to the family unit and (b) actively supporting the family's capacity to protect and meet the needs of itself and its members. This convergence is about the benefits of **family-centered**, family-directed services.

In generic policy, the convergence of Life and Family as Foundation is reflected in statutes that attempt to **prevent** primary disability (for example, removal of hazardous materials such as asbestos and lead; the provision of pre-, peri-, and postnatal services; and the provision of education, family support, assistive technology, and rehabilitative services). Life/Family as Foundation is also evidenced in statutes that provide financial assistance as a means to blunt the effects of poverty on the family, especially its children. Sometimes these are traditional welfare policies (updated to meet the expectations of the time), such as Temporary Assistance to Needy Families, and sometimes they are family support policies, such as Supplemental Security Income.

Another body of policy that evidences the interrelationship of Life and Family are the child protective custody, foster-care, and adoption-assistance statutes. These statutes acknowledge that as a general rule (**family integrity**), separating the child from the family harms the child and is warranted only in order to prevent the (greater) harm that would result if the child were left with a maltreating family.

The convergence of Life and Family as Foundation recognizes that in disability policy, the quality of life of a child or dependent adult with a disability is most affected, and therefore should be addressed, by the family whenever possible. Services should be **family centered**: directed by and to the family as well as to the child or adult with disabilities to the maximum extent appropriate, that is, to the extent the individual derives a benefit from **family unity**, integrity, capacity, and quality of life. For instance, enhancing the capacity of families with children who have disabilities to **prevent** secondary and tertiary disabilities increases a family's capacity and resilience and can help preserve the quality of life of the individual with a disability and of other family members as well. The family-centered prevention policy (in its secondary and tertiary forms) is especially warranted when transitions or other "punctuation marks" in a family's life create new or additional stresses that may otherwise interfere with the family's capacity to meet the special needs of its individual members.

Life/Community. The interrelationship of Life and Community focuses on the benefits that can accrue to sanctity and quality of life through participation within the community.

Quality of life has its social aspects; we are social beings whose quality of life is undeniably tied to those around us. Policies that recognize the connection between quality of life and the community have the purpose of supporting participation in the community; participation itself may be an end, but it certainly also is a means of creating a system of natural or informal supports that benefit family members as they pursue their desired quality of life. Membership and participation in a community give value to life.

In generic policy, Life/Community is recognized in welfare-reform policies. These policies provide public funds to an individual or family only so long as the beneficiary is working or securing an education that leads to work. Stated in another way, welfare policy conditions the provision of aid upon an individual's effort to acquire the capacity to contribute to and participate in the community. Another reflection of the Life/Community convergence is in generic labor policy; for example, "ticket to work" policies seek to reduce an individual's unemployment and thereby increase the quality of life for him or her and his or her families. Policies that require desegregation according to such traits as race, ethnicity, culture, and language also forward the convergence of Life and Community as they attempt to increase tolerance and respect for "diverse" people by increasing contact and understanding among racial, ethnic, cultural, and linguistically diverse groups.

As important as a life in the community is for generic policy, it is even more important for disability policy because historically individuals with disabilities have been provided services only when the family was willing to remove the individual from the community. When provided at all, services were (and sometimes still are) provided in segregated institutional settings or as a condition subsequent to the family's relinquishment of legal custody and the assignment of that custody to the state. (Here we see the connections among Life/Dignity, Life/Family as Foundation, and Life/Community.) Disability policy has only relatively recently acknowledged that when an individual with a disability and his or her family members are welcomed as part of the community, their quality of life can improve as a consequence of increased social contact, decreased stigma, and an increased sense of belonging. Through **integration**, people who have disabilities are also given the opportunity to be **productive and contributory**, to have a different quality of life. In addition, through integration there are greater assurances for sanctity of life as the community comes to recognize and value that person.

The benefits that spring from membership and participation in the community depend on the existence of accommodations and support systems. After all, disability is a distinction that makes a difference in what a person can do, and the difference is made less debilitating when accommodations and other supports are available. Whatever the nature, duration, and intensity of the supports the person with a disability needs, they will advance the person's quality of life, productivity, and contributions in the community only if they are provided *in the community*. Moreover, when services are delivered in typical settings, in the least restrictive

environment individuals with disabilities benefit from their interactions with other community members, as do their families and other members of the community.

The convergence of Life and Community is only secondarily related to the *right* to be a member of and to participate in a community; it is primarily about the value of **integration** into a community and the *benefits* derived by persons with disabilities and their families through opportunities for **productivity and contribution** in a community. Membership and participation in a community add to the individual's and family's quality of life.

Liberty/Dignity. One aspect of Dignity is respect for an individual's right to **autonomy**. Just as Dignity guides decisions involving the sanctity and quality of life, so Dignity also requires that each person be given the opportunity to define and determine the course of his or her own life. Thus, respect for individual privacy, the right to control access to and distribution of personal information (**confidentiality**), and the right to participate in decisions that affect one's life (**empowerment/participatory decision-making**) all proceed from Liberty and Dignity. Accordingly, decisions involving the balance between the benefits and detriments of particular services involve autonomy: the Liberty to choose and the Dignity of self-determination.

In health care, the doctrine of consent to medical treatment reflects this convergence. As a legal principle, consent requires that the individual be competent to act, act voluntarily, and be given enough information to make a knowledgeable decision about whether to accept treatment or not. As a general rule, a competent individual's decision overrides professional judgment; the individual's decision is respected. Even though a physician is presumed to be the most qualified individual to make medical treatment decisions, it would assault the individual's dignity to require him or her to undergo treatment based on the decision of another, even if that other person is an expert in the treatment at hand. When the individual lacks the capacity to make his or her own wishes clear, the doctrine of substituted consent effectuates the person's right to choose by requiring a proxy decision-maker to "step into the shoes" of the individual, to determine what choice he or she would make, and to make that choice.

The historical indignities suffered by individuals with disabilities under the guise of "treatment" highlights the importance of the convergence of Liberty and Dignity. In addition, the right to be free from unwarranted restraints and coerced interventions, the core concept of physical **liberty**, is fundamental to dignity, whether the restraints are physical, chemical, or behavioral in nature. The constitutional rule of the least drastic alternative or means in the provision of services is another example of the Liberty/Dignity convergence.

Liberty/Family as Foundation. Family **autonomy, empowerment/participatory decision-making,** and **privacy and confidentiality** are comparable to

individual Liberty. These concepts require policies that favor family integrity and unity and that recognize the family as the key social unit. Likewise, when the natural family is not suitable for the child, policies in this area allow for adoption and foster care. Within limitations, foster care and adoption allow a family to determine who its members are by giving them an opportunity to take in a nonbiological member. This type of **autonomy** is comparable to the autonomy of adult family members to practice or not practice certain family-planning methods.

Child-protection laws also give families broad but no unlimited discretion as to how family members may behave toward each other. Thus, the family has **autonomy** (Liberty) to raise its children as it wants, subject only to the child's interests in not being harmed. It also shows a strong respect for the core concept of **family integrity and unity**. The interrelation of Liberty and Family as Foundation recognizes that parents have the right to raise children without unjustified outside influence and to be the primary decision-makers in matters that affect their children's welfare.

These family rights and the family's capacity to exercise them in ways that benefit (or at the least do not harm) family members and society also are supported through various family capacity-building policies and practices. Family-centered services (**family-centeredness**) empower the family; in turn they generally help preserve the family's privacy and autonomy. By preserving these freedoms for the family, they expand the freedoms of its individual members.

Generic policy ensures Liberty rights to parents that they hold in trust for their children. For example, the right to choose the religious influences to which a child is exposed is supported by the doctrine of separation of church and state and by policies that make public funds available for home-based and private-school education.

For families whose members include individuals with disabilities, the convergence of Liberty and Family as Foundation justifies policies such as early intervention that are family centered and advance the family's capacity to make informed choices concerning interventions for itself or for its members who have disabilities. Family capacity building increases the ability of the family to meet the needs of its members.

Liberty/Community. Just as Liberty/Dignity advances rights to **autonomy, privacy and confidentiality,** and physical **liberty,** so Liberty/Community stands for the freedoms inherent in being a member of society. These include the freedom of self-government (the right to the franchise and to participatory democratic decision-making), freedom of speech and association, and freedom to choose where you live and where you work. In short, Liberty within a community involves the freedoms of membership.

The convergence of Liberty and Community is reflected in court cases that recognize a citizen's liberty interest in the right to speak, travel, vote, and pursue employment in a chosen field. In addition; zoning laws that define the term *family* and restrict certain land uses to *families* balance

(a) the right of people to associate or to be selective in their associations by choosing where they will live within the community with (b) the right of a group of persons to define themselves as a family. Likewise, statutes and courts define who may choose to associate, or not associate, with whom; these decisions involve disputes concerning the right to exclude certain people (such as nonbelievers or people whose sexual behaviors are deemed immoral) from membership in an organization such as a religious community or scouting group.

In disability policy, the intersection of Liberty and Community speaks to the most basic of societal freedoms, especially the physical **liberty** to live in the community rather than be placed involuntarily into an institution or a hospital. Individuals with disabilities have the general right to be free from confinement and segregation from the community at large (the right to **integration**). They also have the right to have their voices heard concerning matters affecting them, to have their opinions and choices acknowledged in the community (**empowerment/participatory decision-making**) and to be free from constraints upon their ability to contribute to the community or be productive in their daily lives. Liberty within Community values the freedom of each family and individual; it also recognizes the interdependence of community members. Indeed, interdependence can foster the independence and liberty of persons with disabilities when each member of the community is given the opportunity to elicit support from others.

Even as this convergence represents the freedom to live within the community, it also maximizes personal freedoms when state intervention, or even state custody, is deemed necessary. Just as freedom from restraints reflects the convergence of Liberty and Dignity, so the rule of LRE reflects the (physical) liberty core concept at the convergence of Liberty and Community. Similarly, the right to **privacy and confidentiality** becomes particularly important when the state is motivated by paternalistic interests to invade the autonomy of the individual with disabilities.

Equality/Dignity. Dignity is inherent in equality. Antidiscrimination policy ensures equal access and equal opportunity; it asserts that everyone is valuable. It does not turn a blind eye to individual differences; rather, it acknowledges that these differences enrich the nation and accordingly should be given equal opportunities to flourish. Differences should be valued rather than stigmatized, accommodated rather than stifled. Equal justice under the law is a slogan that affirms individual dignity. In affirming individual dignity, policy that requires equal treatment advances the national value of a pluralistic society.

As we pointed out earlier in this article, the three tiers of equality—purely equal treatment, equal treatment plus accommodations, and unequal but not invidious treatment—are the disability field concepts on which equal treatment and equal opportunity are premised. The key, of course, is that for some

people with disabilities in some contexts, accommodations are necessary in order for them to have the same [equal] opportunities as people without disabilities. They are not treated equally; they are treated differently in order to yield equal opportunities.

This distinction seems to escape many policy leaders, including a majority of the members of the current Court. As we pointed out earlier in this article, the Court has attacked the equal-treatment, equal-opportunity claims of people with disabilities. It made favorable decisions in *Cleburne* (holding that the "rational basis" approach in equal protection law is the appropriate one to apply to people with disabilities but that under it, zoning discrimination falls) and *Olmstead v. L. C.* (holding that the ADA and its "integration" regulations forbid unwarranted institutionalization). But these have been followed by rulings that (a) narrowly limited ADAs beneficiaries and the scope of other civil rights laws (see *Sutton*, in which the Court held that people who can mitigate their disabilities are not protected under ADA), (b) struck down some provisions of ADA (see *University of Alabama v. Garrett*, where the Court invalidated the provisions that allow a person with a disability to sue a state for employment-based decisions that take disability into account), and (c) restricted a person's right to sue to enforce civil rights laws (see *Sandoval*, which restricts the private right of action to enforce Title VI, discrimination because of language). Despite these recent decisions, it has been, and we hope soon will be, reestablished that antidiscrimination laws will be sustained and that their recognition of the Dignity of the individual and family will be restated.

Because Equality is assumed to occur through typical processes (e.g., one person, one vote), policy involving Equality and Dignity is never truly generic. By definition, antidiscrimination and entitlement policies benefit individuals (and thus groups of those individuals) who have experienced or are especially vulnerable to discriminatory (that is, unequal and invidious) treatment based on such unalterable traits as their ethnicity (race), culture (language), gender, or disability.

In disability policy, Dignity through Equality of opportunity invokes **antidiscrimination** and the related core concept of **cultural responsiveness**. Discrimination based on disability assaults a person's Dignity; it flouts the principle of Equality. Moreover, respect for racial, ethnic, cultural, or linguistic characteristics (which often are manifestations of an individual's beliefs and values, of his or her roots) is necessary if any one group of individuals is to be valued as much as any other, and if each person, whatever the cultural or other traits, is to be valued equally with every other person. The absence of **cultural responsiveness** in the delivery of services can aggravate the impact of existing disability discrimination or even foster the growth of socially created disability, which accompanies stigma and erodes the Dignity and worth of the individual.

Equality/Family as Foundation. Just as the equal treatment of individuals is connected to their Liberty and life, so equal treatment of families advances the Liberty and lives of family

members. It does more than that, however; it recognizes that the family is the original and principal organizing unit in society. As such, the family has inherent value as a unit, just as its members have inherent value as individuals. Moreover, families are as diverse as individuals. Accordingly, the convergence of the principles of Equality and Family as Foundation should take into account such diverse family characteristics as family structure and culture. Honoring these kinds of family attributes is necessary if services are to preserve or strengthen the integrity of the family and benefit its individual members. The benefits of family-centered services, already discussed in the section on the convergence of Life and Family as Foundation, are undermined by service provision that fails to recognize this diversity among families (**cultural responsiveness**).

Unfortunately, family diversity has often gone unnoticed in policy formation. One particularly good example is family structure. The capacities, needs, and desires of two-parent families (whether or not both parents are wage earners), single-parent families, mixed race/culture families, original or re-constituted families, or same-gender families differ in some significant (but not all) respects. Despite this fact, federal policy does not guard against discrimination on account of family structure, and there are even some federal policies that openly discriminate against family structure, such as the Protection of Marriage Act and the so-called marriage penalty tax (current tax reform efforts are projected to reduce but not eliminate this disparity).

Within disability policy, the principles of Equality/Family as Foundation justify **culturally responsive**, bias-free, family-directed evaluations of family strengths and needs. Part C (concerning early intervention) of the IDEA is a good example of how policies can support these core values and the convergence of the principles of Equality and Family as Foundation. Part C recognizes that **family integrity and unity** cannot be preserved or promoted by policies that discriminate against family structure, culture, or economic status and that **family centeredness** means accepting and accommodating the diversity of each family as a unique entity.

Equality/Community. Discrimination is antithetical to full membership in a community; therefore, the final measure of equality is whether the individual and the individual's family have equal rights, opportunity, and benefit in their communities. The rights of each person to have a voice in government, to contribute to the household and community, and to live within the community of choice reflect the generic claims to Liberty and Community, and they are discussed under Liberty/Community. Together, Equality and Community require these freedoms to be equally available to all. Policies reflecting the convergence of Equality and Community preserve and promote these Liberty rights by requiring that the freedom extended to one member of the community must be extended to all.

Laws that protect voting rights, preserve the right to work, prohibit discrimination in housing, and create affirmative action programs to remedy the effects of past

discrimination all evidence the convergence of Equality and Community in generic policy. However, there is another side to the convergence of Equality and Community that recognizes that for every right there is a responsibility. For equality to truly exist within the community, families and individuals must also contribute to and be productive members of their communities and of society as a whole, according to their capacities to do so. Welfare reform illustrates this other side of the Community/Equality coin by requiring recipients to meet their responsibility to contribute to the community through work or work capacity-building activities (education) that will eventually lead to a greater ability to contribute to the community.

In disability policy, Equality within the Community requires that individuals with disabilities must have comparable access to community resources as other citizens. Accommodations for individuals with disabilities are the necessary means for removing discriminatory barriers to **integration** and to **productivity and contribution** within the community. Equality establishes the degree to which individuals with disabilities and their families are entitled to the rights and benefits of the community; simply put, they are entitled to the same rights and benefits as persons without disabilities.

Core Concept Connections Within and Across Convergences

Having defined the relationships between the Constitutional and Ethical Principles that create each of the three convergences, we now discuss the relationships of these convergences to each of the core concepts of disability policy. As we argued previously, the primary difference between a core concept and a principle is that a principle applies to policy generally but a core concept applies to disability policy specifically. Initially, then, the ramp (Figure 3) reflects how disability policy fits within the framework of generic policies.

The ramp also illustrates how the core concepts connect and bind the convergences together. Each core concept is associated primarily with one of the principles; that principle is either Constitutional or Ethical and reflects the primary source of the particular core concept. For example, the primary source for the core concept of **antidiscrimination** is the Constitutional guarantee of Equality. In addition, each core concept is associated secondarily with another set of principles. These secondary principles are the Ethical Principles if the primary source for the core concept is Constitutional; alternatively, they are the Constitutional Principles if the primary source is an Ethical Principle.

Where the primary and secondary principles converge, we see how connected the core concepts are to each other. As each core concept crosses the convergences, it highlights the connections between the primary and secondary principles. For example, the core concept of **antidiscrimination** has its primary source in the principle of Equality. Equality converges with the three Ethical Principles; thus, we can understand the relationships of Equality/Dignity, Equality/Family as Foundation, and Equality/Community.

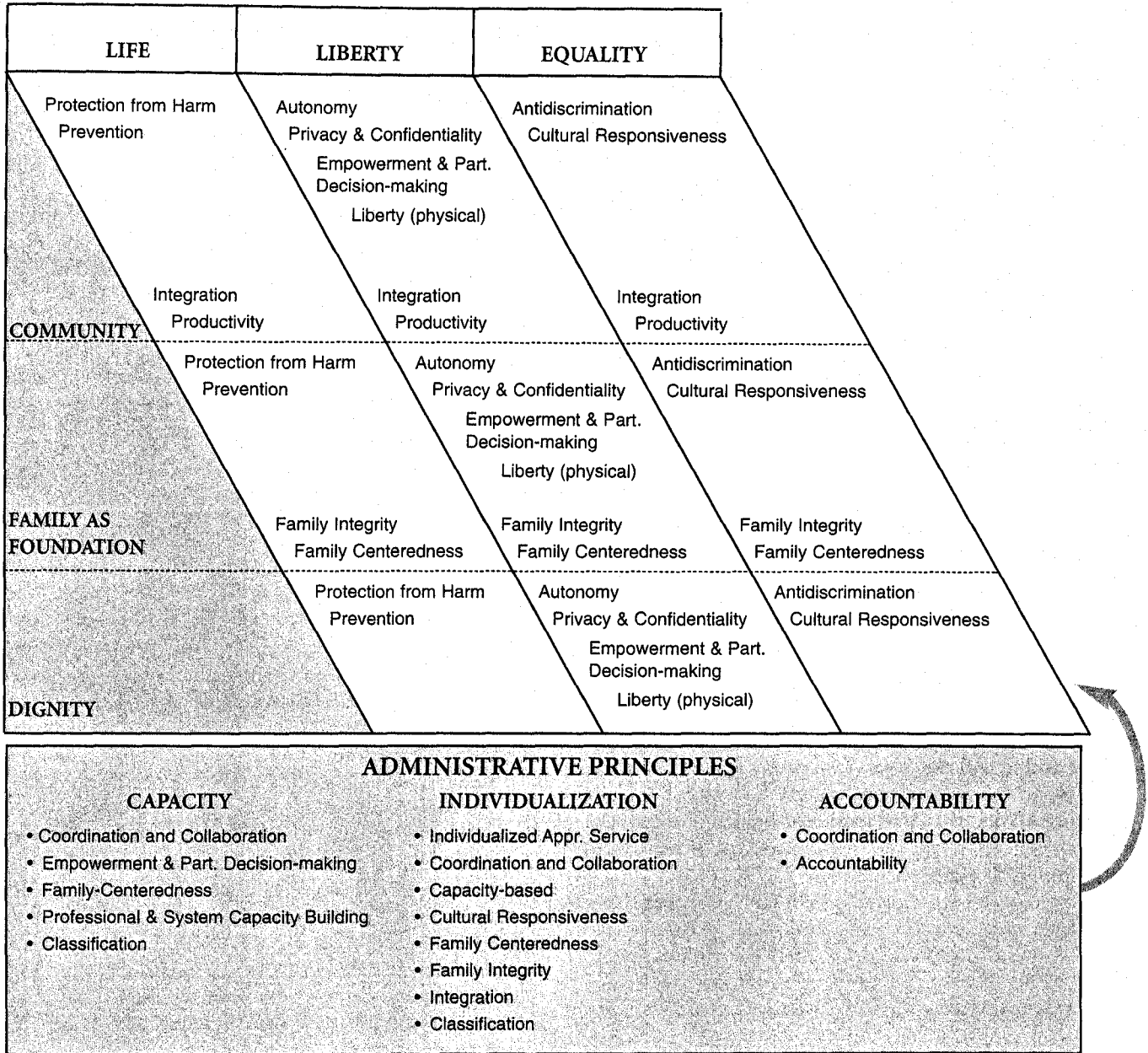


FIGURE 7.

At the Equality/Dignity level, the core concept of **antidiscrimination** promotes the dignity and equality of the individual as a person; at the Equality/ Family as Foundation level, it promotes family equality; and at the Equality/Community level, it extends equality to individuals with disabilities and their families as members of the community.

The Administrative Principles

Good policy development requires not only a resolute focus on the desired outcomes of a policy but also an understanding of how the policy is received and administered by a service delivery

system. The Administrative Principles incorporate core concepts that, when included in laws, regulations, and practice, enable policies to remain true to their original intention. The Administrative Principles constitute the foundation on which Constitutional and Ethical Principles are transformed from ideals into reality and eventually affect the quality of life of individuals with disabilities and their families. Thus, the Administrative Principles sit at the base of the ramp, as shown in Figure 7. Symbolically, their position represents the mediatory role they play between policy as written and policy's outcomes. Capacity, Individualization, and Accountability (the Administrative Principles) reflect the qualities (capacity), foci (the individual beneficiaries), and procedures (legal and other

accountability standards) that must be included in any policy to support its successful implementation.

Capacity. For any policy to achieve its desired outcomes the service-delivery system must have the capacity to implement the policy. This capacity requires sufficient resources (sufficient funding delivered through appropriate funding streams), a sufficient number of qualified individuals, an effective organization and infrastructure, the ability to integrate services or an intra- and interagency/sector level, and the ability to establish partnerships among its professionals and administrators and partnerships between them and the individuals and families they serve.

For the service system to function effectively, it must have a sufficient number of personnel. More than that, these personnel must have sufficient preservice or in-service education and sufficient experience to understand the goals of the policy and to apply state-of-art (best) practices to secure those goals. This type of capacity is manifested in the core concept of **professional and systems capacity-building**, which is defined as building the capacity of a service-delivery system and of the individuals within it to carry out the duties assigned to the system and those individuals designated as its beneficiaries.

Each professional in the system must have the ability to work cooperatively with others and with the beneficiaries of the system. This ability often depends on the interpersonal relationships these individuals establish. The ability also derives from, or is impeded by, the structural mechanisms that operate within and across service-delivery agencies, levels of government (local, state, and federal), and service systems (health care, education, and social and human services). Capacity therefore incorporates the core concept of **service coordination and collaboration**.

Service provision must also be linked by a partnership between the professionals and the family. Most of the time, the family is not only the unit within which a child lives, learns, and grows but also the primary service provider to the child. Furthermore, the family presumptively is the most desirable of service providers because it is the natural unit for fulfilling family functions and meeting the needs of family members. Like other service providers, the family's capacity to nurture the strengths and meet the needs of its members with disabilities should be fostered in order to make services both efficient and effective. The core concepts of **empowerment and participatory decision-making** and **family centeredness** (which relate to **family integrity and unity**) are important parts of the Administrative Principle of Capacity.

Finally, the capacity and resources of society and of any particular community are always limited and, as it is the role of policy to distribute them, distribution decisions should be made fairly. That is not to say that everyone is treated alike. However, once it has been decided who will benefit from a policy, the determination of who qualifies as a beneficiary must be made objectively, impartially, and

nondiscriminatorily, using objective criteria. The Administrative Principle therefore incorporates the core concept of fair and objective **classification** for the distribution of resources.

Individualization. To maximize outcomes, policy tailors service delivery to the specific circumstances of each qualified (entitled) individual and family beneficiary. Individualization recognizes and responds to the strengths, needs, and cultures of individuals and families. Individualized services are provided in community-based programs that localize service delivery. Because consumers often qualify for services from more than one agency or across sectors, individualization requires that various services be coordinated.

The core concept of **individualized and appropriate services** is the primary strategy for achieving the principle of Individualization. Six other core concepts--**capacity-based services, classification, family integrity and unity, cultural responsiveness, family centeredness, and integration**--support the primary concept.

It is worth noting that the core concepts of **family integrity and unity, cultural responsiveness, family centeredness, and integration** are also reflected within the convergences of the Constitutional and Ethical Principles. They thus are not only substantive core concepts, in that they are associated with Constitutional and Ethical Principles, but are also practices and procedures that ensure effective delivery of services and therefore are properly associated with the Administrative Principles. Within the Constitutional and Ethical Principles, these core concepts represent desirable outcomes for the beneficiaries; within the Administrative Principles, they represent desirable individualization strategies.

The core concepts of **capacity-based services** and **classification** highlight specific aspects of **individualized and appropriate services**. **Capacity-based services** address individual strengths as well as needs. **Classification** requires that decisions about the distribution of resources take into account the strengths and resources of each individual beneficiary so that services will be provided in a manner that benefits the person to the maximum extent possible given all the resources available to all other comparably situated beneficiaries.

Another aspect of Individualization is the partnership of professionals with the family and partnerships among professionals in the same or different service-provider systems. How better to individualize services than to enlist the family in the assessment and provision of those services? Not only does this technique, which is an aspect of **service coordination and collaboration**, advance the autonomy of the family and its members, it also increases the ability of the service system to individualize services by drawing on a useful source of information, the family itself. Individualizing services across various agencies, or even within a single agency, requires coordination of service provision. Partnerships with the family and Individualization thus requires both inter- and intra-agency collaboration.

Accountability. The principle of Accountability and the core concept of **accountability** are nearly identical in their

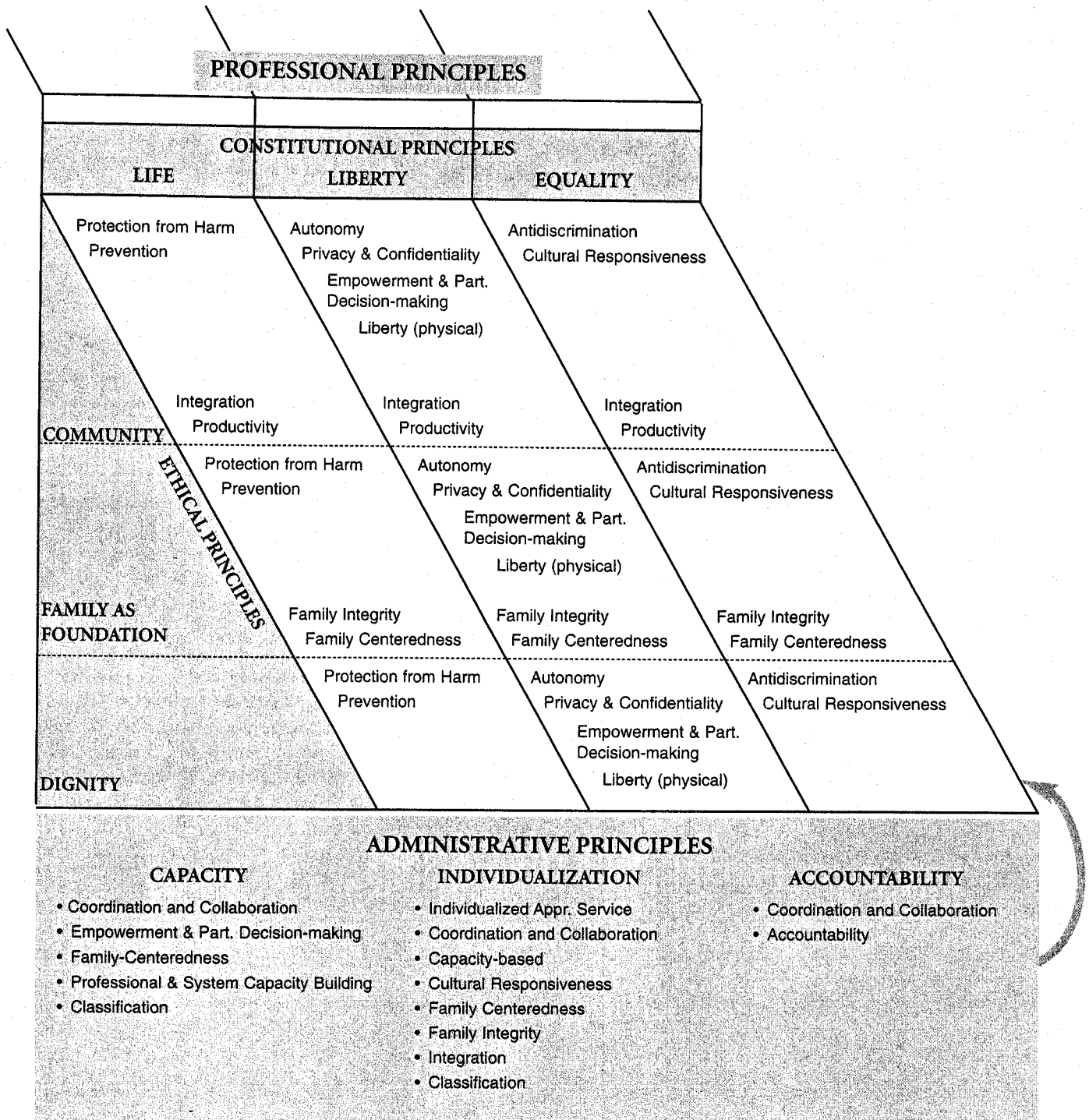


FIGURE 8.

conceptions. This reflects the fact that accountability for outcomes and efficiency is necessary for all policy decisions and all provider systems, whether they are generic or specific to disability. In order to know whether a policy is effective in achieving its goals (outcome-accountability), and efficient in its administration (efficiency-accountability), measures of costs,

activities, and outcomes are needed. Furthermore, the results are more likely to be achieved when a provider system promotes efficacious administrative and service-delivery strategies and provides a remedy and correction for those that fail.

There are many different methods for ensuring accountability (see the definition of accountability) and many different

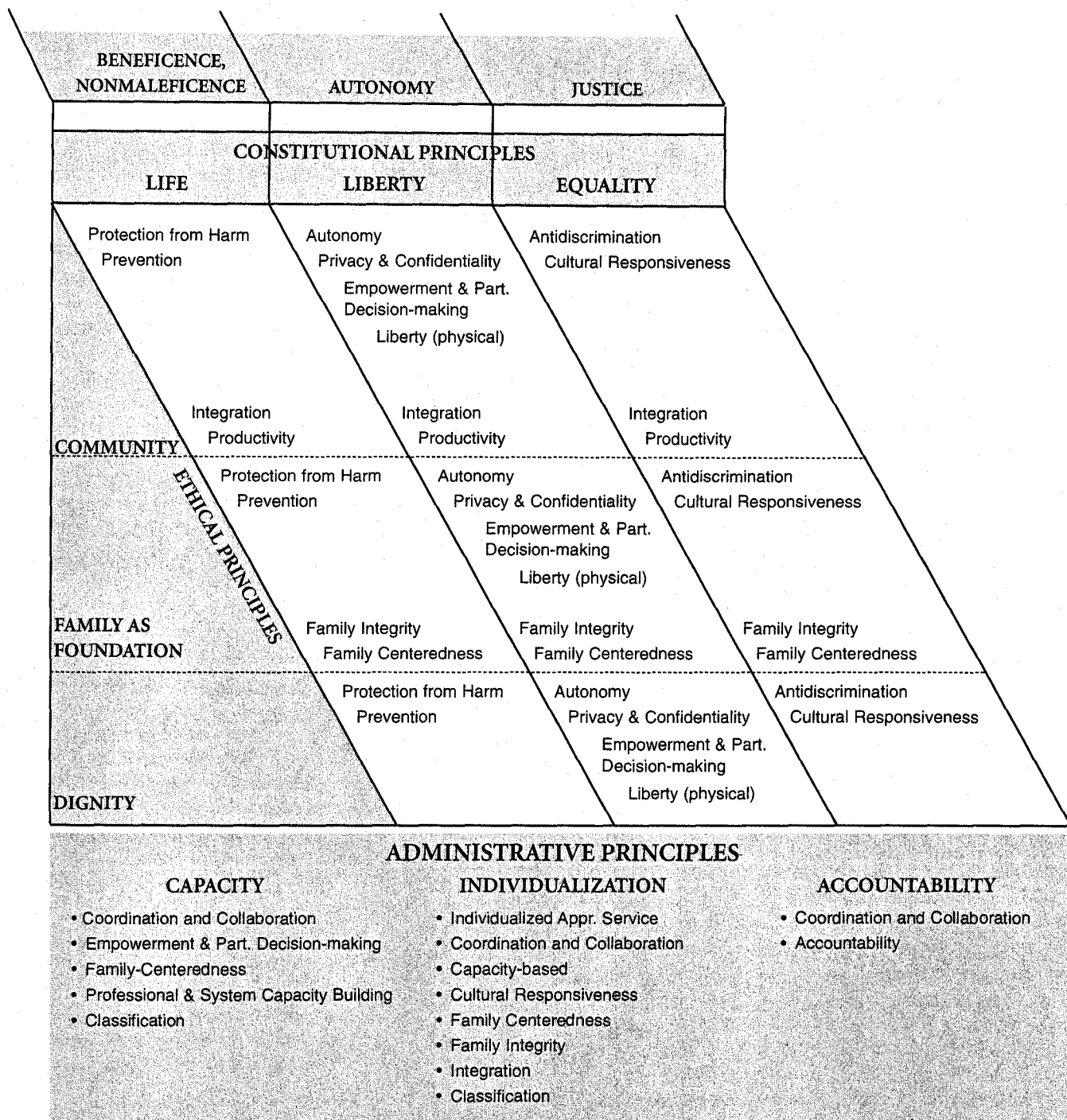


FIGURE 9.

levels of service delivery at which it should be measured Local, state, and federal service systems must contain measures to ensure accountability to individuals and families and to the appropriate legislative and executive agencies of those governments. Each professional discipline (health care, social and human services, and education) should have accountability measures. Accountability measures apply through the

political process to hold individuals instituting the policy accountable for the nature of the policy and individuals administering it accountable for its success or failure. To ensure intergovernmental (local--state--federal) accountability and interstrand (education, health, and human and social services) accountability, the results of accountability measures should be shared among the government levels and across the

service-delivery strands. The core concept of **service coordination and collaboration** is thus involved in the principle of Accountability. This is especially true in the disability field where the horizontal needs of individuals are usually addressed by vertical service systems.

Now that the relationships of the core concepts and the principles have been described, it is appropriate to look at Figure 8, which delineates the entire taxonomy: the Constitutional Principles, the Ethical Principles, and the Administrative Principles, with their associated core concepts. Although it is nearly complete, it still lacks two parts. We now address one of those, the Professional Principles.

The Professional Principles

Each of the three disciplines with which the Beach Center is concerned—social and human services, education, and health care—has its own set of professional values and ethics, which we call the Professional Principles. That they intersect with public policy is undeniable. Sometimes they are the origins upon which a principle rests; in such a case, they reinforce a core concept. Sometimes they are in tension with a principle; in this case, they undermine a core concept or cause conflict with one. By way of example, we use the Professional Principles of health care (see Figure 9) to show the relationships between (a) the Constitutional, Ethical, and Administrative Principles and (b) the Professional Principles.

Drawing upon our research in health policy, we identified four Professional Principles for health care: Beneficence (do good), Nonmaleficence (do no harm), Autonomy (dominion over self), and Justice (fairness and equity; Umbarger, 2000). Combining Beneficence and Nonmaleficence into one principle, the health-care principles roughly correspond with the Constitutional Principles. Moreover, as Figure 9 shows, these health-care principles also interact with the Ethical Principles. As can be seen in Figure 9, we include a "step" in our ramp to separate the Constitutional and Ethical Principles from the health-care principles. In doing so, we recognize that these principles are not identical and that their relationships with the Constitutional Principles are not entirely seamless.

Nevertheless, the relationships among the Constitutional, Ethical, and Professional Principles result in a nearly seamless concept of disability policy, one that may be able to meet

wholistically the needs of individuals with disabilities and their families. This is so because when linked with each other Constitutional, Ethical, and Professional Principles congeal to create a framework—a disability policy structure—in which each set of principles informs, supplements, and makes more powerful the others. That is not simply a theoretical desideratum. The practical consequences can be that a wholistic, unified theory of disability policy can comprehensively address the diverse needs of individuals with disabilities and their families; such a theory can address the horizontal needs of families who seek satisfaction of their needs from a system of vertically designed and vertically delivered policies and services.

Conclusions

Academic research into disability policy, practice, and family quality of life is justified only if it can be applied to improve the system that it studies. Now that we have identified the core concepts of disability policy and placed them into a taxonomy of Professional, Constitutional, Ethical, and Administrative Principles, two questions must be asked: How can this knowledge be used to affect policy, practice, and family quality of life? Does this research have any real-world significance for individuals with disabilities and their families?

Moreover, because our overall analytical framework demonstrates that policies, and thus core concepts, do not exist in a vacuum, and because the Beach Center's core research involves two other strands of research focusing on partnerships and family quality of life, we must ask these questions: How do we connect the core concepts and the taxonomy of principles to these other projects? And, how can each of these three research lines complement the other to further positive outcomes for individuals with disabilities and their families?

It is premature to try to answer these questions. This is so because as we have thought about the core concepts and their associated principles, we have realized that how we "think" about disability—about the condition called disability—is an essential part of, and perhaps a precursor to, the core concepts and the principles.

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