Emerging Disability Policy Framework: A Guidepost for Analyzing Public Policy

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I. INTRODUCTION

A. BACKGROUND AND PURPOSE OF THE ARTICLE

Society has historically imposed attitudinal and institutional barriers that subject persons with disabilities to lives of unjust dependency, segregation, isolation, and exclusion. Attitudinal barriers are characterized by beliefs and sentiments held by nondisabled persons about persons with disabilities. Institutional barriers include policies, practices, and procedures adopted by entities such as employers, businesses, and public agencies.1

Sometimes these attitudinal and institutional barriers are the result of deep-seated prejudice.2 At times, these barriers result from decisions to follow the “old paradigm” of considering people with disabilities as “defective” and in need of “fixing.”3 At other times, these barriers are the result of thoughtlessness, indifference, or lack of understanding.4 It is often difficult, if not impossible, to ascertain precisely why the barriers exist.

In response to challenges by persons with disabilities, their families, and other advocates, our nation’s policymakers have slowly begun to react over the past quarter of a century. They have begun to recognize the debilitating effects of these barriers on persons with disabilities and have rejected the “old paradigm.”

A “new paradigm” of disability has emerged that considers disability as a natural and normal part of the human experience. Rather than focusing on “fixing” the individual, the “new paradigm” focuses on taking effective and meaningful actions to “fix” or modify the natural, constructed, cultural, and social environment. In other words, the focus of the “new paradigm” is on eliminating the attitudinal and institutional barriers that preclude persons with disabilities from participating fully in society’s mainstream.

Aspects of the “new paradigm” were included in public policies enacted in the early 1970s.5 Between the 1970s and 1990, lawmakers further defined and society further accepted the “new paradigm.”6 In 1990, the “new paradigm” was explicitly articulated in the landmark American with Disabilities Act (ADA)7 and further

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7. 42 U.S.C. ch. 126 (1994). President Bush signed the ADA into law on July 26, 1990. Id. Senator Tom Harkin (D. Iowa), the chief sponsor of the ADA, often refers to the legislation as the “20th
refined in subsequent legislation. Many people have documented the historical mistreatment of persons with disabilities. Others have described and analyzed the ADA as a civil rights statute that prohibits discrimination in the areas of employment, public services, public accommodations, and telecommunications. Few people have stepped back to consider the fundamental beliefs and core policies that were reflected in the 1970s legislation, explicitly articulated in the ADA, and further refined in subsequent legislation. Taken as a whole, these efforts have critical implications regarding the design, implementation, and evaluation of programs and policies that affect persons with disabilities.

The purpose of this Article is to provide an Emerging Disability Policy Framework consistent with the “new paradigm” that can be used as a lens or guidepost to design, implement, and evaluate generic, as well as disability-specific, public policies and programs to ensure meaningful inclusion of people with disabilities in mainstream society.

To this end, this Article is targeted to the needs of several audiences. This Article offers a guidepost for designing, implementing, and assessing generic, as well as disability-related programs and policies for federal, state and local policymakers, as well as for persons with disabilities, their families, and their advocates. For researchers, this Article provides a benchmark for studying the extent to which generic and disability-specific policies and programs reflect the “new paradigm” and achieve its goals. For service providers, this Article provides a lens for designing, implementing, and evaluating the delivery of services to persons with disabilities. Finally, for college and university professors teaching courses that include disability policy, this Article provides a framework for policy analysis.

B. RESEARCH APPROACH AND ACTIVITIES

The research methodology applied in developing the Emerging Disability Policy Framework involved a comprehensive review and analysis of authoritative materials on disability policy, including statutes, regulations, and legislative and regulatory histories. The purpose was to discern the fundamental values, principles, and policies inherent in these laws and the extent to which they are consistent with the fundamental goals of disability policy.

In order to validate the Emerging Disability Policy Framework, analyses and interpretations were subject to peer review by key stakeholders in the outcomes of


10. Generic programs include persons with and without disabilities among the beneficiaries of assistance. An example of a generic program is the recently enacted Workforce Investment Act of 1998, Pub. L. No. 105-220, 112 Stat. 936, that establishes an integrated workforce investment preparation and employment system for all job seekers, including individuals with disabilities.
disability policy. These stakeholders included policy makers at the federal, state, and local levels; persons with disabilities, their families, and advocates; researchers; service providers; and other experts in disability policy.

C. STRUCTURE OF THE ARTICLE

This Article includes nine sections. This introduction is followed by a description of the types of laws affecting persons with disabilities. The next six sections of the Article describe the various components of the Emerging Disability Policy Framework:

- Rationale and Statement of Findings
- Precept and Overarching Goals
- Definitions of Disability
- Core Policies
- Methods of Administration
- Model Support Programs

The Article concludes with an audit—a checklist of questions that stakeholders can use to assess the extent to which generic, as well as disability-specific, programs or policies reflect the concepts of the Emerging Disability Policy Framework. Throughout the Article, references are made to specific laws. These references are not intended to be exhaustive; rather, they are intended to be illustrative of a particular point. The specific examples in this Article provide exemplary illustrations from various contexts, such as civil rights, education, employment and health care.

Specifically, Section II provides an overview of the types of laws affecting persons with disabilities, such as civil rights statutes, entitlement programs, formula and discretionary grants, regulatory statutes, and legislation allowing appropriation of funds.

Section III provides examples of rationales, known as statements of findings, for selected policy initiatives. The rationale includes the historical treatment of persons with disabilities, the nature of the problem to be addressed, why the issue is important and why change is needed, and the role of various entities in designing, implementing, and evaluating the changes.

In Section IV, the Article articulates the precept that disability is an immutable characteristic and, like race and gender, is a natural and normal part of the human experience that in no way diminishes a person’s right to participate fully in all aspects of society. Section IV also lists the four overarching goals of disability policy articulated in the ADA—“equality of opportunity, full participation, independent living, and economic self-sufficiency.”

Section V provides several definitions of disability. For purposes of civil rights statutes, the various definitions are used to determine whether an individual is part of the protected class. Definitions for formula grant and entitlement programs are used to determine eligibility.

In Section VI, the Article describes the key concepts that further define and clarify the four overarching goals of disability policy described in Section IV. These key concepts are referred to as “core policies.”

Section VII describes the administrative and accountability provisions (such as monitoring enforcement, procedural safeguards, outcome measures, methods for financing programs, and training) that maximize the likelihood that the “core policies” of the Emerging Disability Policy Framework are implemented correctly. These provisions are referred to as “methods of administration.”

Section VIII explains the support programs (such as systems-change initiatives and research and technical assistance) included in the Emerging Disability Policy Framework, designed to ensure that initiatives conform to best practices.

As described previously, Section IX is the concluding audit—a checklist of questions that stakeholders can use to assess the extent that generic, as well as disability-specific, programs or policies reflect the components of the Emerging Disability Policy Framework: rationale and statement of findings, precept, goals, definitions and eligibility criteria, core policies, methods of administration, and support programs.

Appendix 1 sets out (in a narrative outline form) many of the key components of the Emerging Disability Policy Framework described in the paper. The first Appendix also reiterates general questions for analyzing the extent to which generic and disability-specific programs and policies reflect the Emerging Disability Policy Framework. Appendix 1 can be used as a lens or guidepost to design, implement, and evaluate generic, as well as disability-specific, public policies and programs to ensure meaningful inclusion of people with disabilities into mainstream society. Since the Appendix is designed for use as a free-standing document, it includes its own table of contents. Appendix 2 describes major disability-related legislation enacted between 1956 and 2000. Appendix 3 includes descriptions and references to web sites for federal disability-related legislation, regulations, and court cases. Appendix 4 includes a glossary of acronyms used throughout the paper.

II. CATEGORIES OF LAWS AFFECTING INDIVIDUALS WITH DISABILITIES

Stakeholders who identify problems affecting persons with disabilities and who seek to ameliorate these problems through legislation must consider the most appropriate and politically expedient legislation available.

Current laws affecting people with disabilities can be arranged into the following five general categories:

- Civil rights statutes,
- Entitlement programs,
- Discretionary grant-in-aid programs,
- Regulatory statutes, and
- Miscellaneous provisions that include appropriations, tax legislation, and loans.

For example, some laws, such as entitlement programs, guarantee eligible individuals a specified level of benefits. These laws require that the legislative body appropriate funds sufficient to meet the entitlement. Other laws, such as discretionary grant-in-aid programs, provide benefits only to the extent that the legislative body decides to exercise its discretion to appropriate funds to, in turn, pay for the benefits.
The type of law stakeholders pursue depends on their purposes and priorities. For example, persons with disabilities tend to favor legislation that entitles or guarantees them benefits regardless of legislative funding priorities. On the other hand, policymakers who are primarily concerned with budget issues tend to disfavor legislation that offers guarantees or entitlements and instead prefer grant programs that allow funding discretion.

Some laws cross over into more than one category. Some laws are both civil rights statutes and discretionary grant-in-aid programs. For example, under Part B of the Individuals with Disabilities Education Act (IDEA), children with disabilities are entitled to a free appropriate public education consistent with the Equal Protection Clause of the Fourteenth Amendment to the U.S. Constitution. It is thus a civil rights statute. In addition, Part B of IDEA is a grant-in-aid program providing financial assistance to states.

This section describes each of the five general categories of laws. In addition, the section provides examples of major disability-specific and generic laws for each category.

**A. Civil Rights Statutes**

The first category of laws includes federal civil rights statutes that prohibit covered entities (such as state or local governments, and businesses) from discriminating against individuals on the basis of or by reason of disability. These laws are permanent in nature because they do not expire on a certain date. Federal agencies play a key role with respect to the administration of these civil rights statutes, including policy development, complaint resolution, monitoring, and enforcement. Nothing in these federal civil statutes precludes a state or local community from adopting additional protections.

Examples of civil rights statutes include:

- The Americans with Disabilities Act (ADA), which prohibits discrimination on the basis of disability in employment, public services (including transportation), public accommodations and telecommunications.\(^{12}\)
- Section 504 of the Rehabilitation Act of 1973, which prohibits discrimination by recipients of federal aid, such as hospitals, universities, and public schools.\(^{13}\)
- The Fair Housing Act of 1968 as amended in 1988, which adds persons with disabilities to the groups that are protected from discrimination in multi-family housing and ensures that persons with disabilities may adapt their dwelling place to meet their needs.\(^{14}\)

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Part B IDEA, which guarantees all children with disabilities a free and appropriate public education, in accordance with the Equal Protection Clause of the Fourteenth Amendment to the U.S. Constitution.15

B. ENTITLEMENT PROGRAMS

The second category of laws affecting people with disabilities involves “open and close ended” entitlement programs.

“Open-ended” entitlement programs guarantee eligible individuals a specified level of benefits. As more people become eligible for the program, costs automatically rise. These programs are often referred to as “mandatory spending” programs because Congress must appropriate sufficient funds to pay for the benefits. Examples include:

- **Social Security Disability Insurance (SSDI) Program**
  
  Title II of the Social Security Act, which authorizes a program of federal disability insurance benefits for workers who have both contributed to the Social Security Trust Fund and become disabled (or blind) before retirement age. Spouses with disabilities and dependent children of fully insured workers are also eligible for benefits upon the retirement, disability, or death of the primary beneficiary. This program, which is commonly referred to as the Social Security Disability Insurance (SSDI) program, is administered by the Social Security Administration.16

- **Supplemental Security Income (SSI) Program**

   Title XVI of the Social Security Act, which establishes the Supplemental Security Income (SSI) program, a federally administered cash assistance program for individuals who are aged, blind, or disabled and meet a financial needs test (income and resource limitations).17

- **Medicare Program**

   Title XVIII of the Social Security Act, which establishes the Medicare program. Medicare provides health insurance benefits for elderly persons and certain persons with disabilities (e.g., workers with disabilities receiving SSDI benefits). Title XVIII is divided into three parts. Part A authorizes hospital insurance benefits; Part B provides for supplemental medical insurance benefits; and Part C contains miscellaneous provisions, including coverage for end-stage renal disease.18


Medicaid Program

Title XIX of the Social Security Act, which establishes the Medicaid program. Medicaid is the nation’s major public financing program for providing health and long-term coverage to low-income persons. Medicaid is a state-administered, means-tested entitlement program that is financed by the state and federal governments. Within federal guidelines, states set their own income and asset eligibility criteria for Medicaid. Federal assistance is provided to states for coverage of specific groups of people and benefits through federal matching payments based on the state’s per capita income.

Medicaid covers a broad range of services to meet the needs of beneficiaries. Federally mandated services include: inpatient and outpatient hospital; physician; midwife and certified nurse practitioner; laboratory and x-ray; nursing home and home health care; early and periodic screening, diagnosis and treatment (EPSDT) for children under age twenty-one; family planning and ambulatory services offered by rural health clinics; and federally qualified health centers.

States have the option of paying for additional services such as prescription drugs, personal assistance services, prosthetic devices, hearing aids, and intermediate care facilities for the mentally retarded. States also have the option of limiting the amount, duration, and scope of such services as long as adequate care is provided.

The Secretary of Health and Human Services is authorized to grant waivers to allow a state to, among other things, offer Medicaid-reimbursable home and community-based services and supports (other than room and board) to certain individuals who, in the absence of such services, would require institutional care. These waivers are authorized when the costs (in the aggregate) under the waiver do not exceed the cost of providing institutional care to the target population.

A “close-ended” entitlement program does not create an individual guarantee or entitlement to assistance; rather it provides a state or other entity with a fixed allotment of funds over a specified period of time. In other words, unlike under the mandatory spending programs, individuals receive bene-

fits only to the extent that funds are available. Examples include:

- **Vocational Rehabilitation Program**
  Title I of the Rehabilitation Act of 1973, which assists states in operating a comprehensive, coordinated, effective, efficient, and accountable program of vocational rehabilitation for persons with disabilities.\(^{23}\) At a minimum, states are entitled to last year’s appropriation plus an inflationary increase.\(^{24}\)

- **Children’s Health Insurance Program**
  Title XXI of the Social Security Act, otherwise known as the State Children’s Health Insurance Program (CHIP), which guarantees $40 billion to states until 2007 to provide health insurance for low-income children who do not qualify for Medicaid, including children with disabilities.\(^{25}\)

### C. DISCRETIONARY GRANT-IN-AID PROGRAMS

Discretionary grant-in-aid programs comprise the third category of laws affecting people with disabilities. These programs provide supplementary federal financial assistance to support specified activities carried out by other entities, such as state and local public agencies and private agencies. Some discretionary grant programs are specifically targeted at meeting the needs of persons with disabilities; others are generic and are targeted at specified populations or purposes, which include, but are not limited to, meeting the needs of persons with disabilities.

There are two types of discretionary grant-in-aid programs: formula programs and competitive grant programs. Both types of grant programs are subject to annual appropriations by Congress. These programs are referred to as “discretionary” because Congress may appropriate whatever amount of funds it deems necessary or adequate.

#### 1. Formula Grant Programs

Formula grant programs support ongoing activities of and foster systemic change by state or local government agencies or nonprofit organizations. A “formula” is expounded by the legislation and specifies the exact amount of funds each entity will receive.

Examples of formula grant programs to state and local agencies that are targeted specifically at meeting the needs of individuals with disabilities include:

- **Public Education**
Part B of IDEA, which provides financial assistance to state and local educational agencies to help those agencies meet their constitutional responsibilities to provide a free and appropriate public education to children with disabilities.  

- **Early Intervention**
  Part C of IDEA, which assists states in the implementation of a statewide, comprehensive, coordinated, multidisciplinary, interagency system of early intervention services for infants and toddlers with disabilities and their families.

- **Employment Services**
  Part B of Title VI of the Rehabilitation Act of 1973, which assists states in developing collaborative programs with appropriate entities to provide supported employment services for individuals with the most significant disabilities. Such individuals require ongoing support services to enter or retain competitive employment.

- **Independent Living Services**
  Part B of Title VII of the Rehabilitation Act of 1973, which assists states in providing, expanding, and improving the provision of independent living services.

- **State Developmental Disabilities Councils**
  Part B of the Developmental Disabilities Assistance and Bill of Rights Act, which supports State Developmental Disabilities Councils in each state to assist individuals with developmental disabilities by promoting their independence, productivity, integration, and inclusion into the community.

Some formula grant programs allocate a specified amount to a state and then target funds to nonprofit organizations within each state, focusing exclusively on meeting the needs of persons with disabilities. Examples include:

- **Statewide Networks for Centers for Independent Living**
  Part A of Title VII of the Rehabilitation Act of 1973, which provides financial assistance to develop and support statewide networks for centers for independent living.

- **Protection and Advocacy Systems**

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Part C of the Developmental Disabilities Assistance and Bill of Rights Act, which supports protection and advocacy systems in each state to protect the legal and human rights of individuals with developmental disabilities.32

Examples of generic formula grant programs that include specific references to or set-asides for individuals with disabilities include:

- **Job Training**
  Title I (Workforce Investment Systems) of the Workforce Investment Act of 1998, which provides workforce investment activities—like job training—through state and local workforce investment systems, that increase employment and enhance the productivity and competitiveness of the United States.33

- **School Reform**
  School reform legislation (e.g., Goals 2000: Educate America Act), which encourages comprehensive state and local school reform based on high expectations and standards.34

- **Early Childhood Education**
  Early childhood education includes programs like Head Start, which provides comprehensive services to economically disadvantaged preschool children and their families.35 Recipients must ensure that at least ten percent of program participants are children with disabilities.

- **Social Services**
  The Social Service block grant program (under Title XX of the Social Security Act), which enables participating states to, among other things, provide special services to persons with disabilities and reduce or prevent inappropriate institutional care.36

- **Maternal and Child Health**
  The Maternal and Child Health Services block grant (under Title V of the Social Security Act),37 which enables states to provide and promote family-centered, community-based coordinated care, particularly for children with special health care needs.

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2. Competitive Grant Programs

A second category of discretionary grant-in-aid programs involves awards based on competition, rather than on a formula. Typically, a federal agency will announce the existence of a competition and publish requests for proposals. Applicants then submit proposals, which are often subject to peer review by experts in the field. Finally, the federal agency announces the grant awards.

Competitive grants allow entities to develop a better understanding of a problem, create new knowledge, or train persons to provide necessary services. In addition, the need for federal assistance can best be determined by considering specific information provided in grant applications. Examples include:

- **Rehabilitation Research**
  Research, demonstration projects, and training and related activities with respect to individuals with disabilities, which is funded by the National Institute on Disability and Rehabilitation Research (NIDRR)\(^\text{38}\) and was established under Title II of the Rehabilitation Act of 1973.

- **Assistive Technology**
  The Technology-Related Assistance for Individuals with Disabilities Act of 1988, which provides assistance to states in developing and implementing a consumer-responsive comprehensive statewide program of technology-related assistance for individuals with disabilities.\(^\text{39}\)

- **University Affiliated Programs**
  Part D of the Developmental Disabilities Assistance and Bill of Rights Act, which provides grants to university-affiliated programs to promote independence, productivity, integration, and inclusion into the community of individuals with developmental disabilities through, among other things, interdisciplinary training and information dissemination.\(^\text{40}\)

- **Medical Research**
  Medical research (e.g., gaining a better understanding of autism) is funded by the National Institute of Health, and is authorized under Title IV, Part A of the Public Health Services Act.\(^\text{41}\)

- **ADA Technical Assistance**
  The ADA authorizes technical assistance to individuals with disabilities and covered entities. NIDRR funds ten Disability

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and Business Technical Assistance Centers to help entities comply with the ADA.\textsuperscript{42}

- **Training of Educators**
  Subpart 2 of Part D of IDEA supports preservice and in-service training of general educators as well as special educators, related services personnel, and early intervention personnel.\textsuperscript{43}

- **Training of Parents**
  Section 682 of IDEA supports parent training and information centers.\textsuperscript{44}

- **Work Incentive Outreach Program**
  Section 1149 of the Social Security Act, added by the Ticket to Work and Work Incentives Improvement Act,\textsuperscript{45} directs the Commissioner of the Social Security Administration to establish a community-based work incentives planning and assistance program to disseminate accurate information regarding work incentives.

Sometimes, programs start on a small scale as competitive grant programs and are then amended to become formula grants when the appropriation increases. One example is the following:

Section 509 of the Rehabilitation Act of 1973, which provides assistance to support a system in each state to protect the legal and human rights of individuals with disabilities who need services and are ineligible for other similar programs. The program changed from a competitive to a formula grant when appropriations exceeded $5.5 million.\textsuperscript{46}

\section*{D. Regulatory Statutes}

The fourth category of laws affecting people with disabilities includes regulatory legislation that provides minimum protections for a class of persons (including, but not limited to, persons with disabilities). Examples include:

- **Voter Registration**
  The National Voter Registration Act of 1993 requires states to provide enhanced voter registration services at locations where driver's licenses, public assistance, and state disability-related services are provided.\textsuperscript{47}

\begin{footnotes}
\footnote{42}{ADA § 506, 42 U.S.C. § 12206 (1994).}
\footnote{43}{20 U.S.C. §§ 1461-1474 (Supp. IV 1998).}
\footnote{44}{20 U.S.C. § 1482 (Supp. III 1997).}
\footnote{45}{Ticket to Work and Work Incentives Improvement Act, Pub. L. No. 106-170, 113 Stat. 1860.}
\footnote{47}{Pub. L. No. 103-31, 107 Stat. 77.}
\end{footnotes}
Family Leave

The Family and Medical Leave Act, among other things, allows workers to take up to twelve weeks of unpaid leave to care for newborn children, newly adopted children, and family members with serious health conditions. It also permits workers to take the same leave to recover from their own serious health conditions.48

Telecommunications

Section 225 of the Telecommunications Act of 1996 requires that telecommunications equipment and services be accessible to persons with disabilities if readily available.49

E. MISCELLANEOUS CATEGORY OF LAWS, INCLUDING APPROPRIATIONS, TAX LEGISLATION, AND LOANS

The fifth category of laws affecting people with disabilities includes appropriations bills that provide the funding for various programs. These bills and the accompanying reports often direct various departments and agencies to spend discretionary funds in a specified fashion, including addressing the needs of persons with disabilities.

In addition, the tax code is sometimes used to enhance opportunities for individuals with disabilities directly, or to provide incentives for covered entities to comply with existing responsibilities. Examples include:

- The Disabled Access Tax Credit, 50 which provides tax credits to small businesses for expenses incurred in becoming compliant with the Americans with Disabilities Act.
- The Targeted Jobs Credit, 51 which provides tax credits for hiring new employees with disabilities who are referred by vocational rehabilitation and other specified agencies.

III. STATEMENT OF FINDINGS AND RATIONALE

Once stakeholders have determined the category of legislation that is most appropriate and politically expedient, they must carefully construct a rationale, known as a “Statement of Findings,” for the proposed legislation. A well-constructed Statement of Findings includes four major items:

1. A description of the historical treatment of persons with disabilities,
2. A summary of the nature of the problem addressed by the proposed legislation,

3. Guidance as to why the issue is important and why change is needed, and

4. An explanation of the role of various entities in designing, implementing, and evaluating the legislation.

A well-constructed Statement of Findings facilitates enactment of the legislation by convincing policymakers of its merits. Once the legislation is enacted, the rationale provides a clear statement to guide implementation of the law.

Examples of Statements of Findings from three statutes are described below.

The ADA (civil rights legislation) includes the following in the Statement of Findings:

1. some forty-three million Americans have one or more physical or mental disabilities, and this number is increasing as the population as a whole is growing older;

2. historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem;

3. discrimination against individuals with disabilities persists in such critical areas as employment, housing, public accommodations, education, transportation, communication, recreation, institutionalization, health services, voting, and access to public services;

4. unlike individuals who have experienced discrimination on the basis of race, color, sex, national origin, religion, or age, individuals who have experienced discrimination on the basis of disability have often had no legal recourse to redress such discrimination;

5. individuals with disabilities continually encounter various forms of discrimination, including outright intentional exclusion, the discriminatory effects of architectural, transportation, and communication barriers, overprotective rules and policies, failure to make modifications to existing facilities and practices, exclusionary qualification standards and criteria, segregation, and relegation to lesser services, programs, activities, benefits, jobs, or other opportunities;

6. census data, national polls, and other studies have documented that people with disabilities, as a group, occupy an inferior status in our society, and are severely disadvantaged socially, vocationally, economically, and educationally;

7. individuals with disabilities are a discrete and insular minority who have been faced with restrictions and limitations, subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society, based on characteristics that are beyond the control of such individuals and resulting from
stereotypic assumptions not truly indicative of the individual ability of such individuals to participate in and contribute to society;

8. the Nation’s proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals; and

9. the continuing existence of unfair and unnecessary discrimination and prejudice denies people with disabilities the opportunity to compete on an equal basis and to pursue those opportunities for which our free society is justifiably famous, and costs the United States billions of dollars in unnecessary expenses resulting from dependency and non-productivity.  

In the employment context, when Congress enacted the Rehabilitation Act of 1973, it included, among other things, the following findings:

1. Congress finds that—

   A. [W]ork
   
   i. is a valued activity, both for individuals and society; and
   
   ii. fulfills the need of an individual to be productive, promotes independence, enhances self-esteem, and allows for participation in the mainstream of life in America;

   B. as a group, individuals with disabilities experience staggering levels of unemployment and poverty;

   C. individuals with disabilities, including individuals with the most severe disabilities, have demonstrated their ability to achieve gainful employment in integrated settings if appropriate services and supports are provided;

   D. reasons for the significant number of individuals with disabilities not working, or working at a level not commensurate with their abilities and capabilities, include—
   
   i. discrimination;

   ii. lack of accessible and available transportation;

   iii. fear of losing health coverage under the medicare and medicaid programs . . . or fear of losing existing private health insurance; and

   iv. lack of education, training, and supports to meet job qualification standards necessary to enter or retain or advance in employment . . .

52. ADA § 2(a), 42 U.S.C. § 12101(a) (1994).

In education, Congress included, among other things, the following findings in the IDEA:

2. Before the enactment of the Education for All Handicapped Children Act of 1975 (Public Law 940142)—
   A. the special education needs of children with disabilities were not being fully met;
   B. more than one-half of the children with disabilities in the United States did not receive appropriate educational services that would enable such children to have full equality of opportunity;
   C. 1,000,000 of the children with disabilities in the United States were excluded entirely from the public school system and did not go through the educational process with their peers . . . .

* * *

4. However, the implementation of [IDEA] has been impeded by low expectations, and an insufficient focus on applying replicable research on proven methods of teaching and learning for children with disabilities.

* * *

6. While States, local educational agencies, and educational service agencies are responsible for providing an education for all children with disabilities, it is in the national interest that the Federal government have a role in assisting state and local efforts to educate children with disabilities . . . and to ensure equal protection of the law.

7(A). The Federal government must be responsive to the growing needs of an increasingly more diverse society.54

IV. STATEMENT OF PRECEPT AND OVERARCHING GOALS

In addition to the inclusion of a “Statement of Findings” section, most major disability-specific legislation enacted into law since 1975 includes a statement of precept and goals. As with the “Statement of Findings,” a well-constructed precept and statement of goals further facilitates enactment of the legislation by convincing policymakers of the merits of the legislation. Once the legislation is enacted, the precept and goals provide clear statements to guide implementation of the law. In addition, the precepts and goals provide guidance when there is uncertainty over legislative intent.

Sometimes, the statements of precept and goals are part of the “Statement of Findings” section; other times, they are included as a separate section, sometimes referred to as the “Purpose” section or “Statement of Policy.”

The precept of disability policy and examples of goal statements, which are

EMERGING DISABILITY POLICY FRAMEWORK

included in disability-specific legislation, are set out below.

The precept of disability policy is the following:

[D]isability is a natural part of the human experience that in
no way diminishes the right of individuals to—

A. live independently
B. enjoy self-determination
C. make choices
D. contribute to society
E. pursue meaningful careers and
F. enjoy full inclusion and integration in the economic, politi-
cal, social, cultural, and educational mainstream of Ameri-

The ADA includes the following statement of policy articulating our Nation’s
goals regarding people with disabilities: “[T]he Nation’s proper goals regarding

The Rehabilitation Act of 1973, as amended, includes important statements of

1. The goals of the Nation properly include the goal of providing indi-

involvement.58

The IDEA includes, among other things, the following statements of policy that focus both on the rights of children with disabilities and the rights of parents:

Over twenty years of research and experience has demonstrated that the education of children with disabilities can be made more effective by:

having high expectations for such children—and ensuring their access in the general curriculum to maximum extent possible;

strengthening the role of parents and ensuring that families of such children have meaningful opportunities to participate in the education of their children at school and at home.59

The Developmental Assistance and Bill of Rights Act includes important statements of policy applicable to persons with developmental disabilities and their families that are consistent with the goals articulated in the ADA:

c. POLICY—It is the policy of the United States that all programs, projects, and activities receiving assistance under this Act shall be carried out in a manner consistent with the principles that—

1. individuals with developmental disabilities, including those with the most severe developmental disabilities, are capable of achieving independence, productivity, and integration and inclusion into the community, and often require the provision of services, supports and other assistance to achieve independence, productivity, and integration and inclusion;

2. individuals with developmental disabilities and their families have competencies, capabilities and personal goals that should be recognized, supported, and encouraged, and any assistance to such individuals should be provided in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities of such individuals;

3. individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive and play decisionmaking roles in policies and programs that affect the lives of such individuals and their families;

4. services, supports, and other assistance are provided in a manner that demonstrates respect for individual dignity, personal preferences, and cultural differences;

5. specific efforts must be made to ensure that individuals from racial and ethnic minority backgrounds enjoy effective

and meaningful opportunities for full participation in the developmental disabilities service system;

6. recruitment efforts within developmental disabilities at the level of preservice training, community training, practice, administration and policymaking must focus on bringing larger numbers of racial and ethnic minorities into the field in order to provide appropriate skills, knowledge, role models, and sufficient manpower to address the growing needs of an increasingly diverse population;

7. with education and support, communities can be responsive to the needs of individuals with developmental disabilities and their families and are enriched by the full and active participation and the contributions by individuals with developmental disabilities and their families; and

8. individuals with developmental disabilities should have access to opportunities and the necessary support to be included in community life, have interdependent relationships, live in homes and communities, and make contributions to their families, community, State, and Nation.60

V. DEFINITIONS OF DISABILITY

In addition to constructing a Statement of Findings and the precept and overarching goals of the legislation, stakeholders must define who will be protected or will benefit from the proposed legislation.

All laws include definitions of key terms. The definition of disability is drafted to accomplish the purposes of the legislation. For this reason, the term “disability” may be defined differently in every piece of legislation. Civil rights statutes, for example, require a definition of disability to determine which individuals will be protected by the legislation. The definition of who is a person with a disability is also included in a formula grant and an entitlement program to determine which individuals are eligible for benefits or services.

Examples of definitions from civil rights statutes, entitlement programs, and discretionary grant-in-aid programs are listed below.

The definition of disability included in the ADA and section 504 of the Rehabilitation Act of 1973 (civil rights statutes) is sufficiently broad to reflect the three types of discrimination that people with disabilities face—discrimination based on one’s impairment, discrimination based on a history of having an impairment (even though the individual no longer has the impairment), and discrimination based on being regarded as having an impairment (even though the individual does not actually have that impairment).

Therefore, the definition of “disability” in the ADA includes three prongs to reflect these three types of discrimination. The ADA specifies that the term “disability” means, with respect to an individual, “a physical or mental impairment that

substantially limits one or more of the major life activities of such individual; a
record of such an impairment; or being regarded as having such an impairment.” 61
The identical definition is applicable to section 504 of the Rehabilitation Act of
1973.62

The ADA also includes definitions of the term “qualified individual with a
disability.” For the purpose of Title I of the ADA (relating to employment), the
term means “an individual with a disability who, with or without reasonable ac-
commodation, can perform the essential functions of the employment position that
such individual holds or desires.” 63 For the purpose of Title II of the ADA (public
services), the term means:

[A]n individual with a disability who, with or without reasonable modi-
fications to rules, policies, or practices, the removal of architectural,
communication, or transportation barriers, or the provision of auxiliary
aids and services meets the essential eligibility requirements for the re-
ceipt of services or the participation in programs or activities provided
by a public entity.64

The definition of disability for an adult in the SSI program (an entitlement
program providing income support for low-income individuals with disabilities) is
defined in the following manner:

3.A. An individual shall be considered to be disabled for purposes of this
subchapter if he is unable to engage in any substantial gainful activity by
reason of any medically determinable physical or mental impairment
which can be expected to result in death or which has lasted for a con-
tinuous period of not less than twelve months (or, in the case of an indi-
vidual under the age of 18, if he suffers from any medically determin-
able physical or mental impairment of comparable severity).65

B. For purposes of subparagraph (A), an individual shall be determined
to be under a disability only if his physical or mental impairment or im-
pairments are of such severity that he is not only unable to do his previ-
ous work but cannot, considering his age, education, and work experi-
ence, engage in any other kind of substantial gainful work which exists
in the national economy, regardless of whether such work exists in the
immediate area in which he lives, or whether a specific job vacancy ex-
sists for him, or whether he would be hired if he applied for work. For
purposes of the preceding sentence (with respect to any individual),
“work which exists in the national economy” means work which exists
in significant numbers either in the region where such individual lives or
in several regions of the country.66

C. For purposes of this paragraph, a physical or mental impairment is an

impairment that results from anatomical, physiological, or psychological abnormalities which are demonstrable by medically acceptable clinical and laboratory diagnostic techniques.\textsuperscript{67}

The term “disability,” as it relates to children under the SSI program, is defined as follows:

C.i. An individual under the age 18 shall be considered disabled for the purposes of this title if that individual has a medically determinable physical or mental impairment, which results in marked and severe functional limitations, and which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.

ii. Notwithstanding clause (i), no individual under the age 18 who engages in substantial gainful activity (determined in accordance with regulations prescribed pursuant to subparagraph (E)) may be considered to be disabled.\textsuperscript{68}

The definition of “disability” included under Part B of the IDEA, under which a child is entitled to special education and related services necessary to address his or her unique needs, is limited to children:

A. In general. The term “child with a disability” means a child—

i. with mental retardation, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance (hereinafter referred to as ‘emotional disturbance’), orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities; and

ii. who, by reason thereof, needs special education and related services.

B. Child aged 3 through 9. The term ‘child with a disability’ for a child aged 3 through 9 may, at the discretion of the State and the local educational agency, include a child—

i. experiencing developmental delays, as defined by the State and as measured by appropriate diagnostic instruments and procedures, in one or more of the following areas: physical development, cognitive development, communication development, social or emotional development, or adaptive development; and

ii. who, by reason thereof, needs special education and related services.\textsuperscript{69}

The definition included under Title I of the Rehabilitation Act of 1973 (the


\textsuperscript{68} Id.

vocational rehabilitation program) is limited to an individual with a disability who:

[H]as a physical or mental impairment which for such individual constitutes or results in a substantial impediment to employment; and can benefit in terms of an employment outcome from vocational rehabilitation services provided pursuant to title I, III, or VI.70

Under Title I of the Rehabilitation Act of 1973, an individual is eligible for services if the individual “is an individual with a disability . . . and requires vocational rehabilitation services to prepare for, enter, engage in, or retain gainful employment.”71

The term “developmental disability,” under the Developmental Disabilities Assistance and Bill of Rights Act (supports Developmental Disabilities Councils, Protection and Advocacy Systems, and University Affiliated Programs), means the following:

The term “developmental disability” means a severe, chronic disability of an individual 5 years of age or older that—
A. is attributable to a mental or physical impairment or combination of mental and physical impairments;
B. is manifested before the individual attains age 22;
C. is likely to continue indefinitely;
D. results in substantial functional limitations in three or more of the following areas of major life activity—
   i. self-care;
   ii. receptive and expressive language;
   iii. learning;
   iv. mobility;
   v. self-direction;
   vi. capacity for independent living; and
   vii. economic self-sufficiency; and
E. reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is lifelong or extended duration and is individually planned and coordinated, except that such term, when applied to infants and young children means individuals from birth to age five, inclusive, who have substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disabilities if services are not provided.72

VI. CORE POLICIES

Once the rationale and goals for the proposed legislation are specified and definitions of disability have been established, it is critical for stakeholders to specify the core policies. These statements of core policies are vital because they describe the scope and limitations of the protections. In addition, the core policies describe the nature and type of benefits as well as the circumstances under which benefits and services will be provided.

The numerous core policies can best be understood when they are organized under the four goals of disability policy articulated in the ADA—equality of opportunity, full participation (empowerment), independent living, and economic self-sufficiency.

Examples of core policies from various categories of legislation affecting people with disabilities are provided below.

A. EQUALITY OF OPPORTUNITY

The first goal of disability policy articulated in the ADA is equality of opportunity. For purposes of this paper, the goal is accomplished through the following four broad categories of policies:

- Individualization and Interdisciplinary Assessments,
- Genuine, Effective, and Meaningful Opportunity: Accommodations, Auxiliary Aids and Services, and Program Accessibility,
- Genuine, Effective, and Meaningful Treatment: Modifications of Policies and Procedures, and
- Treatment in the Most Integrated Setting Appropriate.

1. Individualization and Interdisciplinary Assessments

A fundamental concept in disability policy is the importance of focusing on the individual and the individual’s unique needs. Decisions must be based on the unique strengths, resources, priorities, concerns, abilities, and capabilities of each person with a disability, including individuals with the most significant disabilities. It is essential that decisions be based on facts relevant to the individual and objective evidence, not on generalizations about all people with disabilities or all people with a particular disability. Decisions cannot be based on fear, stereotypes, or generalizations. Thus, individualized, fact-specific, case-by-case inquiry is a core principle of disability policy.

Similarly, if an individual with a disability and a nondisabled person both require and are eligible for a service, such as child care, the person with a disability should not be denied the services simply because he or she has a disability. People with disabilities must be judged on the basis of objective criteria and facts, not fear, ignorance, prejudice, or stereotypes. In other words, agencies must use definitions and eligibility criteria that result in even-handed treatment between a person with a particular disability and other similarly situated individuals, including nondisabled persons and persons with other disabilities.
Generic programs (such as job training, welfare, child care, Head Start) must provide universal access, and thereby serve qualified individuals with disabilities instead of simply referring all people with disabilities to disability-specific programs.

Accurate fact-specific, case-by-case inquiries often require individualized assessments and evaluations. In turn, these assessments and evaluations often require interdisciplinary approaches performed on a timely basis by teams of qualified individuals. To ensure the effectiveness and reliability of these assessments, they must be conducted across multiple environments, including “real” settings where the individual functions, as well as clinical settings. In making these fact-specific decisions, it is necessary to use information provided by the individual with a disability and the person’s family or representative.

Once the stakeholders identify and agree to the goals, objectives, services, and accountability measures, this agreement is memorialized in an individualized plan.

In the civil rights context, under section 202 of the ADA and section 504 of the Rehabilitation Act of 1973, the concept of individualization means that “no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.”73 In addition, the ADA regulation74 and the section 504 coordination regulation75 specify that a public entity, in providing any aid, benefit, or service, may not, on the basis of disability:

- deny a qualified individual with a disability the opportunity to participate in or benefit from the aid, benefit, or service;
- unequally treat a qualified individual with a disability in participating in or benefiting from the aid, benefit, or service;
- otherwise limit a qualified individual with a disability in the enjoyment of any right, privilege, advantage or opportunity enjoyed by others receiving the aid, benefit, or service.76

In the employment context, Title I of the Rehabilitation Act of 1973 requires an individualized plan for employment.77 These plans are jointly agreed to and signed by eligible individuals with disabilities (or their representatives in appropriate situations) and vocational rehabilitation counselors. These plans are based on assessments performed by qualified personnel and existing data, including data provided by the individual with a disability.

In the educational context, under the IDEA, making individualized determinations includes providing special education and related services to a child with a disability in accordance with an individualized education program developed by a team of persons, including the parents of the child and, where appropriate, the

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74. 28 C.F.R. § 35.130 (1999).
75. 28 C.F.R. § 41.51(b)(1) (1999).
child. These decisions are based on comprehensive individualized evaluations completed by interdisciplinary teams performed in multiple environments. The evaluation is conducted to determine whether the individual has a disability and is in need of special education and related services, as well as to pinpoint the types of services needed.

In the health care context, under the Early and Periodic Screening, Diagnosis, and Treatment Program (EPSDT), states must adopt a comprehensive process through which individual children are screened for health deficiencies and, where appropriate, further diagnosed, and treated (to the extent medically necessary services are required to treat the condition). Screening services include, among other things, a comprehensive health and developmental history (including assessment of both physical and mental health development and a comprehensive, unclothed, physical exam).

Another key concept in disability policy is to serve all individuals with disabilities, including individuals with the most significant disabilities, and to give priority to those persons when funds are limited.

Historically, public and private entities excluded persons with the most significant disabilities from receiving services made available to nondisabled persons and persons with moderate disabilities. A prime example was many states’ exclusion of children with significant disabilities from public education. For instance, the State of Maine actually had a policy that authorized the local school superintendent of schools to exclude “any child whose physical or mental condition make it inexpedient for him to attend.”

In 1975, the IDEA was enacted, including a “zero reject” policy under which all children with disabilities, including those with the most significant disabilities, are entitled to a free and appropriate public education. Congress adopted this policy to conform to the Equal Protection Clause of the Fourteenth Amendment to the U.S. Constitution, under which all children with disabilities should enjoy the same right to receive a free public education as all nondisabled children. For children with the most significant disabilities, public “education” is defined broadly to include care, treatment, living facilities, and rehabilitation.

The vocational rehabilitation program presumes that all persons with disabilities, including those with the most significant disabilities, can benefit from vocational rehabilitation services in terms of an employment outcome. To deny services to a person with a disability, a state agency must demonstrate by clear and convincing evidence (the highest standard of proof used in civil actions) that an individual is incapable of benefiting from vocational rehabilitation services. When a state is unable to serve all eligible individuals, it must adopt an “order of selection”

80. Id.
82. 42 C.F.R. § 441.56(a)(4) (1999).
83. ME. REV. STAT. ANN. tit. 20, § 911 (West 1964). The Maine statute was repealed in 1975 to ensure state compliance with IDEA.
under which it first serves those individuals with the most significant disabilities.\textsuperscript{86}

Entitlement programs, such as the SSI program (income support for low-income individuals with disabilities),\textsuperscript{87} have always targeted individuals with the most significant disabilities as intended beneficiaries.

2. Genuine, Effective, and Meaningful Opportunity: Accommodations, Auxiliary Aids and Services, and Program Accessibility

Eliminating gross exclusions and denials of the same treatment to all individuals is insufficient to assure genuine, effective, and meaningful opportunity for certain individuals with disabilities. For some individuals with disabilities, adjustments to regular programs, separate or different treatment, or the provision of support services may be necessary in order to ensure that an opportunity is genuine, effective, and meaningful for those individuals. It may be necessary to provide services based on the unique needs of the individual rather than on the basis of the needs of the “average” person. For example, it may be the “same” opportunity to provide verbal directions to a person who is deaf and to a nondisabled person. The opportunity, however, is not genuine, effective, and meaningful unless there is an accommodation to ensure that the person who is deaf receives the communication (e.g., is provided with a qualified sign language interpreter).

In the civil rights context, the ADA regulation\textsuperscript{88} and the section 504 coordination regulation\textsuperscript{89} generally set forth the concept of effective and meaningful opportunity. A covered entity may not, on the basis of disability, provide a qualified individual with a disability with a benefit or service that is not as effective as that provided to others. When action is necessary to provide qualified individuals with disabilities with benefits or services that are as effective as those provided to others, it is acceptable to provide different or separate treatment.

Specific applications of the “effective and meaningful” standard are also included in the ADA and section 504 coordination regulations:

A reasonable accommodation must be provided to employees in order to remove workplace barriers unless it would result in an undue hardship to the employer.\textsuperscript{90}

Programs in existing facilities must be accessible and new buildings must be readily accessible to and usable by individuals with disabilities.\textsuperscript{91}

Appropriate auxiliary aids and services must be provided by covered entities, including communication accessibility and

\begin{itemize}
\item \textsuperscript{88} 28 C.F.R. § 35.130(b)(1)(iv) (1999).
\item \textsuperscript{89} 28 C.F.R. § 41.53 (1999).
\item \textsuperscript{90} 28 C.F.R. § 1630.9(a) (1999); 28 C.F.R. § 41.53 (1999) (providing examples of reasonable accommodations, including modifying a workplace policy, acquisition or modifications of equipment, the provision of qualified readers and interpreters and appropriate adjustment or modification of examinations).
\item \textsuperscript{91} 28 C.F.R. § 35.150 (1999); 28 C.F.R. § 35.151 (1999); 28 C.F.R. § 41.57 (1999).
\end{itemize}
the provision of materials in accessible formats.92

In addition, an entity cannot place a surcharge on a particular individual with a disability or any group of individuals with disabilities to cover the cost of measures, such as the provision of reasonable accommodations, auxiliary aids, and services.93 Furthermore, the regulations include a provision that an individual with a disability is not required to accept an accommodation, aid, service, opportunity, or benefit provided under the ADA.94

In the education context, the concept of “effective and meaningful opportunity” is reflected in the IDEA as the right of every child with a disability, regardless of the nature or severity of the disability, to receive a free and appropriate public education (FAPE).95 This right includes, among other things, the right to be taught by educators who have the skills and knowledge necessary to meet the needs of children with disabilities and the adoption by local school districts of promising practices, materials, and technology to aid children with disabilities.96

In the employment context, to ensure “effective and meaningful opportunity” to benefit from vocational rehabilitation, Title I of the Rehabilitation Act of 1973 describes a broad range of vocational rehabilitation services that a program must provide for an individual with a disability. Examples of services include rehabilitation technology services, interpreter services, and on the job or other related personal assistance services provided while an individual with a disability is receiving vocational rehabilitation.97

In the health care context, the EPSDT program specifies that a state must guarantee that eligible children receive all medically necessary services required to treat a medical condition.98 The state may satisfy this obligation directly or through contract or other arrangements with service providers.


Public policy in legislation establishes specific rules and procedures of general application to individuals meeting specified criteria. What happens, however, when the rule itself or the application of a rule has the purpose or effect of denying an individual with a disability genuine, effective, and meaningful opportunity to benefit from the program, service, or activity on the basis of the individual’s disability?

An important tenet of disability policy is that rules of general applicability must be modified to take into consideration the unique needs of individuals with disabilities (rather than be based on needs of the “average” person) unless the modification would fundamentally alter the nature of the service, program, or activity. To apply this tenet, it is critical to look behind a rule of general applicability

92. 28 C.F.R. §§ 35.160-.164 (1999); 28 C.F.R. § 41.51(b), (c) (1999).
93. 28 C.F.R. § 35.130(f) (1999).
94. 28 C.F.R. § 35.130 (c) (1999).
to ascertain its purposes and policy objectives. It is necessary to determine whether
a reasonable modification to the rule will enable the individual with a disability to
satisfy the underlying purposes, functions, and policy objectives of the rule. It may
also include adopting separate or different rules when necessary to ensure genuine,
effective, and meaningful opportunity. In other words, it is critical that there be a
level playing field for both individuals with disabilities and nondisabled individu-
als.

In the civil rights context, the ADA regulation 99 and the section 504 coordi-
nation regulation100 specify that a public entity shall make reasonable modifications
to its policies or procedures when the modifications are necessary to avoid dis-
crimination on the basis of disability, unless the public entity can demonstrate that
making the modifications would fundamentally alter the nature of the service, pro-
gram, or activity. For example, an entity might adopt a rule specifying that it will
only cash checks for persons who have a valid driver’s license. The purpose of the
rule is to ascertain that the persons cashing the check are who they purport to be.
Since people who are blind cannot drive and, therefore, do not have driver’s li-
censes, this rule has the effect of denying them a genuine opportunity to take ad-
vantage of the check-cashing service. The ADA and section 504 require that the
entity modify its rule, for example, by accepting a different form of photo identifi-
cation.

Another example would be if an entity adopts a “no animal” rule in its facil-
ity. In order to accommodate persons with disabilities, the rule must be modified to
allow for “service dogs,” unless the service dog could be shown to pose a direct
threat to the health of others.

In the educational context, the modification of rules for disciplining children
with disabilities must ensure that such children are not inappropriately excluded,
segregated, or denied services on the basis of their disabilities.101 At the same time,
the modified rule must ensure that the underlying functions and purposes of these
rules (for example, keeping the schools safe and conducive to learning, holding
children responsible for their actions, and preventing inappropriate behavior from
recurring) are not fundamentally altered.

4. Treatment in the Most Appropriate Integrated Setting

Maximum appropriate integration and inclusion of an individual with a dis-
ability consistent with the individual’s unique needs is another fundamental tenet of
disability policy. In the civil rights context, the ADA statute recognizes that “his-
torically, society has tended to isolate and segregate individuals with disabilities . . .
and such forms of discrimination against individuals with disabilities continue to
be a serious and pervasive social problem.”102

The ADA regulation specifies that although special treatment or different
programs may be required in some instances in order to ensure genuine opportu-
nity, the provision of unnecessarily separate or different services is

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100. 28 C.F.R. § 41.51(b) (1999).
discriminatory. For example, a person who can benefit from the generic jobs program (a program providing services to persons with or without disabilities) in a state cannot be sent automatically to the vocational rehabilitation program (a program serving only persons with disabilities) if the individual qualifies for services in the generic program with the provision of reasonable auxiliary aids.

The ADA regulation also specifies that a public entity must administer services, programs, and activities in the “most integrated setting appropriate” to the needs of qualified individuals with disabilities. The preamble to Title II defines this requirement to mean “a setting that enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible.” The section 504 coordination regulation includes a provision that is identical to the provision in the ADA regulations.

In the education context, the IDEA specifies that:

To the maximum extent appropriate, children with Disabilities . . . are educated with children who are not disabled, and special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability of a child is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily.

The IDEA regulations require that services be provided in the least restrictive environment (requiring that a continuum of program options be provided) consistent with the unique needs of the child with a disability.

In the social services context, the Developmental Disabilities Assistance and Bill of Rights Act defines “inclusion and integration” to mean:

The use by individuals with developmental disabilities of the same community resources that are used by and available to other citizens; living in homes close to community resources, with regular contact with citizens without disabilities in their communities; the full and active participation by individuals with developmental disabilities in the same community activities and types of employment as citizens without disabilities, living, learning, working and enjoying life in regular contact with citizens without disabilities; and having friendships and relationships with individuals and families of their own choosing.

Under the Medicaid program, states may apply for a waiver to allow home-
and community-based placements in lieu of placement in institutional settings.110

B. FULL PARTICIPATION—EMPOWERING INDIVIDUALS AND FAMILIES

The second goal of disability policy articulated in the ADA is full participation by individuals with disabilities, their families, and their representatives in decisions affecting their lives at the individual and systems level. Full participation is achieved by empowering individuals with disabilities and their families and advocates. Empowerment includes the concepts of self-determination, self-advocacy, real and informed choice, and active participation in the decision-making process.

At the individual level, full participation includes involvement in decisions concerning, among other things, whether, when, and where to receive services and supports, which services to receive, by whom services should be provided, and which measures of progress should be used.

At the systems level, the concept of full participation requires various forms of citizen participation in the design, implementation, and evaluation of programs and policies, including public hearings, consideration of public comment, and the use of advisory committees/councils. The trend in federal legislation is to provide these advisory committees with more consumer direction and control. In fact, in some cases, legislation includes consumer-controlled councils (consisting of a majority of persons with disabilities), which make individuals with disabilities equal decision-making partners with professionals and agency officials. This includes encouraging joint responsibility with the government agency for the development of a state plan.

In the vocational rehabilitation program under Title I of the Rehabilitation Act of 1973, the individual with a disability (or the individual’s representative as appropriate) and a qualified vocational rehabilitation counselor must jointly agree to and sign an individualized plan for employment.111 The state vocational rehabilitation counselor must afford the individual the opportunity to exercise informed choice in selecting an employment outcome, the specific vocational rehabilitation services to be provided under the plan, the entity that will provide the vocational rehabilitation services, and the methods used to procure the services.112

Title I of the Rehabilitation Act of 1973 also directs the establishment of a State Rehabilitation Council. The functions of the Council include, in partnership with the designated state unit, developing, agreeing to, and reviewing state goals and priorities, and evaluating the effectiveness of the vocational rehabilitation program and reports of progress.113 A majority of Council members must be persons with disabilities. Under Title VII of the Rehabilitation Act of 1973, the state vocational rehabilitation director and the chair of the statewide independent living council must jointly develop the state plan relating to independent living services and centers for independent living.114

In the social security context, the Ticket to Work and Self-sufficiency pro-

gram provides a “ticket” to specified recipients of the SSDI program and the SSI program to obtain vocational rehabilitation. The disabled recipient may assign the “ticket” to any service provider of his/her choice within the employment network that is willing to accept the assignment. In addition, the Ticket to Work and Work Incentives Improvement Act establishes a Ticket to Work and Work Incentives Advisory Panel.

In the educational context, Part B of the IDEA requires that parents become partners in the process of developing their child’s individualized education program (IEP) and participate in the child’s placement process. Whenever appropriate, the IEP team must also include the participation of the child with a disability. A state may provide for the transfer of rights under the IDEA from parents to children with disabilities when children reach the age of majority. Part B also requires that the state advisory committee consist of a majority of persons with disabilities or parents of children with disabilities.

Under Part C of the IDEA, infants and toddlers and their families are entitled to a family-directed assessment of the resources, priorities, and concerns of the family and the identification of the supports and services necessary to enhance the family’s capacity to meet the developmental needs of the infant or toddler. The individualized family service plan must be developed by a multidisciplinary team, including the parents.

The philosophy of self-determination is articulated in the Developmental Disabilities Assistance and Bill of Rights Act. The term “self-determination” is defined as:

[A]ctivities that result in individuals with developmental disabilities, with appropriate assistance, having—

The ability and opportunity to communicate and make personal decisions;

The ability and opportunity to communicate choices and exercise control over the type and intensity of services, supports and other assistance the individuals receive;

The authority to control resources to obtain needed services, support and other assistance; The opportunity to participate in, and contribute to, their communities; and

Support, including financial support, to advocate

116. Id.
for themselves and others, to develop leadership skills, through training in self-advocacy, to participate in coalitions, to educate policy makers, and to play a role in the development of public policies that affect individuals with developmental disabilities.\textsuperscript{123}

Under the Protection and Advocacy for Mentally Ill Individuals Act:

\[F\]amily members of individuals with mental illness play a critical role in being advocates for the rights of individuals with mental illness where: (1) the individuals are minors, (2) the individuals are legally competent and choose to involve the family members, and (3) the individuals are legally incompetent and the legal guardians, conservators, or other legal representatives are members of the family.\textsuperscript{124}

In the Medicaid program, real choice is still unavailable in many states for those individuals with disabilities who prefer services (such as personal assistance services) in community-based settings rather than in institutions. This is because personal assistance services is an optional benefit under Medicaid and many states do not provide these services at all, or do not provide these services on a statewide basis. Most states, however, are increasing choice by taking advantage of the “home and community-based” waiver option for providing community-based services to targeted groups, often on less than a statewide basis.\textsuperscript{125}

\textbf{C. INDEPENDENT LIVING}

The goals of “full participation” and “independent living” are closely related and overlap to some degree. Full participation, or empowerment, focuses on the role of the individual and the family with respect to the provision of services and supports by public and nonprofit agencies.

The goal of fostering independent living articulated in the ADA includes enabling the individual to live in the community and participate in community activities through support for independent living skills development and specialized planning, support for long-term services and supports, including personal assistance services and supports, and the provision of cash assistance.

The philosophy of independent living includes the philosophies of consumer control, peer support, self-help, self-determination, equal access, and individual and system advocacy.\textsuperscript{126}

\textsuperscript{123} Developmental Disabilities Assistance and Bill of Rights Act, S. 1809, 106th Cong. § 102(2) (1999).
\textsuperscript{125} Social Security Act § 1915(c), 42 U.S.C. § 1396n(c) (1994) (amended 1999).
1. Independent Living Skills Development and Specialized Planning

To enhance opportunities for persons with significant disabili-ties to live independently in the community and effectively participate in community activities, federal programs provide training, resources, peer counseling, and support.

Title VII of the Rehabilitation Act of 1973 establishes centers for independent living and provides support for state efforts to provide, expand, and improve the provision of independent living services.127

Independent living services, as defined in the Rehabilitation Act of 1973, include:

- Training in individual and systems advocacy;
- Services related to securing housing or shelter, including services related to community group living and adaptive housing services;
- Mobility training;
- Training in the use of assistive technology devices and services and other supportive services and supports;
- Training in the management of personal assistance services;
- Training in the use of public transportation; and
- Training to develop skills specifically designed for youth with disabilities to promote self-awareness and esteem, develop self-empowerment skills, and explore career options.128

In the education context, the IDEA was amended in 1997 to include preparation for “independent living” as one of the primary purposes of the legislation.129 The child’s individualized education plan and transition plan must include strategies for preparing children with disabilities for independent living.130

The Developmental Disabilities Assistance and Bill of Rights Act sets forth as one of its primary purposes supporting efforts to enhance the “independence” of persons with developmental disabilities.131

2. Long-Term Services and Supports, Including Personal Assistance Services and Supports

Long-term services and supports are necessary to enable certain persons with disabilities to live in the community. Personal assistance services and supports are a significant form of long-term services. “Personal assistance services” include a range of services, provided by one or more individuals, designed to assist an individual with a disability to perform daily living activities on or off a job, that the individual would typically perform if not for the disability. Such services must be designed to increase the individual’s ability to perform everyday activities on or off such job.  

In the employment context, Title I of the Rehabilitation Act of 1973 authorizes the expenditure of funds to support personal assistance services while the individual is receiving other vocational rehabilitation services. In the health care context, personal assistance services may be provided (optional, not mandatory benefit) to individuals with disabilities under the Medicaid program, and frequently are included as part of Home and Community Based Services waivers.

3. Cash Assistance and Other Programs of Assistance

The provision of cash assistance under the SSI and SSDI programs is designed, in part, to enable a person to remain in the community rather than live in an institution. Additional examples include housing assistance and Food Stamps.

D. ECONOMIC SELF-SUFFICIENCY

The fourth goal of disability policy, as articulated in the ADA, is to foster economic self-sufficiency—economic security, stability, and productivity of persons with disabilities. Federal legislation accomplishes this goal through:

- Systems providing employment-related skills (education and training);
- Cash assistance programs that include work incentive provisions; and
- Tax policy that provides incentives to employers to hire

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135. Social Security Act § 1915(c), 42 U.S.C. § 1396n(c) (Supp. IV 1998). Additional categories of long-term services and supports may be provided under the Waiver program.
persons with disabilities, and deductions and credits for disability-related expenditures that enable a person with a disability to work.

1. Systems Providing Employment-Related Services and Supports

In the education context, the IDEA was amended in 1997 to include preparing youth with disabilities for “employment” as one of the primary purposes of the legislation.  

In the employment context, Title I of the Rehabilitation Act of 1973 provides assistance to enhance the employability of individuals with disabilities through the provision of vocational rehabilitation services. Recent amendments to Title I require that the vocational rehabilitation program be an integral component of a statewide workforce development system under the Workforce Investment Act.

2. Cash Assistance Programs and Other Programs of Assistance that Include Work Incentives

SSI law includes incentives for SSI beneficiaries with disabilities to work, including earned income disregards and permission for these individuals to remain eligible for Medicaid (which in some states enables these individuals to continue to receive personal assistance services). The 1997 amendments to the law allow states to increase the income limit for Medicaid coverage of certain SSI beneficiaries (families with income up to 250% of the federal poverty guidelines), and enable these individuals to buy into Medicaid by paying a portion of premium costs. Under the Ticket to Work and Work Incentives Improvement Act, states may establish one or two new optional Medicaid eligibility categories under which individuals can buy into Medicaid. Under the first option, states may cover individuals who, except for earnings, would be eligible for SSI. If a state provides Medicaid coverage to individuals described in the first option, the state may also provide coverage to employed persons with disabilities (aged sixteen to sixty-four) whose medical condition has improved, but who continue to have a severe medically determinable impairment. Under both of these options, states may establish uniform limits on assets, resources, and earned and unearned income (or both) for this group that differ from the federal SSI requirements. In addition, the Ticket to Work and Work Incentives Improvement Act authorizes a state to apply to the Secretary of Health and Human Services for approval of a demonstration project under which a specified maximum number of individuals who are workers with a potentially severe disability can buy into Medicaid.

3. Tax Policy

The Disabled Access Tax Credit provides tax credits to small businesses for expenses incurred in complying with the ADA. The Targeted Jobs Credit provides tax credits for hiring new employees with disabilities referred by vocational rehabilitation and other specified agencies.

VII. METHODS OF ADMINISTRATION

After stakeholders have provided the rationale and goals for the proposed legislation, established definitions of disability, and specified the core policies, they must then consider the inclusion of administrative or accountability provisions. These provisions, which are referred to as “methods of administration,” include such provisions as monitoring and enforcement to ensure implementation, procedural safeguards to ensure that individuals are afforded due process of law, outcome measures to determine the impact of the legislation, and methods for financing programs.

These methods of administration are designed to maximize the likelihood that the rights afforded by the civil rights statutes are realized and the services and benefits made available under entitlement and grant-in-aid programs are provided and implemented in accordance with best practices. Examples of methods of administration from various categories of legislation affecting people with disabilities are provided below.

A. METHODS OF ADMINISTRATION, IN GENERAL

The criteria and methods used for administering a program, service, or activity (i.e., official written policies and the actual practices of an entity) must be consistent with the rights and needs of individuals with disabilities and their families.

In the civil rights context, the ADA regulation specifies that:

a public entity may not, directly or through contractual or other arrangements, utilize criteria and or methods of administration: (i) That have the effect of subjecting qualified individuals with disabilities to discrimination on the basis of disability; (ii) That have the purpose or effect of defeating or substantially impairing accomplishment of the objectives of the public entity’s program with respect to individuals with disabilities; or (iii) That perpetuates the discrimination of another public entity if both public entities are subject to common administrative control or are agencies of the same State.

This provision prohibits both blatantly exclusionary policies or practices and nonessential policies and practices that appear neutral but have the effect of denying genuine, effective, and meaningful opportunity.

A similar provision is set out in the section 504 coordination regulations.\textsuperscript{149} Regulations issued by the Department of Labor implementing section 504 of the Rehabilitation Act of 1973 (as well as other civil rights statutes) include, in the job training context, a provision describing the obligations to develop “Methods of Administration,” which must be in writing and reviewed and updated on a periodic basis.\textsuperscript{150}

At a minimum, the Methods of Administration must describe how the state and recipients will:

- Appoint equal opportunity officers;
- Provide notice and communications;
- Provide data information collection, maintenance and quantifiable analysis of records and data kept;
- Review policies, practices, procedures, and implementation;
- Conduct and carry out investigations, oversight, monitoring (including development of monitoring instruments), and enforcement (including prompt corrective action, or, as necessary, applying sanctions when non-compliance is found);
- Carry out complaint processing; and
- Conduct equal opportunity training.

\textbf{B. STATE AND LOCAL PLANS, APPLICATIONS AND WAIVERS}

State entitlement programs and many grant-in-aid programs, particularly formula grant programs, require the submission of state and local plans or applications, which describe how the public agency plans to satisfy the program’s applicable requirements in the form of grant terms and conditions.\textsuperscript{151} Waivers provide exemptions or alternative methods of implementation, including testing new or innovative strategies for providing services.\textsuperscript{152}

\textbf{C. MONITORING AND ENFORCEMENT BY GOVERNMENT AGENCIES}

Federal laws specify monitoring and enforcement responsibilities of public agencies. In several instances, congressional concern over past or potential non-compliance by state and local grantees has prompted the inclusion of special monitoring and enforcement directives and procedures within the statute. These procedures apply to enforcement by the federal government with respect to compli-

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\textsuperscript{149} 28 C.F.R. § 41.51(b)(3) (1999).
\textsuperscript{150} 29 C.F.R. § 37.54 (1999).
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ance by the state, as well as to enforcement by state agencies with respect to compliance by local agencies. For example, the 1997 amendments to the IDEA provide the Secretary of Education with authority to withhold all or some funds (including withholding funding of administrative salaries) when violations by state educational agencies are found (including failure to comply with the terms of any agreement to achieve compliance between the Secretary and a state within timelines specified in the agreement). 153 The Secretary of Education may refer the matter to the Department of Justice for appropriate enforcement action. 154

State educational agencies also have the authority to withhold funds in whole or in part. 155 In addition, the IDEA requires that the public be notified when enforcement action is contemplated by the state educational agency. 156 Further, local educational agencies must make available to parents of children with disabilities and the general public all documents relating to compliance by the agency. 157

Section 504 of the Rehabilitation Act of 1973 is administered by an Office for Civil Rights in each federal department or agency. The agency has authority to, among other things, investigate and resolve individual complaints and conduct monitoring reviews of compliance by recipients of federal aid. 158 The agency may also order agencies to take remedial action. 159

Comparable authority exists for federal agencies—such as the Department of Justice and the Equal Employment Opportunity Commission—that are responsible for enforcing the ADA. 160

D. PROCEDURAL SAFEGUARDS

Many of the laws covering individuals with disabilities, particularly civil rights laws (such as the ADA, section 504 of the Rehabilitation Act of 1973, and the IDEA) include procedural safeguards to ensure that means exist for remediying violations of an individual’s guaranteed rights. Procedural safeguards include:

- The right to receive a notice of rights; 161
- The right to examine records; 162
- The right to file a complaint; 163

154. Id.
158. For example, see 45 C.F.R. § 84.61 (1999) (incorporating by reference the compliance and enforcement regulations implementing Title VI of the Civil Rights Act of 1964).
159. 45 C.F.R. § 84.6 (1999).
160. For Department of Justice regulations pertaining to state and local government agencies, see 28 C.F.R. §§ 35.170-190 (1999). Also see EEOC Compliance and Enforcement procedures described in Technical Assistance on the Employment Provisions (Title I) of the ADA—Explanation of Key Legal Requirements.
EMERGING DISABILITY POLICY FRAMEWORK

- Mediation and other forms of nonadversarial dispute resolution; 164
- Administrative due process hearings and administrative review; 165 and
- Redress through a private right of action in court, including damages and the awarding of attorneys fees to prevailing parties. 166

Entitlement programs also include procedural protections. For example, the SSI program provides for administrative review, appeal to a federal district court, and limited attorney’s fees for a prevailing claimant. 167

Under the Medicaid program, Medicaid beneficiaries have a right to the following: (1) a hearing before an impartial decision-maker concerning denials, reductions, terminations, or delays in Medicaid benefits, (2) a written decision within ninety days, and (3) an appeal to a state court. 168

E. ACCOUNTABILITY FOR RESULTS (OUTCOME MEASURES)

Many programs require that grantees report program performance as part of an annual evaluation.

In the education context, the 1997 amendments to the IDEA go a step further by requiring the establishment of specific performance goals and objectives. 169 Such goals and objectives must promote the purposes of the Act and be consistent, to the maximum extent appropriate, with other goals and standards for nondisabled children established by the State. The IDEA also ensures that individuals with disabilities are included in general state- and district-wide assessments, 170 with appropriate modifications where necessary.

The IDEA also provides that a child’s individualized education program must include a statement of how the child’s progress toward the annual goals will be measured, and how the child’s parents will be informed regularly by means such as periodic report cards. 171

In the employment context, Title I of the Rehabilitation Act of 1973 directs the Commissioner of the Rehabilitation Services Administration to establish standards and performance indicators for vocational rehabilitation programs. 172 Additionally, the legislation authorizes the Commissioner to withhold funds if a state falls below established standards until the state agrees to enter into an approved program improvement plan. 173

Accountability provisions may also require specific information that is of particular concern to policy makers. For example, the 1997 amendments to the IDEA require reporting of expulsion and suspension rates for children with disabilities compared to nondisabled children to determine whether there are significant discrepancies among school districts in their approach to disciplining children that may result from failure to implement the law. These amendments specifically require that school districts report disproportionate identification of and placement of children with disabilities on the basis of race.

Some generic programs are similarly beginning to include specific outcome measures for persons with disabilities. For example, the School-to-Work Opportunities Act of 1994 provides for the establishment of a system of performance measures for assessing state and local school-to-work programs that requires, among other things, reporting of outcomes disaggregated for students with disabilities. The Workforce Investment Act specifies that each state must prepare an annual report on its progress in achieving state performance measures, including performance indicators for individuals with disabilities. The Workforce Investment Act also includes incentives for states that exceed expectations in their programs and integration.

Many states have adopted school reform measures in recent years that include, among other things, statewide performance goals and objectives, as well as state- and district-wide assessments. The law requires that these reforms must include goals for individuals with disabilities. In many states, the methods for administering these programs failed to address the needs of children with disabilities. In 1997, the IDEA was amended to ensure that states adopted performance goals and objectives and that state- and district-wide assessments included children with disabilities and provided appropriate accommodations, where necessary.

F. REPRESENTATION AT THE INDIVIDUAL AND SYSTEMS LEVEL

Congress has provided for the establishment of and support for entities whose responsibilities include advocating for and representing persons with disabilities whose rights have been abridged. Every state has a protection and advocacy system for persons with developmental disabilities authorized under the Developmental Disabilities Assistance and Bill of Rights Act. In addition to these protection and advocacy systems for persons with developmental disabilities, federal law also provides protection for persons with mental illness under the Protection and Advocacy for Mentally Ill Individuals Act. Importantly, persons with disabilities not otherwise eligible for assistance under these programs may receive assistance under the Protection and Advocacy of Individual Rights, codified in section 509 of the

178. See 20 C.F.R. § 666.200 (1999) (stating that a state is eligible to receive an Incentive Grant if it exceeds expectations).
Rehabilitation Act of 1973. Furthermore, protection and advocacy services are authorized for persons needing assistive technology under a set-aside included in the Assistive Technology Act of 1998, disabled SSI and SSDI beneficiaries, and persons with disabilities who are clients or applicants for assistance under the Rehabilitation Act of 1973 (Client Assistance Program).

Part C of Title VII of the Rehabilitation Act of 1973 authorizes centers for individual living to provide advocacy and individual representation.

Parent training and information centers are authorized under the IDEA to, among other things, help parents to understand their rights under the Act and to participate in decisionmaking processes.

G. SINGLE LINE OF RESPONSIBILITY/COORDINATION AND COLLABORATION AMONG AGENCIES

Many programs place accountability for their administration on a single agency to avoid “buckpassing,” and prescribe the type of organizational structure that must be established. For example, under the Medicaid program, every state must designate a single agency responsible for implementing the program. The state educational agency must administer the IDEA program, and the state must designate a sole state agency to administer the vocational rehabilitation program under the Rehabilitation Act of 1973.

At the same time, many of these programs provide mechanisms for ensuring interagency linkages and coordination. Linkages are particularly critical between programs targeted at persons with disabilities and generic systems that include persons with disabilities as program beneficiaries. These provisions are designed to ensure that no one “falls between the cracks.” Legislation also includes provisions for ensuring that all agencies (including those which are not the agency responsible for implementing a particular program) pay their fair share for services, which an individual may be entitled to under multiple funding authorities.

For example, the 1997 amendments to the IDEA elaborate in painstaking detail the responsibility of the Governor to ensure the development of mechanisms for, among other things, sharing financial responsibility for services required under the act that may also be required under other legislation.

Title I of the Workforce Investment Act and the recent amendments to the Rehabilitation Act of 1973 also specifically detail the need to develop memoranda of understanding by identifying the respective roles of various agencies pro-

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Providing job training and employment-related services for persons with disabilities.

In 1988, the Medicaid legislation was amended. The changes clarified the circumstances under which Medicaid reimbursement would be available for covered services that were included in a child’s “individualized education program” or “individualized family service program” for infants and toddlers with disabilities under the IDEA.194

**H. SERVICE COORDINATION**

Often, individuals with disabilities and their families require a comprehensive array of services and supports. These services and supports, however, may be authorized under separate federal or state programs, which have distinct eligibility rules. This array of requirements often places a burden on individuals and families. It is critical that the focus of public policy be on service coordination and the provision of case management to assist and enable individuals with disabilities and their families to receive the rights, procedural safeguards, and authorized services under the various programs.

For example, Part C of the IDEA provides for the identification of the service coordinator in the Individualized Family Service Plan for infants and toddlers with disabilities and their families.195 The coordinator is chosen from the profession that is most immediately relevant to the child’s or family’s needs and should be otherwise qualified to carry out all applicable responsibilities under Part C.196 The service coordinator is responsible for the implementation of the Individualized Family Service Plan and coordination with other agencies and persons.197

Specifically the regulations define “service coordination” to mean:

a.1. . . the activities carried out by a service coordinator to assist and enable a child eligible under this part and the child’s family to receive the rights, procedural safeguards, and services that are authorized to be provided under the State’s early intervention program.

2. Each child eligible under this part and the child’s family must be provided with one service coordinator who is responsible for—

   i. Coordinating all services across agency lines; and

   ii. Serving as the single point of contact in helping parents to obtain the services and assistance they need.

3. Service coordination is an active, ongoing process that involves—

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197. Id.
i. Assisting parents of eligible children in gaining access to the early intervention services and other services identified in the individualized family service plan;

ii. Coordinating the provision of early intervention services and other services (such as medical services for other than diagnostic and evaluation purposes) that the child needs or is being provided;

iii. Facilitating the timely delivery of available services; and

iv. Continuously seeking the appropriate services and situations necessary to benefit the development of each child being served for the duration of the child’s eligibility.

b. Specific service coordination activities. Service coordination activities include—

1. Coordinating the performance of evaluations and assessments;

2. Facilitating and participating in the development, review, and evaluation of individualized family service plans;

3. Assisting families in identifying available service providers;

4. Coordinating and monitoring the delivery of available services;

5. Informing families of the availability of advocacy services;

6. Coordinating with medical and health providers; and

7. Facilitating the development of a transition plan to preschool services, if appropriate.198

In 1985, the Medicaid program was amended to provide case management services.199 However, the amendment allows such services on less than a statewide or comparable basis to targeted groups.200 Case management services must be provided under the EPSDT program when they are medically necessary.201 The Medicaid program also authorizes Medicaid agencies to enter into cooperative arrangements with State Maternal and Child Health agencies when waiver services are provided to children.202

198. 42 U.S.C. § 1396n(g) (1994); 34 C.F.R. § 303.23 (1999).
200. Id.
I. FINANCING SERVICE DELIVERY

In order to ensure that agencies do not adopt schemes for financing service delivery that have the effect of denying equal opportunity or the accomplishment of other goals of disability policy, legislation includes specific rules prescribing and proscribing agency conduct.

In the education context, the IDEA includes several provisions which ensure that educational agencies adopt criteria and methods of administration that achieve policy objectives enumerated in the legislation as well as in other laws.

For example, over the years, several states have adopted criteria and methods for reimbursing local school districts for serving students with significant disabilities requiring services that cost substantially more than services provided to non-disabled students. These states were providing significant reimbursement to local school districts for placing children with significant disabilities in schools outside the district. The same district, however, received little or no reimbursement if it served the same children with significant disabilities in community schools. The policy effectively violated the requirement that children with disabilities be educated in the most integrated setting appropriate. The IDEA was amended in 1997 to make such state reimbursement policies illegal.203

J. PRIVACY, CONFIDENTIALITY, ACCESS TO RECORDS, AND INFORMED CONSENT

Legislation typically contains provisions protecting confidentiality of records204 and requiring informed consent205 before entities take certain actions affecting persons with disabilities. In the advocacy context, protection and advocacy systems can be thwarted in their efforts to ascertain whether allegations of abuse and neglect of residents with disabilities residing in residential facilities are real if they are not provided reasonable access to individuals with disabilities and their records. Thus, the legislation gives protection and advocacy systems access, at reasonable times and locations, to any resident of any facility that is providing services, supports, and other assistance to such resident as well as access to necessary information.206

K. COMPREHENSIVE SYSTEM OF PERSONNEL DEVELOPMENT AND PERSONNEL STANDARDS

Most of the state formula grant programs require that state and local entities responsible for implementing the law achieve comprehensive systems of personnel development to ensure that personnel providing services to persons with disabilities

are knowledgeable about state-of-the-art practices. These programs also require that personnel satisfy certain minimum qualification standards.

L. RACIAL, ETHNIC, AND LINGUISTIC DIVERSITY

The trend in disability policy is to recognize and be responsive to the growing needs of an increasingly more diverse society. For example, the law specifically requires that data is reported to determine if significant disproportionality based on race is occurring in a state with respect to identification and placement.

Under the Rehabilitation Act of 1973, the Commissioner of the Rehabilitation Services Administration and the Director of the National Institute on Disability Rehabilitation Research must reserve a specified amount of funds for expanding outreach to minority entities. The activities may include making awards to minority entities to conduct research, training, technical assistance, or a related activity. The state plan must describe outreach procedures to identify and serve all individuals who are minorities.

Under Part B of the Developmental Disabilities Assistance and Bill of Rights Act, Developmental Disabilities Councils must, among other things, develop a coordinated “array of culturally competent services.” “Culturally competent” includes “services, supports, or other assistance that are conducted or provided in a manner that is responsive to the beliefs, interpersonal styles, attitudes, language and behaviors of individuals who are receiving services, and in a manner that has the greatest likelihood of ensuring maximum participation in the program.”

M. FISCAL PROVISIONS

Most federal programs prohibit grantees from lowering the fiscal support they previously provided for an activity before they received federal funds. For example, the IDEA includes both “supplement, not supplant” as well as “maintenance

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210. See Rehabilitation Act of 1973 § 19(b), 29 U.S.C. § 718(b) (1994 & Supp. IV 1998) (requiring a percentage of funds to be devoted to outreach to minority entities). The term “minority entity” means an entity that is a historically black college or university, a Hispanic-serving institution of higher education, an Indian tribal college or university, or another institution of higher education whose minority students enrollment is at least fifty percent.


212. See Developmental Disabilities Assistance and Bill of Rights Act § 102(7), 42 U.S.C. § 6001(7) (1994 & Supp. IV 1998) (defining the term “culturally competent” as services that are provided in a manner that ensures the greatest likelihood of maximum participation in the program).

of effort\textsuperscript{214} provisions. The supplanting provision prohibits an entity from replacing state and local funds with federal funds. The maintenance of effort provision requires that an entity allot at least the amount of funds it alloted in the previous year for a specified purpose.

In addition, several laws include “payor-of-last-resort” provisions requiring public agencies to exhaust other funding streams before using funds authorized under a particular program.\textsuperscript{215}

\textbf{N. FINANCIAL MANAGEMENT AND REPORTING PROVISIONS}

Grantees must comply with administrative provisions designed to ensure that grant funds are spent in an effective and efficient fashion. Provisions include fiscal control and fund accounting, periodic reporting of financial transactions, record-keeping, and access for auditors.\textsuperscript{216}

\textbf{VIII. PROGRAM SUPPORTS}

Stakeholders provide the rationale and goals for the proposed legislation, establish definitions for disability, specify the core policies, and develop methods of administration provisions. In addition, stakeholders must ensure that initiatives conform to the best practices and are state-of-the-art. They accomplish this by adopting program supports, such as grants, to support systemic change, research, training, and technical assistance.

Examples of program supports from various categories of legislation affecting people with disabilities are provided below.

\textbf{A. SYSTEMIC CHANGE}

Grants designed to support systemic change include:

- The Technology-Related Assistance for Individuals with Disabilities Act of 1988, which provides assistance to states to develop and implement a consumer-responsive comprehensive statewide program of technology-related assistance for individuals with disabilities.\textsuperscript{217}

- Subpart 1 of part D of the IDEA, which assists state educational agencies and their partners in reforming and improving their systems for providing educational and early intervention to improve educational results for children with disabilities.\textsuperscript{218}


• Section 672 of the IDEA, which authorizes support for statewide projects designed to improve the quality of special education and related services for children with significant disabilities.219

• Parts B, C, and D of the Developmental Disabilities Assistance and Bill of Rights Act, which supports systemic change by Developmental Disabilities Councils, Protection and Advocacy Systems, and University Affiliated Programs.220

• Part C of Title VII of the Rehabilitation Act of 1973, which supports systemic change by Centers for Independent Living.221

• Section 203 of the Ticket to Work and Work Incentives Improvement Act,222 which authorizes the Secretary of the Department of Health and Human Services to develop and establish state infrastructures to support working individuals with disabilities.

B. TRAINING OF PERSONS WITH DISABILITIES AND THEIR FAMILIES

Grant programs that support training of persons with disabilities and their families include section 682 of the IDEA, which supports training and information centers for parents of children with disabilities,223 as well as the Developmental Disabilities Assistance and Bill of Rights Act, which supports Developmental Disabilities Councils, protection and advocacy systems, and Centers for Independent Living. In addition, the Ticket to Work and Work Incentives Improvement Act establishes a community-based work incentives planning and assistance program under the Social Security Act for the purpose of disseminating accurate information to individuals about work incentives.224 Finally, the Commissioner of the Social Security Administration is authorized to make grants to protection and advocacy systems for work incentives assistance to disabled beneficiaries.225

C. PERSONNEL PREPARATION AND TRAINING

Grant programs also support personnel preparation and training. Examples include:

• Part D of the Developmental Disabilities Assistance and

221. 29 U.S.C. §§ 796f to 796f-6 (Supp. IV 1998).
Bill of Rights Act supports interdisciplinary programs operated by universities or by public or nonprofit entities associated with a college or university. It also provides a leadership role in the promotion of independence, productivity, and integration and inclusion into the community of individuals with developmental disabilities.\textsuperscript{226}

- Subpart 2 of part D of the IDEA supports pre-service and inservice training of general educators, special educators, related services personnel, and early intervention personnel.\textsuperscript{227}
- Title III of the Rehabilitation Act of 1973 provides training to ensure that skilled personnel are available to provide rehabilitation services to individuals with disabilities.\textsuperscript{228}

\textbf{D. RESEARCH, DEMONSTRATIONS, TECHNICAL ASSISTANCE, AND DISSEMINATION OF INFORMATION}

Grant programs also support research, demonstrations, technical assistance, and dissemination of information. Examples include:

- Title II of the Rehabilitation Act of 1973, which establishes the National Institute on Disability and Rehabilitation Research (NIDRR);\textsuperscript{229}
- Part D of the IDEA;\textsuperscript{230}
- Research funded by the National Institutes of Health authorized under Title IV of the Public Health Services Act.\textsuperscript{231}

\textbf{IX. CONCLUSION}

This section includes general questions for analyzing the extent to which disability-specific and generic programs or policies reflect the statement of findings rationale, precept, goals, definitions, core policies, methods of administration, and program supports set out in the Emerging Disability Policy Framework. In other words, this section of the paper serves as a guidepost for evaluating, expanding, and improving the design and implementation of public policies affecting persons with disabilities.

Answering these questions may entail, among other things, reviewing previous studies, reports and current data, conducting analyses of proposed and final policy pronouncements, and surveying stakeholders. Not all questions articulated in this section are applicable to all programs and policies. For example, some ques-

\textsuperscript{231} 42 U.S.C. §§ 281-300 (1994).
tions may only be applicable to generic programs serving persons with and without disabilities.

A. Questions Relating to Statement of Findings and Rationale

Is the program long-standing, undergoing major reform, or new? If new, does it replace an existing program?

Was the program established on a sound premise?

Has the program historically excluded persons with disabilities or specific categories of persons with disabilities? For example, has a policy, procedure, or accepted practice historically disqualified persons with significant disabilities from receiving services, or has a generic program automatically referred all persons with disabilities to disability-specific programs?

Is there a history of segregation of persons with disabilities into specific slots or components of the program?

Is there a history of denial of genuine, effective, and meaningful services in the program?

Is there a history of ensuring that people with disabilities enjoy choice in assessments, planning, services provided, selection of service providers, and measures of progress?

Is there a history of fostering independent living and ensuring self-sufficiency?

What efforts have been made to ascertain the prevalence of persons with disabilities among the prospective pool of eligible recipients of a generic program?

What efforts have been made to ascertain the scope of unmet need?

Is the public agency considering the historical treatment of persons with disabilities in the development of new policies and procedures and in the methods of administration it uses?

B. Questions Relating to Core Precept

Does the program include a statement articulating the core precept on which it is based? Is the core precept of the program consistent with the precept of disability policy: that disability is a natural and normal part of the human experience that in no way diminishes a person’s right to participate fully in the program, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities of the individual?

C. A Question Relating to Overarching Goals

Do the goals of the program reflect the goals of federal disability policy articulated in the ADA—equality of opportunity, full participation (empowerment), independent living, and economic self-sufficiency for persons with disabilities?
D. QUESTIONS RELATING TO DEFINITION OF DISABILITY

Does the definition of disability reflect the purposes of the particular legislation?

How does the definition of disability relate to definitions used in other programs?

Does it relate to the definition used in section 504 and the ADA?

E. QUESTIONS RELATING TO Core Policies

1. Questions Relating to Equality of Opportunity

   a. Individualization

   Do the policies and procedures governing eligibility and application for and delivery of services under the program:

   - Account for the unique strengths, resources, priorities, concerns, abilities, and capabilities of each person with a disability, including individuals with significant disabilities?
   - Account for the added dimension of poverty?
   - Use definitions and eligibility criteria that result in even-handed treatment between a person with a particular disability and other similarly situated individuals, including nondisabled persons and persons with other disabilities?
   - Satisfy the broad, nondiscriminatory eligibility criteria by ensuring universal access to generic programs for persons with disabilities?
   - Support and promote the treatment of persons with disabilities as individuals based on facts and objective evidence and not based on generalizations, stereotypes, fear, ignorance, or prejudice?
   - Enable people to make fact-specific decisions, use interdisciplinary assessments performed by qualified personnel, conduct timely assessments across multiple environments, and use information provided by the individual with a disability and the person’s family or representative?
   - Use individualized plans to identify and describe needs, goals, objectives, services, and accountability measures?

   b. Genuine, Effective, and Meaningful Opportunity

   Do the policies and procedures governing eligibility and application for and delivery of services under the program offer opportunities that are genuine, effective, and meaningful? This includes:
EMERGING DISABILITY POLICY FRAMEWORK

- Providing “appropriate” services and supports designed to meet the unique needs of the individual, not the needs of the “average” person.
- Making reasonable modifications to policies, practices, and procedures, unless it would fundamentally alter the nature of the program.
- Providing auxiliary aids and services, unless it would result in an undue hardship to the covered entity.
- Providing reasonable accommodations to employees, unless it would result in an undue hardship to the covered entity.
- Making a program physically accessible.
- Providing communication accessibility.

c. Inclusion and Integration

Do the policies and procedures governing eligibility and application for and delivery of services under the program foster the inclusion and integration of persons with disabilities, or do the policies and procedures unnecessarily or unjustifiably isolate or segregate persons with disabilities?

2. Questions Relating to Full Participation

Do the policies and procedures governing the program foster the empowerment of persons with disabilities, real and informed choice, and active participation in decision-making process at the individual and system level (including self-advocacy)?

More specifically, do the policies and procedures governing the program foster:

- Active involvement and real and informed choice of the individual with a disability in areas including:
  - Opportunity to receive information about policies that affect the individual?
  - Assessments?
  - Planning?
  - Services?
  - Selection of service providers?
  - Measures of progress?
- Active involvement and real and informed choice of family members and other representatives (under appropriate circumstances) in decisions affecting the individual with a disability and the family, including:
• Opportunity to receive information about policies that affect the individual?
• Assessments?
• Planning?
• Services?
• Selection of service providers?
• Measures of progress?
• Active involvement in policy decisions at the system level (respecting the design, implementation, and evaluation of a program), including:
  • Consideration of input from consumers?
  • Participation on governing boards and councils?
  • Joint sign-off on policies by governing board/council?

3. Questions Relating to Independent Living

Do the policies and procedures governing the program foster the ability and capabilities of individuals with disabilities to live independently through support for independent living skill development, including:

• Training in individual and systems advocacy?
• Service related to securing food, clothing, and shelter?
• Training the management of personal assistants and the use of assistive technology?
• Specialized planning for transitioning to independent living?

Do the policies and procedures governing the program enable the person with a disability to live independently through the provision of long-term services and supports (e.g., consumer-directed personal assistance services and supports or assistive technology devices and services)?

Do the policies governing the program enable the person with a disability to live independently in the community with the aid of cash assistance or other forms of assistance?

4. Questions Relating to Economic Self-Sufficiency

Do the policies and procedures governing the program foster the economic security, stability, and productivity of persons with disabilities consistent with their actual (not perceived) capabilities, strengths, needs, interests, and priorities through support for:

- Systems that include universal access to generic services as well as access to specialized services and supports as an inte-
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Training, education, and employment of choice (including self-employment)?

Ongoing on-the-job supports?

Specialized planning (e.g., transition planning for children in high school)?

Cash assistance programs that reflect the goal of maximizing economic self-sufficiency, including policies that provide incentives to work (e.g., waive or modify income and resource limits, and retain eligibility for acute and long-term services and supports)?

F. QUESTIONS RELATING TO METHODS OF ADMINISTRATION

1. Questions Relating to State and Local Plans, Applications, and Waivers

Does the plan/application include specific policies and procedures governing implementation for persons with disabilities?

Do waiver requests have the effect of enhancing or diminishing opportunities for persons with disabilities? For example, is a waiver request designed to test new strategies for delivering services that reflect the goals of disability policy articulated in the ADA? Or is the waiver request based on “perceptions” that individuals with disabilities cannot succeed or participate in the program or assessment generally applicable to nondisabled persons?

Does the plan/application explain how people with disabilities and their representatives were involved in the process of completing the plan/application?

In addition to the inclusion of an assurance of nondiscrimination, does the plan/application include specific policies and procedures relating to implementation of the program consistent with section 504 of the Rehabilitation Act of 1973 and the ADA?

2. Questions Relating to Monitoring and Enforcement by Government Agencies

What are the respective roles and responsibilities of federal, state, or local agencies for monitoring and enforcement?

Does the monitoring instrument developed by the government agency include specific inquiries related to persons with disabilities? What are they?

Does the government agency use a monitoring instrument for ascertaining compliance with section 504 of the Rehabilitation Act of 1973 and the ADA? If so, what is included?

Do on-site monitoring reviews include assessments relating to meeting the needs of persons with disabilities and ensuring nondiscrimination?
What sanctions are available and used? Under what circumstances?
What incentives are available and used?
How are findings of noncompliance used by the agency? Are findings of noncompliance used for purposes of ongoing continuous quality improvement reviews?
What remedies are available?
Is there a complaint resolution procedure that includes complaints involving discrimination on the basis of disability?

3. Questions Relating to Procedural Safeguards for Individuals, Their Families, and Representatives

Do the policies and procedures governing the program provide:
- Notice of rights?
- Examination of records?
- The right to file a complaint?
- The use of mediation and other forms of dispute resolution?
- Administrative due process hearings and administrative review?
- Redress through private right of action in court, including remedies and the awarding of attorneys’ fees to prevailing parties?

4. Questions Relating to Accountability for Results (Outcome Measures)

Does the agency include outcome measures that address issues of specific relevance to persons with disabilities?
Does the agency disaggregate data so the agency can determine whether its program is meeting the needs of persons with disabilities or persons with specific categories of disabilities as part of a process of continuous improvement?

5. Questions Relating to Representation at the Individual and Systems Level

Does the public agency provide support for representation and advocacy at the individual and systems level? If so, does that support include backing for systems providing protection and advocacy, and self-advocacy training?


Is there a single agency (state or local) responsible for implementing the program for all beneficiaries, including persons with disabilities? If not, how does the agency ensure compliance for persons with disabilities?
Does the agency require the assignment of an individual who will be re-
sponsible for ensuring implementation of the program for persons with
disabilities, particularly with respect to implementation of the program
consistent with section 504 of the Rehabilitation Act of 1973 and the
ADA?

Has the agency developed policies and procedures for collaboration
among agencies to ensure meaningful and effective delivery of neces-
sary services to persons with disabilities, including cost sharing ar-
rangements?

7. A Question Relating to Service Coordination (Case Management)

Has the agency developed policies and procedures for service coordina-
tion to ensure that individuals with disabilities, particularly those with
the most significant disabilities, receive the services they need, particu-
larly where services are provided by multiple agencies?

8. Questions Relating to Financing Service Delivery

Does the system for allocating funds among agencies and service pro-
viders facilitate or thwart accomplishment of the goals articulated in the
ADA and the policies that effectuate the goals? For example, does the
outcome-based reimbursement scheme used to pay service providers
recognize and reward those who serve persons with the most significant
disabilities and who, therefore, cost more than the average recipient of
services (risk adjustment)?

Is the network of service providers adequate to address the needs of per-
sons with disabilities eligible for assistance under the program?

Is the financing system for services (e.g., personal assistance services,
assistive technology) consumer-directed?

9. Question Relating to Privacy, Confidentiality, Access to Records, Informed Con-

Does the agency include specific policies and procedures protecting the
rights of persons with disabilities to privacy? Confidentiality? Access to
Records?

Does the agency include specific policies and procedures requiring in-
formed consent?

10. Questions Relating to Comprehensive System of Personnel Development

Does the agency include specific training components regarding the im-
plementation of its program (e.g., policy, “promising practices,” and re-
source allocation) for persons with disabilities?

Does the agency include specific training for its personnel regarding im-
plementation of its program consistent with section 504 of the Rehabili-
tation Act of 1973 and the ADA?
11. A Question Relating to Responsiveness to Cultural Diversity

Does the agency include policies and procedures that address the special needs of persons with disabilities from diverse cultural backgrounds?


Do the “supplement, not supplant” and “maintenance of effort” provisions ensure continuation of funding from state and local sources for services provided to persons with disabilities?


Do the fiscal control and fund accounting procedures enable oversight with respect to the provision of funding for persons with disabilities consistent with legislative intent?

G. A QUESTION RELATING TO PROGRAM SUPPORTS

To the extent an agency supports efforts to improve the quality of services provided through initiatives, such as systems change grants, training, research, technical assistance, demonstrations, and information dissemination, do these initiatives include specific components or specific initiatives that address the unique needs of persons with disabilities?

Using the above questions and explanations of policy expounded in this paper, stakeholders will be better equipped to remove the attitudinal and institutional barriers that have traditionally subjected persons with disabilities to lives of unjust dependency, segregation, isolation and exclusion. Through the Emerging Disability Policy Framework, individuals with disabilities will be able to fully participate in society’s mainstream.
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APPENDIX I

An Overview of the Emerging Disability Policy Framework: A Guidepost for Analyzing Public Policy

Robert Silverstein

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Society has historically imposed attitudinal and institutional barriers that subject persons with disabilities to lives of unjust dependency, segregation, isolation, and exclusion. Attitudinal barriers are characterized by beliefs and sentiments held by nondisabled persons about persons with disabilities. Institutional barriers include policies, practices, and procedures adopted by entities such as employers, businesses, and public agencies.232

Sometimes, these attitudinal and institutional barriers are the result of deep-seated prejudice.233 At times, these barriers result from decisions to follow the “old paradigm” of considering people with disabilities as “defective” and in need of “fixing.”234 At other times, these barriers are the result of thoughtlessness, indifference, or lack of understanding.235 It is often difficult, if not impossible, to ascertain precisely why the barriers exist.

In response to challenges by persons with disabilities, their families, and other advocates, our nation’s policymakers have slowly begun to react over the past quarter of a century. They have begun to recognize the debilitating effects of these barriers on persons with disabilities and have rejected the “old paradigm.”

A “new paradigm” of disability has emerged that considers disability as a natural and normal part of the human experience. Rather than focusing on “fixing” the individual, the “new paradigm” focuses on taking effective and meaningful actions to “fix” or modify the natural, constructed, cultural, and social environment. In other words, the focus of the “new paradigm” is on eliminating the attitudinal and institutional barriers that preclude persons with disabilities from fully participating in society’s mainstream.

Aspects of the “new paradigm” were included in public policies enacted in the early 1970s.236 Between the 1970s and 1990, lawmakers further defined and society further accepted the “new paradigm.”237 In 1990, the “new paradigm” was explicitly articulated in the landmark Americans with Disabilities Act (ADA)238 and  


further refined in subsequent legislation.\textsuperscript{239}

Many people have documented the historical mistreatment of persons with disabilities. Others have described and analyzed the ADA as a civil rights statute that prohibits discrimination in the areas of employment, public services, public accommodations, and telecommunications. Few people have stepped back to consider the fundamental beliefs and core policies that were reflected in the 1970s legislation, explicitly articulated in the ADA, and further refined in subsequent legislation. Taken as a whole, these efforts have critical implications regarding the design, implementation and evaluation of programs and policies that affect citizens with disabilities.

The purpose of this overview is to provide a Disability Policy Framework consistent with the “new paradigm” that can be used as a lens or guidepost\textsuperscript{240} to design, implement, and evaluate generic,\textsuperscript{241} as well as disability-specific, public policies and programs to ensure meaningful inclusion of people with disabilities in mainstream society.

To this end, this overview is targeted to the needs of several audiences. For federal, state, and local policymakers as well as persons with disabilities, their families and advocates, this overview offers a guidepost for designing, implementing, and assessing generic, as well as disability-related, programs and policies. For researchers, this overview provides a benchmark for studying the extent to which generic and disability-specific policies and programs reflect the “new paradigm” and achieve its goals. For service providers, this Appendix provides a lens for designing, implementing and evaluating the delivery of services to persons with disabilities. Finally, for college and university professors teaching courses that include disability policy, this overview provides a framework for policy analysis.

This overview is divided into two parts. Part I describes the various components of the Emerging Disability Policy Framework. Using the Emerging Disability Policy Framework described in Part I, Part II of the overview includes an audit—a checklist of questions that stakeholders can use to assess the extent to which generic and disability-specific programs or policies reflect the components of the Emerging Disability Policy Framework.

\textbf{PART I}

\textbf{AN OVERVIEW OF THE EMERGING DISABILITY POLICY FRAMEWORK}

\textbf{INTRODUCTION}

Part I provides an overview of the major components of the Emerging Dis-


\textsuperscript{240} See \textit{Re-Charting the Course—First Report of the Presidential Task Force on Employment of Adults with Disabilities} (Nov. 15, 1998).

\textsuperscript{241} Generic programs include persons with and without disabilities among the beneficiaries of assistance. An example of a generic program is the recently enacted Workforce Investment Systems Act, 29 U.S.C. ch. 30 (Supp. IV 1998), that establishes an integrated workforce investment preparation and employment system for all job seekers, including individuals with disabilities.
EMERGING DISABILITY POLICY FRAMEWORK

ability Policy Framework, including:

- Statement of Findings and Rationale
- Precept and Overarching Goals
- Definitions of Disability
- Core Policies
- Methods of Administration
- Program Support

STATEMENT OF FINDINGS AND RATIONALE

Every piece of disability-specific legislation promulgated since 1973 includes a carefully constructed rationale known as a “Statement of Findings.” A well-constructed Statement of Findings includes the following four major items:

1. A description of the historical treatment of persons with disabilities;
2. A summary of the nature of the problem addressed by the proposed legislation;
3. An explanation of why the issue is important and why change is needed; and
4. A description of the role of various entities in designing, implementing, and evaluating the legislation.

A Statement of Findings facilitates enactment of the legislation by convincing policymakers of its merits. Once the legislation is enacted, the rationale provides a clear statement to guide implementation and enforcement of the law.242

PRECEPT AND OVERARCHING GOALS

In addition to the inclusion of a Statement of Findings, most major disability-specific legislation includes a statement of precept and goals. As with the Statement of Findings, a well-constructed precept and statement of goals further facilitates enactment of the legislation by convincing policymakers of the merits of the legislation. Once the legislation is enacted, the precept and goals provide clear statements to guide implementation of the law. In addition, the precepts and goals provide an explanation when there is uncertainty regarding legislative intent.

The statements of precept and goals are either included within the Statement of Findings or within a separate section. They are sometimes referred to as a “Purpose” section or a “Statement of Policy.”

The precept of Disability Policy Framework is that disability is a natural and normal part of the human experience that in no way diminishes a person’s right to participate fully in all aspects of life, consistent with the unique strengths, re-

According to the Americans with Disabilities Act, “the Nation’s proper goals regarding individuals with disabilities are to assure:

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

DEFINITIONS OF DISABILITY

In addition to constructing a Statement of Finding and the precept and overarching goals of the legislation, stakeholders must define who will be protected or benefited from the proposed legislation. All laws include definitions of key terms. The definition of the term “disability” within the specific legislation is drafted to accomplish its specific purposes. For example, civil rights statutes contain a definition of “disability” that enables the reader to determine which individuals will be protected by the legislation. The definition of “person with a disability” is also included in formula grants and entitlement programs to determine which individuals are eligible for benefits or services.

CORE POLICIES

Once the rationale and goals for the proposed legislation are specified and definitions of disability are established, it is critical for stakeholders to specify the core policies. These statements describe the scope and limitations of the protections, the nature and type of benefits and services, and the circumstances under

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245. Two civil rights statutes pertaining to persons with disabilities are of particular relevance. The first is the Americans with Disabilities Act, 42 U.S.C. ch. 126 (1994), and implementing regulations, 28 C.F.R. pt. 35 (1999), which prohibits discrimination by employers, state and local agencies, public accommodations, and telecommunications. The second law is section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 (1994), which prohibits discrimination by recipients of federal financial assistance. Pursuant to Executive Order 12250, the Department of Justice is responsible for coordinating the implementation of section 504 by various federal agencies, each of which is responsible for issuing its own section 504 regulation. The section 504 coordination regulations issued by the Department of Justice are set out in 28 C.F.R. pt. 41 (1999). The ADA definition of “disability” is set out in section 3(2) of the ADA, 42 U.S.C. § 12102(2) (1994). The section 504 definition of “individual with a disability” is set out in section 6(20) of the Rehabilitation Act of 1973, 29 U.S.C. § 705(20) (1994).

246. See, for example, the definition of “disability” for an adult in the Supplemental Security Income program, Social Security Act § 1614(a)(3)(A), 42 U.S.C. § 1382c(a)(3)(A) (1994) (“An individual shall be considered disabled . . . if he is unable to engage in any substantial gainful activity by reason of any medically determinable . . . impairment [lasting—or expected to last—no less than twelve months] . . . .”). See also the definition included under Part B of the Individuals with Disabilities Education Act under which a child is entitled to special education and related services, IDEA § 602(3), 20 U.S.C. § 1401(3) (Supp. IV 1998) (defining children’s disabilities as those encompassing mental retardation and learning disabilities, as well as health impairments and emotional disturbance).
which benefits and services will be provided.

The numerous core policies can best be understood when they are organized under the four goals of disability policy articulated in the ADA—equality of opportunity, full participation (empowerment), independent living, and economic self-sufficiency. Core policies from various categories of legislation affecting people with disabilities are provided below.

A. EQUALITY OF OPPORTUNITY

The goal of equality of opportunity (nondiscrimination) articulated in the ADA includes three core components: (1) individualization, (2) genuine, effective, and meaningful opportunity, and (3) inclusion and integration.

1. Individualization

This is accomplished through the following actions:

- Making decisions on the basis of the unique strengths, resources, priorities, concerns, abilities, and capabilities of each person with a disability, including individuals with significant disabilities.\(^{247}\)

- Treating a person with a disability as an individual based on facts and objective evidence, and not based upon generalizations, stereotypes, fear, ignorance, prejudice, or pernicious mythologies.\(^{248}\)

- Using definitions and eligibility criteria that result in even-handed treatment of a person with a particular disability and other similarly situated individuals, including non-disabled persons and persons with other disabilities.\(^{249}\)

- Satisfying the broad, nondiscriminatory eligibility criteria by ensuring universal access to generic programs for persons with disabilities.\(^{250}\)

- Using interdisciplinary assessments performed on a timely basis by qualified personnel conducted across multiple environments in making fact-specific decisions. Using information provided by the individual with a disability, the person’s family, or the representative.\(^{251}\)

\(^{247}\) See Developmental Disabilities Assistance and Bill of Rights Act § 101(c)(3), 42 U.S.C. § 6000(c)(3) (1994) (providing that disabled people and their families should be the “primary decision-makers” about what services they need).


\(^{249}\) See 28 C.F.R. § 35.130 (1999) (prohibiting a public entity from treating a disabled person unequally or providing substandard services); 28 C.F.R. § 41.51(b)(1) (1999) (prohibiting the same conduct as the previous regulation).

\(^{250}\) 28 C.F.R. § 35.130 (1999); 28 C.F.R. § 41.51(b)(1) (1999).

Developing individualized plans that identify and describe needs, goals, objectives, services, and accountability measures.252

2. Genuine, Effective, and Meaningful Opportunity

Ensure that the opportunities that are made available to persons with disabilities are genuine, effective, and meaningful.253 This includes the following actions:

- Providing “appropriate” services and supports that address the unique needs of the individual, not the needs of the “average” person.254
- Making reasonable modifications to policies, practices, and procedures, unless it would fundamentally alter the nature of the program.255
- Providing auxiliary aids and services, unless it would result in an undue hardship to the covered entity.256
- Providing reasonable accommodations to employees, unless it would result in an undue hardship to the covered entity.257
- Making programs physically accessible.258
- Providing accessible communications.259

3. Inclusion and Integration

Foster the inclusion and integration of persons with disabilities in programs, projects, and activities provided by covered entities. Persons with disabilities should not unnecessarily or unjustifiably be isolated, segregated, or denied effective opportunities to interact with nondisabled persons and to participate in mainstream activities. This can be accompanied by the following:

- Administering programs, projects, and activities in the most integrated setting appropriate to the needs of the individual.260
• Providing services in the least restrictive environment (continuum of program options).  

**B. FULL PARTICIPATION**

The second goal of disability policy articulated in the ADA is full participation. This means empowering persons with disabilities, fostering self-determination, allowing real and informed choice, and participating actively in decision-making processes at the individual and system level (including self-advocacy).  

1. Involvement and Choice by the Individual in Decisions Affecting the Individual

Foster the active involvement and real and informed choice of the individual with a disability in decisions directly affecting the individual by encouraging the following:

• Opportunities to receive information about policies that affect the individual;
• Assessments of the individual’s progress;
• Planning;
• Services and supports for the individual (including the right to refuse or terminate services); and
• Selection of service providers.  

2. Involvement and Choice by the Individual’s Family in Decisions Affecting the Individual

Facilitate active involvement and real and informed choice of family members (under appropriate circumstances) in decisions affecting the individual with a disability and the family, including the following:

• Opportunities to receive information about policies that affect the individual;
• Assessments of the individual’s progress;
• Planning;
• Services and supports for the individual (including the right to refuse or terminate services); and

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Selection of service providers.\endnote{264}

3. Involvement by Individuals and Families at the System Level

Encourage active involvement in policy decisions at the system level, including the following:

- Opportunities to comment on agency proposals and agency response;
- Participation in governing boards or councils that make or recommend policies relating to the program; and
- Joint sign-off between the public agency and the governing board or council.\endnote{265}

C. INDEPENDENT LIVING

The third goal of disability policy articulated in the ADA is to foster the ability and capabilities of individuals with disabilities to live independently.

1. Independent Living Skills Development and Specialized Planning

Support independent living skill development and specialized planning, by the following:

- Training in individual and systems advocacy;
- Services related to securing food, clothing, and shelter;
- Management of personal assistants and other support personnel; and
- Use of assistive technology devices.\endnote{266}

2. Long-Term Services and Supports, Including Personal Assistance Services and Supports

Support for long-term services and supports, including personal assistance services and supports necessary to enable an individual to live independently in the community, including consumer-directed and agency-directed personal assistance services and supports.\endnote{267}

\endnote{264}{Ticket to Work and Self-Sufficiency Program, Social Security Act as added by Pub. L. No. 106-170, 113 Stat. 1860.}
\endnote{267}{See, e.g., 29 U.S.C. § 723 (1994 & Supp. IV 1998) (offering personal assistance services to those individuals receiving vocational rehabilitation services under the Rehabilitation Act of 1973 § 103); 42 U.S.C. § 1396d (1994) (amended 1999) (explaining that personal assistance services are an optional benefit under the Medicaid program); 42 U.S.C. § 1396a (1994) (amended 1999) (stating that assistance services are also an authorized benefit under the Medicaid home- and community-based services waiver).}
3. Cash Assistance and other Forms of Support

Support for cash assistance and other programs of assistance that enable the individual to live independently in the community include, for example:

- Cash assistance,
- Health care,
- Transportation,
- Housing, and
- Food.

D. ECONOMIC SELF-SUFFICIENCY

The fourth goal of disability policy articulated in the ADA is to foster the economic security, stability, and productivity of persons with disabilities consistent with their actual (not perceived) capabilities, strengths, needs, interests, and priorities.

1. Systems Providing Employment-Related Services and Supports

Systems providing employment-related skills and supports include, for example:

- Education,
- Training,
- Self-employment (entrepreneurship), and
- Ongoing assistance on-the-job.

2. Cash Assistance and Other Programs of Assistance

Support for cash assistance and other programs, such as the following:

- Cash assistance, including worker incentive provisions;

268. See 42 U.S.C. § 1381 (1994) (authorizing the Supplemental Social Security Income program, a federally administered cash assistance program designed to provide minimum income for, among others, persons who are blind and disabled); 42 U.S.C. § 401(b) (1994) (initiating a program of federal disability insurance benefits for, among others, workers who have contributed to the Social Security trust fund and become disabled or blind before retirement age).


274. Id.

275. See Social Security Act § 1905(q), 42 U.S.C. § 1396n(q) (1994) (enabling individuals to continue to receive personal assistance services).

276. Title XVI of the Social Security Act authorizes the Supplemental Security Income program, a federally administered cash assistance program designed to provide a minimum income for, among others, persons who are blind and disabled. 42 U.S.C. § 1381 (1994). Section 1619 of the Social Security Act creates incentives for SSI beneficiaries with disabilities to work, including permitting these individuals to retain eligibility for Medicaid. See 42 U.S.C. § 1382h (1994) (enabling these individuals to continue to receive personal assistance services). See also Social Security Act § 1905(q), 42 U.S.C. §
3. Tax Policy Providing Incentives

Tax policy that provides incentives to employers, consistent with business objectives, to hire people with disabilities and that provides deductions and credits for employment-related expenditures enabling an individual with a disability to work include incentives for employers\(^{280}\) and individuals with disabilities.

**METHODS OF ADMINISTRATION**

After providing the rationale and goals for the proposed legislation, establishing definitions for disability, and specifying the core policies, stakeholders must then consider the inclusion of administrative or accountability provisions. These provisions, which are referred to as “methods of administration,” include such provisions as monitoring and enforcement to ensure implementation, procedural safeguards to ensure individuals are afforded due process of law, outcome measures to determine the impact of the legislation, and methods for financing programs.

These methods of administration are designed to maximize the likelihood that the protections afforded by the civil rights statutes are realized, and that the services and benefits made available under entitlement and grant-in-aid programs are provided and implemented in accordance with best practices. Examples of methods of administration from various categories of legislation affecting people with disabilities are provided below.

**A. STATE PLANS, APPLICATIONS, AND WAIVERS**

State plans and applications describe how the public agency plans to satisfy the applicable requirements, including core policies and methods of administration. Waivers provide exemptions or alternative methods of implementation, including testing the provision of new services.\(^{281}\)

**B. MONITORING AND ENFORCEMENT BY GOVERNMENT AGENCIES**

Monitoring and enforcement maximizes the likelihood that recipients and
contractors will comply with applicable requirements and implement the program to ensure results for persons with disabilities. This includes preparing monitoring instruments, conducting monitoring reviews, issuing reports, requiring corrective action, imposing sanctions, and securing remedies for individuals.282

C. PROCEDURAL SAFEGUARDS

Procedural safeguards for individuals include the following:

- The right to notice of rights;283
- The right to examine records;284
- The right to file a complaint;285
- The right to use of mediation and other forms of alternative dispute resolution;286
- The right to an administrative due process hearing and administrative review;287 and
- The right to seek redress through private right of action in court, including remedies and the awarding of attorneys fees to prevailing parties.288

D. ACCOUNTABILITY FOR RESULTS (OUTCOME MEASURES)

This area facilitates accountability for results using standards and performance indicators that reflect the expected outcomes for recipients with disabilities, the use of sanctions for failure to meet expected outcomes,289 and rewards for exceeding expectations.290

E. REPRESENTATION AT THE INDIVIDUAL AND SYSTEMS LEVELS

This area facilitates public support for representation and advocacy at the individual and systems level to ensure meaningful involvement and choice. This includes the following:

• Systems providing protection and advocacy at the individual and systems level; and
• Self-advocacy training.

F. SINGLE LINE OF RESPONSIBILITY, COORDINATION, AND LINKAGES AMONG AGENCIES

It is beneficial to place accountability for the administration of a program in a single agency to avoid “buckpassing.” At the same time, it is necessary to provide mechanisms for interagency coordination and collaboration to ensure that no one “falls between the cracks” and that agencies provide for the effective delivery of services.

G. SERVICE COORDINATION (CASE MANAGEMENT)

It is essential to provide service coordination to assist individuals in receiving necessary services when a comprehensive array of services is required and such services are provided or paid for by multiple agencies.

H. FINANCING SERVICE DELIVERY

This area includes proscribing methods for financing services through the allocation of funds or the establishment of cost reimbursement schemes (including outcome-based reimbursement schemes) that have the effect of denying effective opportunities for persons with the most significant needs.

I. PRIVACY, CONFIDENTIALITY, ACCESS TO RECORDS, AND INFORMED CONSENT

Protecting privacy and confidentiality and requiring informed consent minimizes the extent of government intrusion. Access to records assures that indi-
individuals have the necessary information to make informed choices.\textsuperscript{298}

\textbf{J. COMPREHENSIVE SYSTEM OF PERSONNEL DEVELOPMENT}

Personnel who provide services to beneficiaries must satisfy qualification standards to perform assigned tasks in an effective and efficient manner. Personnel knowledgeable about civil rights statutes and promising practices are preferred because they are able to provide state-of-the-art services to persons with disabilities.\textsuperscript{299}

\textbf{K. RESPONSIVENESS TO CULTURAL DIVERSITY}

Services must be provided in a culturally competent manner and be responsive to the beliefs, interpersonal styles, attitudes, language, and behaviors of individuals receiving services to ensure maximum participation in the program.\textsuperscript{300}

\textbf{L. FISCAL PROVISIONS}

Public agencies must use program funds to supplement—and not supplant—other sources of funding and must maintain their own fiscal effort.\textsuperscript{301}

\textbf{M. FINANCIAL MANAGEMENT AND REPORTING}

Grant funds should be managed in such a way to ensure fiscal control and fund accounting.\textsuperscript{302}

\textbf{PROGRAM SUPPORT}

Stakeholders provide the rationale and goals for the proposed legislation, establish definitions for disability, specify the core policies, and develop methods of administration provisions. In addition, stakeholders must ensure that initiatives conform to best practices and are state-of-the-art by adopting program supports, such as grants, to support systemic change, research, training, and technical assistance. Examples of program supports from various categories of legislation affecting people with disabilities are provided below.

\textbf{A. SYSTEMS CHANGE INITIATIVES}

This includes funding designed to assist public agencies in developing and implementing comprehensive reforms at the system or institutional level (policies, practices, and procedures).\textsuperscript{303}
B. Training of Individuals with Disabilities and Their Families

This area requires supporting model approaches for training individuals with disabilities and their families.304

C. Training of Personnel Regarding Promising Practices

This legislation provides support for personnel preparation and training, including training of specialists, generalists, and leaders.305

D. Research, Technical Assistance, and Information Dissemination

This area includes support research, technical assistance, and information dissemination which all ensure that the programs are effective, state-of-the-art, and efficient.306

Part II

General Questions for Analyzing the Extent to Which Disability-Specific or Generic Programs or Policies Reflect the Disability Policy Framework

Introduction

Using the Disability Policy Framework described in Part I of Appendix 1, this part includes general questions for analyzing the extent to which disability-specific and generic programs or policies reflect the precept, goals, definitions, core policies, methods of administration, and program supports set out in the Disability Policy Framework. In other words, this part of this Appendix serves as a guidepost for evaluating, expanding, and improving the design and implementation of public policies affecting persons with disabilities.

Answering these questions may entail, among other things, reviewing previous studies and reports, reviewing data, conducting analyses of proposed and final policy pronouncements, and conducting surveys of stakeholders. Not all questions articulated in this part are applicable to all programs and policies; for example, some questions may only be applicable to generic programs serving nondisabled


persons, as well as persons with disabilities.

**QUESTIONS RELATING TO STATEMENT OF FINDINGS AND RATIONALE**

Is the program longstanding, undergoing major reform, or new? If new, does it replace an existing program?

Was the program established on a sound premise?

Has the program historically excluded persons with disabilities or specific categories of persons with disabilities? For example, has a policy, procedure, or accepted practice historically disqualified persons with significant disabilities from receiving services, or has a policy, procedure or accepted practice by a generic program automatically referred all persons with disabilities to disability-specific programs?

Is there a history of segregation of persons with disabilities into specific slots or components of the program?

Is there a history of denial of genuine, effective, and meaningful services in the program?

Is there a history of ensuring that people with disabilities enjoy choice in assessments, planning, services provided, selection of service providers, and measures of progress?

Is there history of fostering independent living and ensuring self-sufficiency?

What efforts have been made to ascertain the prevalence of persons with disabilities among the prospective pool of eligible recipients of a generic program?

What efforts have been made to ascertain the scope of unmet need?

Is the public agency considering the historical treatment of persons with disabilities in the development of new policies and procedures and in the methods of administration it uses?

**QUESTIONS RELATING TO PRECEPT**

Does the program include a statement articulating the core precept on which it is based? Is the core precept of the program consistent with the precept of disability policy that disability is a natural and normal part of the human experience that in no way diminishes a person’s right to fully participate in the program, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities of the individual?

**A QUESTION RELATING TO OVERARCHING GOALS**

Do the goals of the program reflect the goals of federal disability policy articulated in the ADA—equality of opportunity, full participation (empowerment), independent living and economic self-sufficiency for persons with disabilities?
QUESTIONS RELATING TO DEFINITION OF DISABILITY

Does the definition of disability reflect the purposes of the particular legislation?

How does the definition of disability relate to definitions used in other programs?

Does it relate to the definition used in section 504 and the ADA?

QUESTIONS RELATING TO CORE POLICIES

A. QUESTIONS RELATING TO EQUALITY OF OPPORTUNITY

1. Individualization

Do the policies and procedures governing eligibility and application for and delivery of services under the program:

Account for the unique strengths, resources, priorities, concerns, abilities, and capabilities of each person with a disability, including individuals with significant disabilities?

Account for the added dimension of poverty?

Use definitions and eligibility criteria that result in even-handed treatment between a person with a particular disability and other similarly situated individuals, including nondisabled persons and persons with other disabilities?

Satisfy the broad, nondiscriminatory eligibility criteria by ensuring universal access to generic programs for persons with disabilities?

Support and promote the treatment of persons with a disabilities as individuals based on facts and objective evidence, not based on generalizations, stereotypes, fear, ignorance, or prejudice?

Use interdisciplinary assessments performed by qualified personnel, conduct timely assessments across multiple environments, and use information provided by the individual with a disability and the person’s family or representative in making fact-specific decisions?

Use individualized plans to identify and describe needs, goals, objectives, services, and accountability measures?

2. Genuine, Effective, and Meaningful Opportunity

Do the policies and procedures governing eligibility and application for and delivery of services under the program offer opportunities that are genuine, effective, and meaningful? Do the policies and procedures:

Provide “appropriate” services and supports designed to meet the unique needs of the individual, not the needs of the “average” person?
EMERGING DISABILITY POLICY FRAMEWORK

Make reasonable modifications to policies, practices, and procedures, unless it would fundamentally alter the nature of the program?

Provide auxiliary aids and services, unless it would result in an undue hardship to the covered entity?

Provide reasonable accommodations to employees, unless it would result in an undue hardship to the covered entity?

Make a program physically accessible?

Provide for communication accessibility?

3. Inclusion and Integration

Do the policies and procedures governing eligibility and application for and delivery of services under the program foster the inclusion and integration of persons with disabilities, or do the policies and procedures unnecessarily or unjustifiably isolate or segregate persons with disabilities?

**B. A QUESTION RELATING TO FULL PARTICIPATION**

Do the policies and procedures governing the program foster the empowerment of persons with disabilities, real and informed choice, and active participation in decision-making processes at the individual and system level (including self-advocacy)?

More specifically, do the policies and procedures governing the program foster:

Active involvement and real and informed choice of the individual with a disability in areas including:

- Opportunity to receive information about policies that affect the individual?
- Assessments?
- Planning?
- Services?
- Selection of service providers?
- Measures of progress?

Active involvement and real and informed choice of family members and other representatives (under appropriate circumstances) in decisions affecting the individual with a disability and the family, including:

- Opportunity to receive information about policies that affect the individual?
- Assessments?
- Planning?
- Services?
Selection of service providers?
Measures of progress?
Active involvement in policy decisions at the system level (respecting the design, implementation and evaluation of a program), including:
  Consideration of input from consumers?
  Participation on governing boards and councils?
  Joint sign-off on policies by the governing board/council?

C. QUESTIONS RELATING TO INDEPENDENT LIVING

Do the policies and procedures governing the program foster the ability and capabilities of individuals with disabilities to live independently through support for independent living skill development, including:
  Training in individual and systems advocacy?
  Service related to securing food, clothing, and shelter?
  Training the management of personal assistants and the use of assistive technology?
  Specialized planning for transitioning to independent living?

Do the policies and procedures governing the program enable the person with a disability to live independently through the provision of long-term services and supports, for example, consumer-directed personal assistance services and supports and assistive technology devices and services?

Do the policies governing the program enable the person with a disability to live independently in the community through cash assistance or other forms of assistance?

D. QUESTIONS RELATING TO ECONOMIC SELF-SUFFICIENCY

Do the policies and procedures governing the program foster the economic security, stability, and productivity of persons with disabilities consistent with their actual (not perceived) capabilities, strengths, needs, interests, and priorities through support for:
  Systems that include universal access to generic services as well as access to specialized services and supports as an integral component of the system?
  Training, education, and employment of choice (including self-employment)?
  Ongoing supports on-the-job?
  Specialized planning (e.g., transition planning for children in high school)?
  Cash assistance programs that reflect the goal of maximizing
EMERGING DISABILITY POLICY FRAMEWORK

economic self-sufficiency, including policies that provide incentives to work (e.g., waive or modify income and resource limits, and retain eligibility for acute and long-term services and supports)?

QUESTIONS RELATING TO METHODS OF ADMINISTRATION

A. QUESTIONS RELATING TO STATE AND LOCAL PLANS, APPLICATIONS, AND WAIVERS

Does the plan/application include specific policies and procedures governing implementation for persons with disabilities?

Do waiver requests have the effect of enhancing or diminishing opportunities for persons with disabilities? For example, is a waiver request designed to test new strategies for delivering services that reflect the goals of disability policy articulated in the ADA? Or is the waiver request based on “perceptions” that individuals with disabilities cannot succeed or participate in the program or assessment generally applicable to nondisabled persons?

Does the plan/application explain how people with disabilities and their representatives were involved in the process of completing the plan/application?

In addition to the inclusion of an assurance of nondiscrimination, does the plan/application include specific policies and procedures relating to implementation of the program consistent with section 504 of the Rehabilitation Act of 1973 and the ADA?

B. QUESTIONS RELATING TO MONITORING AND ENFORCEMENT BY GOVERNMENT AGENCIES

What are the respective roles and responsibilities of federal, state, and local agencies for monitoring and enforcement?

Does the monitoring instrument developed by the government agency include specific inquiries related to persons with disabilities? If so, what are they?

Does the government agency use a monitoring instrument for ascertaining compliance with section 504 of the Rehabilitation Act of 1973 and the ADA? If so, what is included?

Do on-site monitoring reviews include assessments relating to meeting the needs of persons with disabilities and ensuring nondiscrimination?

What sanctions are available and used? Under what circumstances?

What incentives are available and used?

How are findings of noncompliance used by the agency? Are findings of noncompliance used for purposes of ongoing continuous quality improvement reviews?

What remedies are available?
Is there a complaint resolution procedure that includes complaints involving discrimination on the basis of disability?

C. QUESTIONS RELATING TO PROCEDURAL SAFEGUARDS FOR INDIVIDUALS, THEIR FAMILIES, AND REPRESENTATIVES

Do the policies and procedures governing the program provide for:
- Notice of rights?
- Examination of records?
- The right to file a complaint?
- The use of mediation and other forms of alternative dispute resolution?
- Administrative due process hearings and administrative review?
- Redress through private right of action in court, including remedies and the awarding of attorneys’ fees to prevailing parties?

D. QUESTIONS RELATING TO ACCOUNTABILITY FOR RESULTS (OUTCOME MEASURES)

Does the agency include outcome measures that address issues of specific relevance to persons with disabilities?

Does the agency disaggregate data so the agency can determine whether its program is meeting the needs of persons with disabilities or persons with specific categories of disabilities as part of a process of continuous improvement?

E. QUESTIONS RELATING TO REPRESENTATION AT THE INDIVIDUAL AND SYSTEMS LEVEL

Does the public agency provide support for representation and advocacy at the individual and systems level, including support for systems providing protection and advocacy, and self-advocacy training?

F. QUESTIONS RELATING TO SINGLE LINE OF RESPONSIBILITY/COORDINATION AND LINKAGES AMONG AGENCIES

Is there a single agency (state or local) responsible for implementation of the program for all beneficiaries, including persons with disabilities? If not, how does the agency ensure compliance for persons with disabilities?

Does the agency require the assignment of an individual who will be responsible for ensuring implementation of the program for persons with disabilities, particularly with respect to implementation of the program consistent with section 504 of the Rehabilitation Act of 1973 and the ADA?

Has the agency developed policies and procedures for collaboration among agencies to ensure meaningful and effective delivery of neces-
sary services to persons with disabilities, including cost sharing ar-
rangements?

G. A QUESTION RELATING TO SERVICE COORDINATION (CASE MANAGEMENT)

Has the agency developed policies and procedures for service coordina-
tion to ensure that individuals with disabilities, particularly those with
the most significant disabilities, receive the services they need, particu-
larly where services are provided by multiple agencies?

H. QUESTIONS RELATING TO FINANCING SERVICE DELIVERY

Does the system for allocating funds among agencies and service pro-
viders facilitate or thwart accomplishment of the goals articulated in the
ADA and the policies that effectuate the goals? For example, does the
outcome-based reimbursement scheme used to pay service providers
recognize and reward those who serve persons with the most significant
disabilities and who cost more than the average recipient of services
(risk adjustment)?

Is the network of service providers adequate to address the needs of per-
sons with disabilities eligible for assistance under the program?

Is the financing system for services (for example, personal assistance
services, assistive technology) consumer-directed?

I. QUESTIONS RELATING TO PRIVACY, CONFIDENTIALITY, ACCESS TO RECORDS, AND
INFORMED CONSENT

Does the agency include specific policies and procedures protecting the
rights of persons with disabilities to privacy? Confidentiality? Access to
records?

Does the agency include specific policies and procedures requiring in-
formed consent?

J. QUESTIONS RELATING TO COMPREHENSIVE SYSTEM OF PERSONNEL DEVELOPMENT

Does the agency include specific training components regarding the im-
plementation of its program (e.g., policy, “promising practices,” and re-
source allocation) for persons with disabilities?

Does the agency include specific training for its personnel regarding im-
plementation of its program consistent with section 504 of the Rehabili-
tation Act of 1973 and the ADA?

K. A QUESTION RELATING TO RESPONSIVENESS TO CULTURAL DIVERSITY

Does the agency include policies and procedures that address the special
needs of persons with disabilities from diverse cultural backgrounds?

L. A QUESTION RELATING TO FISCAL PROVISIONS

Do the “supplement, not supplant” and “maintenance of effort” provi-
sions ensure continuation of funding from state and local sources for services provided to persons with disabilities?

M. QUESTIONS RELATING TO FINANCIAL MANAGEMENT AND REPORTING

Do the fiscal control and fund accounting procedures enable oversight with respect to the provision of funding for persons with disabilities consistent with legislative intent?

QUESTIONS RELATING TO PROGRAM SUPPORT

To the extent an agency supports efforts to improve the quality of services provided through initiatives (such as systems change grants, training, research, technical assistance, demonstrations, and information dissemination), do these initiatives include specific components or specific initiatives that address the unique needs of persons with disabilities?
1956 - Social Security Amendments of 1956 (P.L. 84-880)

Established the Disability Insurance Trust Fund under Title II of the Social Security Act and provided for payment of benefits to workers with disabilities under the Social Security Disability Insurance program. Benefits were limited to workers age fifty and older.

1958 - Captioned Films for the Deaf Act (P.L. 85-905)

Permitted the Office of Education to purchase, lease, or accept films (primarily recreational films), provide captions for them, and distribute them through state schools for the deaf, as well as through other appropriate state agencies.

1960 - Social Security Amendments of 1960 (P.L. 86-778)

Eliminated the limitation on benefits to workers over age fifty (1956), and encouraged workers by authorizing a nine-month trial work period during which the beneficiary could have earnings without jeopardizing benefits.

1963 - Social Security Act Amendments of 1963 (P.L. 88-156)

Established a new project grant program to improve prenatal care for women from low income families for whom the risk of mental retardation and other birth defects was known to be inordinately high. In addition, authorizations for grants to the states under the Maternal and Child Health and Crippled Children’s programs (originally established in 1935 under P.L. 74-271) were increased and a research grant program was added.

1963 - Mental Retardation Facilities Construction Act of 1963 (P.L. 88-164)

Authorized federal support for the construction of mental retardation research centers, university-affiliated training facilities, and community service facilities for children and adults with mental retardation.

1965 - Elementary and Secondary Education Act of 1965 (P.L. 89-10)

The core of the Act, Title I, authorized a multi-billion dollar program of aid to assist the states and local school districts in providing compensatory education to educationally disadvantaged children residing in low-income areas.

1965 - Social Security Act Amendments of 1965 (P.L. 89-97)

Title XVIII (Medicare) authorized health insurance benefits for eligible elderly persons or eligible persons with disabilities. Direct payments are made for medical services on behalf of eligible participants through “fiscal intermediaries,” for example, private health insurance companies. “Part A” reimbursed hospitals and other covered entities. “Part B” provided supplemental medical insurance benefits. Title XIX authorized grants-in-aid to the states for the establishment of a
medical assistance program to improve the accessibility and quality of medical care for low-income individuals (Medicaid).

1965 - Elementary and Secondary Education Act Amendments of 1965 (P.L. 89-313)

Authorized aid to state agencies operating and/or supporting schools for children with disabilities.


Authorized assistance for students with physical or mental disabilities who were in residential schools operated or substantially supported by the state. Part B of Title IV of the Act made federal funds available to state agencies for library services for individuals who were certified by a responsible authority as unable to read or to use conventional printed materials as a result of physical limitations. Such services could be provided through public or nonprofit library agencies or organizations.

1966 - Military Medical Benefits Act Amendments of 1966 (P.L. 89-614)

Expanded health care benefits for dependents of active duty members of the uniformed services (the Army, Navy, Marine Corps, Air Force, Coast Guard, and the commissioned corps of Public Health Service). Under the expanded benefits of the Civilian Health and Medical Program of the Uniformed Services Program (CHAMPUS) for the handicapped, the spouse or child of an active duty member is eligible for services if he or she has a serious physical disability or is moderately to severely mentally retarded.

1967 - Mental Retardation Amendments of 1967 (P.L. 90-170)

Authorized federal funds to assist in the cost of initiating services in community mental retardation facilities.


Expanded instructional media programs to provide for the production and distribution of educational media for the use of persons with all types of disabling conditions (not just deafness), their parents, actual or potential employers, and other persons directly involved in working on behalf of persons with disabilities.

1967 - Social Security Act Amendments of 1967 (P.L. 90-248)

Added a list of mandatory and optional services under the Medicaid program and required participating states to offer early and periodic screening, diagnosis, and treatment services to all Medicaid-eligible children.


The child care component provided federal assistance for meals served in
Institutions providing nonresidential day care for children. Facilities eligible to participate included day care centers, settlement houses, recreation centers, and institutions providing day care for youngsters with disabilities.


Required buildings and facilities designed, constructed, altered, or financed by the federal government after 1969 to be accessible to and usable by persons with disabilities.

1968 - Vocational Education Act Amendments (P.L. 90-576)

Required each state to earmark ten percent of its basic grant for services for youth with disabilities.


Created a separate Act, The Education of the Handicapped Act (EHA). Part B authorized grants to states to assist them in initiating, expanding, and improving programs for the education of children with disabilities. EHA also established several competitive grant programs such as personal preparation, research, and demonstration.


Required eligible local jurisdictions to plan and design mass transit facilities and services so that they would be accessible to and usable by people with disabilities.


Included broad responsibilities for a state planning and advisory council to plan and implement a comprehensive program of services for persons with developmental disabilities. In addition, the legislation authorized grants to support interdisciplinary training in institutions of higher education of personnel providing services to persons with developmental disabilities (currently known as university-affiliated programs).

1971 - Amendments to Title XIX of the Social Security Act (Medicaid Program) (P.L. 92-223)

Authorized public mental retardation programs to be certified as intermediate care facilities and requires that these programs offer, among other things, “active treatment.”

1972 - Small Business Act Amendments of 1972 (P.L. 92-595)

Expanded the authority of the Small Business Administration to provide direct and guaranteed loans for nonprofit sheltered workshops employing persons with disabling conditions and individuals with disabilities interested in establishing their own businesses.
1972 - Social Security Amendments of 1972 (P.L. 92-603)

Repealed existing public assistance programs and added in their place a new Title XVI (Supplemental Security Income, SSI) program. This program authorizes cash benefits for individuals and couples who are aged, blind, or disabled. In addition, children under eighteen years of age with disabilities or blindness are eligible for benefits, provided that their disabilities were comparable in severity to adult recipients. Medicare coverage was authorized for Social Security beneficiaries with disabilities after they fulfilled a specified waiting period.


Tied increases in benefit levels under the disability insurance program to the Consumer Price Index, thus authorizing automatic annual cost-of-living adjustments in benefit payments.


Authorized the use of funds under the Highway Program “to provide adequate and reasonable access for the safe and convenient movement of physically handicapped persons, such as across curbs constructed or replaced at all pedestrian crosswalks throughout the states.” Improvement funds may also be used for providing accessible rest stop facilities.

1973 - Rehabilitation Act of 1973 (P.L. 93-112)

Included a complete revision of the state formula grant supporting the vocational rehabilitation program and the competitive programs supporting personnel development, research, and demonstrations. In addition, the legislation, among other things, added “Section 502,” which established the Architectural and Transportation Barriers Compliance Board to enforce the Architectural Barriers Act of 1968 and provide technical assistance to agencies subject to section 504 regulations. In addition, the legislation added “Section 504,” which prohibited discrimination against otherwise qualified persons with disabilities in any program or activity receiving federal funds.

1973 - Amtrak Improvement Act of 1973 (P.L. 93-146)

The National Railroad Passenger Corporation was directed to take all steps necessary to ensure that no elderly or handicapped individual is denied intercity transportation on any passenger train operated by or on behalf of the Corporation. Steps include: acquiring special equipment and devices and conducting special training for employees; designing and acquiring new equipment and facilities and eliminating architectural and other barriers in existing equipment or facilities; and providing special assistance to persons who are elderly or disabled while boarding and alighting and within terminal areas.

1974 - Housing and Community Development Amendments of 1974 (P.L. 93-383)

Expanded the low-income rent subsidy program under “Section 8” to include families consisting of single persons with disabilities. The legislation also extended
the “Section 202” direct loan program to nonprofit agencies to projects for persons with mental as well as physical disabilities.

1974 - Elementary and Secondary Education Amendments of 1974 (P.L. 93-380)

Included amendments to Part B of the Education of the Handicapped Act (EHA) that laid the basis for comprehensive planning, the delivery of additional financial assistance to the states, and the protection of handicapped children’s rights.


Required project applicants to assure that the fares charged to the elderly or persons with disabilities during nonpeak hours do not exceed one-half of generally applicable rates for other riders during peak hours. In addition, localities were permitted under this Act to transport riders who are elderly or disabled free of charge and still be eligible for federal grant aid.

1974 - Community Services Act (P.L. 93-644)

Stipulated that ten percent of children enrolled in the Head Start program must be children with disabilities.

1974 - Social Services Amendments of 1974 (P.L. 93-647)

Consolidated social service grants to states under a new Title XX of the Social Security Act.

1975 - Developmental Disabilities Assistance and Bill of Rights Act (P.L. 94-103)

Created a “bill of rights” for persons with developmental disabilities, funded services for persons with developmental disabilities, added a new funding authority for university affiliated facilities, and established a system of protection and advocacy organizations in each state.

1975 - Education for All Handicapped Children Act (P.L. 94-142)

Amended the Education of the Handicapped Act to mandate a free appropriate public education for all children with disabilities in a state, regardless of the nature or severity of the child’s disability (Part B of the Education of the Handicapped Act).

1977 - Tax Reduction and Simplification Act (P.L. 95-30)

Congress authorized a special tax credit to induce businesses to hire certain categories of chronically unemployed workers, disadvantaged youth, welfare recipients, and other hard to place persons, including individuals with disabilities.

1977 - Legal Services Corporation Act Amendments of 1977 (P.L. 95-222)

Required the Corporation to establish procedures for determining and implementing service priorities, taking into account the relative needs of clients eligible for assistance, including people with disabilities and other individuals facing spe-
cial difficulties in accessing legal services.


Expanded the jurisdiction of the Civil Rights Commission to include protection against discrimination on the basis of handicap.

1978 - Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments (P.L. 95-602)

Established the National Institute of Handicapped Research and new programs for people with disabilities, including comprehensive service centers, independent living centers, recreation programs, and pilot programs for employment. The legislation also updated and made functional the definition of the term “developmental disability” and clarified the functions of the university-affiliated programs.

1979 - Food Stamp Act of 1979 (P.L. 96-58)

Authorized food stamps for residents of community living arrangements for persons with blindness or disabilities, by redefining “eligible households” to include disabled or blind recipients of benefits under Title II or Title XVI of the Social Security Act who are residents in a public or private nonprofit group living arrangement that is certified by the appropriate state agency or agencies regulations issued under section 1616(e) of the Social Security Act.

1980 - Civil Rights of Institutionalized Persons Act (P.L. 96-247)

Authorized the U.S. Department of Justice to sue states for alleged violations of the rights of institutionalized persons, including persons in mental hospitals or facilities for people with mental retardation.

1980 - Social Security Act Amendments (P.L. 96-265)

Authorized special cash payments (section 1619(a)) and continued Medicaid eligibility (section 1619(b)) for individuals who receive Supplemental Security Income (SSI) benefits but, nonetheless, engage in substantial gainful activity. The provision was made effective for three years.

1980 - Federal Advisory Committee Act (P.L. 96-523)

Permitted the employment of personal assistants for federal employees with disabilities both at their regular duty station and while on travel status.

1981 - Omnibus Budget Reconciliation Act (P.L. 97-35)

Consolidated six programs authorized under Title V of the Social Security Act into a single block grant authority (Maternal and Child Health) to address, among other things, the needs of children with special health care needs. In addition, the existing Title XX program was converted into a Social Services Block Grant Program.

Authorized the Secretary of Health and Human Services to grant “home and community-based” waivers to enable states to furnish personal assistance and other
services to individuals who, without such services, would require institutional care as long as costs under the waiver do not exceed the cost of providing institutional care to the target population.

Limited Child Care Program to children up to age twelve, except children with disabilities, for whom no age limit was set.


Placed the Handicapped Assistance Loan Program administratively within the regular SBA loan system.


Permitted states to cover under their Medicaid plans home care services for certain children with disabilities, even though family’s income and resources exceeded state’s normal eligibility standards.

1982 - Job Training Partnership Act (P.L. 97-300)

Revamped the Comprehensive Employment and Training Act (CETA). The Act emphasizes training for private sector jobs. The Act established a “State Job Training Coordinating Council” and the “Private Industry Council (PIC)”.


Required that workplace telephones used by persons with hearing aids and emergency phones be hearing-aid-compatible.

1984 - Rehabilitation Act Amendments of 1984 (P.L. 98-221)

Transformed the National Council on Disability from an Advisory Board in the Department of Education into an independent federal agency.

1984 - Voting Accessibility for the Elderly and Handicapped Act (P.L. 98-435)

Required that registration and polling places for federal elections be accessible to persons with disabilities.


Required states to enact procedures or programs within child protection agencies to respond to cases in which medical treatment is withheld from disabled infants.


Extended the section 1619 worker incentive program under SSI for an additional three years. The 1984 amendments also required the Secretary of HHS to publish uniform standards for SSI and SSDI disability determinations.


Added a statement of purpose to the Act and authorized protection and advo-
cacy systems to have access to the records of persons with developmental disabili-

ties residing in institutions.


Authorized states to cover case management services on less than a statewide
or comparable basis to targeted groups under Medicaid; expanded the definition of
“habilitation” for Home and Community-Based Waiver recipients with develop-
mental disabilities to cover certain pre-vocational services and supported employ-
ment for previously institutionalized individuals; authorized states to cover venti-
lator-dependent children under the waiver program if they would otherwise require
continued inpatient care.

1986 - Protection and Advocacy for Mentally Ill Individuals Act of 1986 (P.L. 99-
319)

Established a formula grant program operated by existing protection and ad-
vocacy systems primarily focusing on incidences of abuse and neglect of mentally
ill individuals.


Changed the name of the school from “Gallaudet College” to “Gallaudet Uni-
versity,” and extended the statutory authority of the National Training Institute for
the Deaf (a residential facility for postsecondary technical training and education
for individuals who are deaf in order to prepare them for successful employment)
(Title II).

Established a Commission on Education of the Deaf under Title III of the Act.
The Commission consists of twelve members that study the quality of infant and
eyearly childhood programs, as well as elementary, secondary, postsecondary, adult,
and continuing education programs for individuals who are deaf. The Commission
makes recommendations to the President and Congress for improving current pro-
grams and practices.


Overturned a Supreme Court decision and authorized courts to award reason-
able attorneys fees to parents who prevail in due process proceedings and court
actions under part B of the Education of the Handicapped Act.

1986 - Air Carriers Access Act (P.L. 99-435)

Prohibited discrimination against persons with disabilities by air carriers and
provided for enforcement by the U.S. Department of Transportation.


Included a new grant program for states to develop an early intervention sys-
tem for infants and toddlers with disabilities and their families and provide greater
incentives for states to provide preschool programs for children with disabilities
between the ages of three and five.

1986 - Amendments to the Job Training Partnership Act (P.L. 99-496)

Required special consideration for persons with disabilities in the awarding of discretionary grants.


Authorized construction/renovation grants and loans to institutions of higher education. Among the purposes for which funds under this Act may be used is to bring academic facilities into compliance with the Architectural Barriers Act of 1968 and section 504 of the Rehabilitation Act of 1973.

1986 - Rehabilitation Act Amendments of 1986 (P.L. 99-506)

Clarified that supported employment is a viable outcome of vocational rehabilitation and specified that states must plan for individuals making the transition from school to work.


Extended “targeted jobs tax credit” through 12/31/88.

1986 - Employment Opportunities for Disabled Americans Act (P.L. 99-643)

Made the section 1619(a) and 1619(b) work incentives a permanent feature of the Social Security Act. The Act also added provisions to enable individuals to move back and forth among regular SSI, section 1619(a) and section 1919(b) eligibility status.

1987 - Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987 (P.L. 100-146)

Updated language in the legislation, strengthened the independence of the State Planning Councils, strengthened authority of protection and advocacy systems to investigate allegations of abuse and neglect, and created separate line items for core funding and training for university affiliated programs.

1987 - Housing and Community Development Act of 1987 (P.L. 100-242)

Required HUD to earmark fifteen percent of section 202 funds for non-elderly persons with disabilities.

1988 - Civil Rights Restoration Act (P.L. 100-259)

Amended the Rehabilitation Act of 1973’s definition of an individual with a disability and defined coverage of section 504 as broad (e.g., extending to an entire university) rather than narrow (e.g., extending to just one department of the university) when federal funds are involved.

1988 - Education Amendments of 1988 (P.L. 100-297)
Made a number of changes in Chapter 1, including the provisions dealing with aid to state-operated and supported schools for children with disabilities.


Clarified the circumstances under which Medicaid reimbursement would be available for services included in a child’s individualized education program (IEP) or individualized family services plan (IFSP) under the Individuals with Disabilities Education Act.

1988 - Hearing Aid Compatibility Act of 1988 (P.L. 100-394)

Required most telephones manufactured or imported into the United States to be compatible for use with telecoil-equipped hearing aids.

1988 - Temporary Child Care for Handicapped Children and Crisis Nurseries Act of 1986 (P.L. 100-403)

Authorized the Secretary of Health and Human Services to make grants to states for public and nonprofit agencies to furnish temporary, non-medical care services to children with disabilities and special health care needs.

1988 - Technology-Related Assistance for Individuals with Disabilities Act (P.L. 100-407)

Provided grants to states to develop statewide assistive technology programs.

1988 - Fair Housing Act Amendments (P.L. 100-430)

Added persons with disabilities as a group protected from discrimination in housing and ensured that persons with disabilities are allowed to adapt their dwelling place to meet their needs.


Allowed the Administrator of General Services Administration (GSA) to take such actions as are necessary to assure that the federal telecommunications system is fully accessible to hearing and speech impaired individuals.

1988 - Small Business Administration Reauthorization and Amendment Act of 1988 (P.L. 100-590)

Enlarged the class of organizations eligible to receive Handicapped Assistance Loans to include both public and private entities.

1988 - Traffic Safety for Handicapped Individuals Act (P.L. 100-641)

Required the Department of Transportation to issue regulations establishing a uniform parking system for people with disabilities.

Specified, among other things, that at least thirty percent of the Maternal and Child Health Block Grant under Title V of the Social Security Act must be used to improve services for children with special health care needs.

Included a major expansion in required services under Medicaid’s Early and Periodic Screening, Diagnosis, and Treatment Program (EPSDT).

Required the Social Security Administration (SSA) to establish a permanent outreach program for children who are blind or otherwise disabled.

**1990 - Americans with Disabilities Act (ADA) (P.L. 101-336)**

Guaranteed the civil rights of people with disabilities by prohibiting the discrimination against anyone who has a mental or physical disability in the area of employment, public services, transportation, public accommodations, and telecommunications.


Rewrote the vocational legislation, eliminated the ten percent earmarking for disabled youth, but included specific language to assure students with disabilities access to qualified vocational programs and supplementary services.

**1990 - Television Decoder Circuitry Act (P.L. 101-431)**

Required closed caption circuitry (computer chip) to be part of all televisions with screens thirteen inches or larger manufactured for sale and use in the United States.


Stimulated the improvement of the vocational and life skills of students with disabilities to enable them to be better prepared for the transition to adult life and services.


Renamed the Education of the Handicapped Act and reauthorized programs under the Act to improve support services to students with disabilities, especially in the areas of transition and assistive technology.


Maintained and further strengthened programs authorized under the Act.


Established a limited purpose optional state coverage of community supported living arrangements services for persons with mental retardation and related conditions (authority has since expired).

Authorized community supported living arrangements and stressed individu-
alized support rather than the standardized services common to the ICF/MR pro-
gram.
   Included a provision called the “access credit” that enables small businesses
to claim credit against taxes for half of the first $10,000 of eligible costs of com-
plying with the ADA.

1990 - National Affordable Housing Act (P.L. 101-625)

   Established a distinct statutory authority to fund supportive housing for peo-
ple with disabilities, with a separate financing mechanism and selection criteria.


   Enhanced infants and toddlers program and extended the IDEA support pro-
grams.


   Reversed numerous U.S. Supreme Court decisions that restricted the protec-
tions in employment discrimination cases and authorized compensatory and puniti-
ve damages under Title V of the Rehabilitation Act of 1973 and ADA.


   Authorized increased set aside funds under section 16(b) of the Act to assist
facilities in meeting the special transportation accessibility needs of those who are
elderly or disabled.


   Included changes that increase access to state vocational rehabilitation sys-
tems for those with the most significant disabilities, enabled consumers to have
greater choice and control in the rehabilitation process, and provided opportunities
for career advancement.

1993 - Family and Medical Leave Act (P.L. 103-3)

   Allowed workers to take up to twelve weeks of unpaid leave to care for new-
born and adopted children and family members with serious health conditions or to
recover from serious health conditions.

1993 - National Voter Registration Act (P.L. 103-31)

   Required states to liberalize their voter registration rules to allow people to
register to vote by mail, when they apply for driver’s licenses, or at offices that
provide public assistance and programs for individuals with disabilities such as
vocational rehabilitation programs.

1993 - National and Community Service Trust Act of 1993 (P.L. 103-82)

   Established a national service program, including tuition assistance and a liv-
ing allowance for individuals age seventeen and older who volunteer part-time or
full-time in community service programs.
1994 - Technology-Related Assistance for Individuals with Disabilities Act Amendments (P.L. 103-218)

Reauthorized the 1988 “Tech Act,” that was established to develop consumer-driven, statewide service delivery systems that increase access to assistive technology devices and services to individuals of all ages with disabilities. The 1994 amendments emphasize advocacy, systems changes activities and consumer involvement.


Provided a framework for meeting national educational goals and carrying out systemic school reform for all children, including children with disabilities.


Rewrote and updated provisions pertaining to State Planning Councils and extended and strengthened provisions pertaining to protection and advocacy systems, university affiliated programs, and programs of national significance.

1994 - School-to-Work Opportunities Act of 1994 (P.L. 103-239)

Authorized funds for programs to assist students, including students with disabilities, in the transition from school to work.

1994 - Improving America’s Schools Act of 1994 (IASA) (P.L. 103-382)

Reauthorized the Elementary and Secondary Education Act (ESEA), which provides the framework of federal grants to states for elementary and secondary education programs. Among other provisions, the legislation amends the Individuals with Disabilities Education Act to establish a new state program supporting statewide systems of support for families of children with disabilities.


Included new family resource and support program that supports state efforts to develop, operate, expand and enhance a network of community-based, prevention-focused, family resource and support programs which would be equipped to address, among other things, the additional family support needs of families with children with disabilities.

1996 - Telecommunications Act of 1996 (P.L. 104-104)

Required telecommunications manufacturers and service providers to ensure that equipment is designed, developed, and fabricated to be accessible to and usable by individuals with disabilities, if readily achievable.

1996 - Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1996 (P.L. 104-183)
Extended authority to fund Developmental Disabilities Councils, Protection and Advocacy Systems, University Affiliated Programs, and Projects of National Significance.


Improved access to health care for twenty-five million Americans by guaranteeing that private health insurance is available, portable, and renewable; limiting pre-existing condition exclusions; and increasing the purchasing clout of individuals and small employers through incentives to form private, voluntary coalitions to negotiate with providers and health plans.


Provided a new, more restrictive definition of disability for children under the Supplemental Security Income program (SSI), focusing on functional limitations, mandating changes to the evaluation process for claims and continuing disability reviews, and requiring redeterminations to be performed before a child turns eighteen.


Included a provision that prohibits insurance companies from having lower lifetime caps for treatment of mental illness compared with treatment of other medical conditions.

1997 - Individuals with Disabilities Education Act Amendments of 1997 (P.L. 105-17)

Included the first major changes to Part B since enactment in 1975, extended the early intervention program, and included a significant streamlining of the discretionary programs.

1997 - Balanced Budget Act of 1997 (P.L. 105-33)

Established the State Children’s Health Insurance Program (SCHIP) to expand health insurance coverage for low-income children not covered by Medicaid; Authorized the Social Security Administration to make redeterminations of childhood SSI recipients who attain age eighteen using adult disability criteria one year after they turn eighteen; Provided that states must continue Medicaid coverage for disabled children who were receiving SSI benefits as of August 22, 1996 and would have been eligible except their eligibility terminated because they did not meet the new SSI childhood disability criteria; Permitted states to allow workers with disabilities whose family income is less than 250% of poverty to buy into Medicaid (and pay premiums based on sliding scale of income); Eliminated the requirement of prior institutionalization with respect to habilitation services provided under the Medicaid Home and Community-Based Waiver;
Provided that “qualified alien” noncitizens lawfully residing in the United States who received SSI on August 22, 1996, would remain eligible for SSI—i.e., eligibility “grandfathered”;
Provided that “qualified aliens” lawfully residing in the United States on August 22, 1996 would be eligible for SSI if they meet the SSI definition of disability or blindness;
Directed the Secretary in consultation with specified organizations to conduct a study of Medicaid’s EPSDT program;
Permitted states to mandate adults (including adults with disabilities) into Medicaid managed care by an amendment to state Medicaid plan and not by having a waiver approved. Exempts SSI eligible kids, certain foster care and adopted kids, and certain Native Americans; and
Directed the Secretary to undertake a study of any special challenges of serving children with special health care needs and chronic conditions in Medicaid managed care.
Consolidated many of the federal job training programs and provided workforce investment activities through statewide and local workforce investment systems. The law also reauthorized the Rehabilitation Act of 1973 by providing greater linkages with the generic workforce investment systems, increased consumer choice and involvement, and greater accountability (outcome measures).
Reauthorized and extended the programs formerly authorized under the Technology-Related Assistance for Individuals with Disabilities Act, while limiting to thirteen years a state’s eligibility for a systems change grant.
1998 - Crime Victims and Disabilities Awareness Act (P.L. 105-301)
Directed the Attorney General to conduct a study to examine the nature and extent of crimes committed against people with disabilities.
1999 - Ticket to Work and Work Incentives Improvement Act (P.L. 106-170)
Provided health care and employment preparation and placement services to individuals with disabilities that will enable those individuals to do the following:
Reduce their dependency on cash benefit programs;
Encourage states to adopt the option of allowing individuals with disabilities to purchase Medicaid coverage that is necessary to enable such individuals to maintain employment;
Provide individuals with disabilities the option of maintaining Medicare coverage while working; and
Establish a return to work ticket program that will allow individuals with disabilities to seek the services necessary to obtain and retain employment and reduce their dependency on cash benefit programs.
APPENDIX 3

WEBSITES FOR FEDERAL DISABILITY-RELATED LEGISLATION, REGULATIONS, AND COURT CASES:

URL: http://www.access-board.gov

ADA Technical Assistance Program (ADATA): A comprehensive resource for information on the Americans with Disabilities Act. Updated weekly.
URL: http://www.adata.org

Disability and Business Technical Assistance Centers (DBTACs): The ten regional centers provide information, training, and technical assistance to employers, people with disabilities, and other entities with responsibilities under the ADA. Updated weekly to monthly.
URL: http://www.adata.org/text-dbtac.html

URL: http://www.eeoc.gov

URL: http://www.fcc.gov/cib/dro

Health Care Finance Administration (HCFA) of the Department of Health and Human Services: Federal agency that administers the Medicare, Medicaid, and Child Health Insurance Programs. Updated weekly.
URL: http://www.hcfa.gov

The Department of Health and Human Services (DHHS), Office of Civil Rights: Promotes and ensures that people have equal access to and opportunity to participate in and receive services in all HHS programs without facing unlawful discrimination. Updated weekly to monthly.
URL: http://ocr.hhs.gov

Health Resources and Services Administration (HRSA) of the Department of Health and Human Services: An agency that helps provide health resources for medically underserved populations. Updated weekly to monthly.
URL: http://www.hrsa.dhhs.gov

Housing and Urban Development (HUD), Department of: Provides information and technical assistance relating to housing and disabilities. Updated
weekly to monthly.
   URL: http://www.hud.gov/disabled.html

   **Job Accommodation Network (JAN):** JAN is an information network and consulting resource that enables qualified workers with disabilities to be hired or retained. It brings together information from many sources about practical ways of making accommodations for employees and applicants with disabilities. Updated weekly to monthly.
   URL: http://janweb.icdi.wvu.edu

   **Department of Justice (ADA Home Page) (DOJ):** Americans with Disabilities Act information and technical assistance line. Updated weekly.
   URL: http://www.usdoj.gov/crt/ada/adahom1.htm

   **The Department of Labor (DOL):** Provides information and technical assistance relating to the American workforce and disabilities. Updated weekly to monthly.
   URL: http://www.dol.gov

   **National Council on Disability (NCD):** Promotes policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature of severity of the disability, and empowers individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society. Updated monthly.
   URL: http://www.ncd.gov

   **National Institute on Disability and Rehabilitation Research (NIDRR) of the Department of Education:** Provides leadership and support for a comprehensive program of research related to the rehabilitation of individuals with disabilities. Updated weekly to monthly.
   URL: http://www.ed.gov/offices/OSERS/NIDRR

   **Office of Special Education and Rehabilitative Services (OSERS) of the Department of Education:** Administers programs and projects relating to the provision of a free appropriate public education to all children, youth and adults with disabilities, from birth through age twenty-one. Updated weekly to monthly.
   URL: http://www.ed.gov/offices/OSERS

   **Presidential Task Force on Employment of Adults with Disabilities (PTFEAD) of the Department of Labor:** The task force evaluates existing Federal programs to determine what changes, modifications, and innovations may be necessary to remove barriers to employment opportunities faced by adults with disabilities. Updated weekly to monthly.

   **Rehabilitation Services Administration (RSA) of the Department of Edu-**
Lists overseas programs that enable individuals with physical or mental disabilities to obtain employment through such supports as counseling, medical care, job training, and other individualized services. Updated weekly to monthly.

URL: http://www.ed.gov/offices/OSERS/RSA

**Social Security Administration (SSA) - Disability Information Page:** Provides information and technical assistance relating to social security and disabilities. Updated weekly to monthly.

URL: http://www.ssa.gov/odhome/odhome.htm

**Thomas:** An on-line site that provides legislative information: Text of bills, committee reports, historical documents, links to the U.S. Senate, House of Representatives, Executive, Judicial, and State/Local governments. Updated daily.

URL: http://thomas.loc.gov

**Transportation, Department of:** Provides information and technical assistance relating transportation and disabilities. Updated weekly to monthly.

URL: http://www.fta.dot.gov

**“HOT” LEGAL SITES FOR DISABILITY COURT CASES:**

**Findlaw:** On-line access to legal resources. This site is very user friendly. Updated weekly.

URL: http://www.findlaw.com

**Legal Information Institute (LII):** On-line access to legal documents. Excellent resource. Updated weekly to monthly.

URL: http://www.law.cornell.edu/ii.html
APPENDIX 4

GLOSSARY OF ACRONYMS:

ADA is an acronym for the Americans with Disabilities Act. The ADA is an omnibus civil rights statute providing a clear and comprehensive national mandate for the elimination of discrimination against persons with disabilities. It provides clear, strong, consistent, and enforceable standards addressing discrimination against such individuals. Areas covered by the ADA include employment (Title I), public services and transportation (Title II), public accommodations (Title III), and telecommunications-relay systems for persons who have communication impairments (Title IV).

CHIP is an acronym for Children’s Health Insurance Program. CHIP is codified in Title XXI of the Social Security Act. CHIP entitles states to $40 billion over the next ten years to provide health insurance for low-income children who do not qualify for Medicaid, including children with disabilities.

EPSDT is an acronym for Early and Periodic Screening, Diagnosis, and Treatment. EPSDT is a mandatory service under the Medicaid program. Under EPSDT, children are screened for health deficiencies, diagnosed, and then treated to the extent that a service is medically necessary.

FAPE is an acronym for “free appropriate public education” under the Individuals with Disabilities Education Act. FAPE means special education and related services provided without charge in conformity with an individualized education program.

IDEA is an acronym for the Individuals with Disabilities Education Act. The purposes of this Act are to:

Ensure that all children with disabilities have available to them a free and appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for employment and independent living. It also ensures that the rights of children with disabilities and parents of such children are protected, and it assists states and local educational agencies to provide for the education of such children (Part B of the IDEA);

Assist states in implementation of a statewide, comprehensive, coordinated, multidisciplinary, interagency system of early intervention services for infants and toddlers with disabilities and their families (Part C—formerly Part H—of the IDEA);

Ensure that educators and parents have the necessary tools to improve educational results for children with disabilities by supporting systemic change activities, coordinated research and personnel preparation, coordinated technical assistance, dissemination, and support, and technology development and media services (Part D of the IDEA).

IEP is an acronym for Individualized Education Program. Every child with a disability is entitled to an IEP under the IDEA. An IEP is a written statement that includes a statement of the child’s present level of educational performance; measurable annual goals, including benchmarks or short-term objectives; a statement of special education, related and supplementary aids and services provided to the child; a statement of needed transition services; and periodic report cards.
NIDRR is an acronym for The National Institute on Disability and Rehabilitation Research in the U.S. Department of Education. NIDRR provides research, demonstration projects, training, and related activities to maximize the full inclusion, integration into society, employment, independent living, family support, and economic and social self-sufficiency of individuals with disabilities of all ages.

SECTION 504 is an acronym for section 504 of the Rehabilitation Act of 1973. Section 504 prohibits discrimination on the basis of disability by recipients of federal financial assistance.

SSDI is an acronym for the Social Security Disability Income program, established under Title II of the Social Security Act. SSDI provides federal disability insurance benefits for workers who have contributed to the Social Security Trust Fund and become disabled or blind before retirement age. Spouses with disabilities and dependent children of fully insured workers (often referred to as the primary beneficiary) also are eligible for disability benefits upon the retirement, disability, or death of the primary beneficiary.

SSI is an acronym for Supplemental Security Income program established under Title XVI of the Social Security Act. SSI is a federally administered cash assistance program for individuals who are aged, blind, or disabled and meet a financial needs test (income and resource limitations).