

**THE HISTORY, SIGNIFICANCE, AND IMPACT OF
DISABILITY POLICY UPON THE
SEVERELY DISABLED**

THESIS

**Presented to the Graduate Council of
Southwest Texas State University
in Partial Fulfillment of
the Requirements**

For the Degree

Master of ARTS

By

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**San Marcos, Texas
December 18, 1998**

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To Katy Poo

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ABBREVIATIONS

ACCD	The Association of Citizens with Disabilities
ADAPT	American Disabled for Attendant Programs Today
ADL	Activities of Daily Living
AFB	The American Foundation for the Blind
AHCA	American Health Care Association
AHCPR	Agency of Health Care Policy and Research
APTA	The American Public Transit Association
CASA	Community Attendant Services Act
CBA	Community-Based Alternatives Program
CBO	Congressional Budget Office
CLASS	Community Living Assistance and Support Services
COP	Community Options Program
CPS	The Current Population Survey
DALTCP	The Federal Office of Disability, Aging and Long Term Care Policy
DDS	Disability Determination Service Office
DHHS	The U.S. Department of Health and Human Services
DOT	The U.S. Department of Transportation
DWTC	Disabled Worker Tax Credit
EEOC	The U.S. Office of Equal Employment Opportunities Commission
FCC	The Federal Communications Commission

GAO	The Federal General Accounting Office
HCFA	U.S. Health Care Finance Agency
HEW	The U.S. Department of Health, Education and Welfare
HIV	Human Immunodeficiency Virus
HUD	The U.S. Department of Housing and Urban Development
IADL	Instrumental Activities of Daily Living
ICF-MR	Intermediate Care Facility for the Mentally Retarded
IWPP	Individual Work and Rehabilitation Program
MAO	Medical Assistance Only
NCD	The National Coalition on Disability
NCHS	The National Nursing Home Survey
NCHS	National Center for Health Statistics
NMES	The National Medical Expenditures Survey
OASDI	Old Age, Survivors and Disability Insurance
OCR	The U.S. Office of Civil Rights
PHCS	Primary Home Care Services
QCBS	Qualified Community-Based Services
QHCBS	Qualified Home and Community-Based Services
RN	Registered Nurse
RTW	Return to Work Ticket
SCU	Special Care Units
SIPP	The Survey of Income and Program Participation

SSA	The Federal Social Security Administration
SSDI	Social Security Disability Insurance
SSI	Social Security Insurance
The ARC	The Association for Retarded Citizens
TWSSP	Ticket to Work and Self-Sufficiency Program
UCPA	United Cerebral Palsy Association
VOR	The Voice of the Retarded

CHAPTER 1

INTRODUCTION TO THE STUDY

The purpose of this study is to examine disability statutes as well as Congressional history and advocate activities to determine if there is a trend in disability policy that adversely affects or excludes the most severely disabled sector of the disabled population. My thesis statement is, “The current trend of disability policy adversely affects or excludes the severely disabled sector of the disabled population.”

For the purpose of this study, the term “severely disabled persons” refers to that segment of the disabled population that is incapacitated. “Incapacitated” refers to people whose disability(s) is so severe they are rendered incapable of making decisions for themselves and are dependent upon others for their most basic needs. Advocates for the severely disabled contend that an institutionalized setting is often necessary for the severely disabled in order to stabilize and maintain their health and general well being. This segment of the population generally requires 24-hour skilled nursing and/or medical therapy care and is often referred to as a chronically ill/medically fragile population. The number of the approximately 3.3 million institutionalized residents in the U.S. (U.S. Department of Commerce Economics and Statistics Administration, 1990) who are in an institutionalized residential setting as a result of a disability is undetermined. Although my

interest is on policies affecting the institutionalized population, it would be impossible to study this segment of the population without taking into account the sometimes competing interest and goals of the approximately 9 million non-institutionalized disabled people (McNeil, 1997, *Americans with Disabilities*) who presently live in the community. With that argument in mind, this study will focus on the impact of current and proposed disability policy on the institutionalized portion of the severely disabled population. For this study, the non-institutionalized segment of the disabled population is referred to as the “able disabled.”

Assimilation of data for disabled populations is complicated and difficult, at best. With the exception of institutional regulatory policy, disability data and the vast majority of disability studies do not specifically address the institutionalized portion of the disabled population. Disability data and statistics do, however, categorize the non-institutionalized disabled population into “not severe” and “severe” categories. Therefore, statistics and data in this study which indicate a “severe” category refer, unless otherwise stated, to the non-institutionalized disabled population who is represented by advocates for the “able disabled”. However, for this study, references to the “severely disabled” indicate the incapacitated, and generally institutionalized, portion of the disabled population and those who are represented by advocates for the “severely disabled”.

The evolution of historical disability policy involves the alteration of the definition of what constitutes a “disability” and thereby alters who qualifies as “disabled”. The unintentional consequence of altering the definition is that it removes any realization of distinctions between subsets of the disabled population, any distinctions of *degree* of

disability, and any distinctions between the subset populations which have different program/service needs. The “disabled community”, like any other community, is comprised of people with different types of disabilities, different levels of disability severity and different service needs. There are specialized agendas within the disability community for different categories of people, such as hearing impaired, blind, or mentally retarded, with differing types and levels of disabilities, despite a universal definition of “disabled”.

The different disabled groups and their advocates frequently disagree on policy issues and often have opposing policy positions and conflicting service needs. The severely disabled must depend on advocates, who are poorly organized and poorly politicized, to speak for them. And, the severely disabled are incapable of soliciting an advocate for assistance. On the other hand, not only can the able disabled advocate for themselves, but they and their Advocates are highly organized and have developed strong Congressional support because they purport to advocate for *all* people with disabilities. However, the study reveals that they do so according to an agenda which primarily benefits only the able disabled subset of the disabled population. Advocates for the able disabled contend that all members of the disabled population have the right to live independently in the community, not “warehoused” in institutions, regardless of their level of severity (ADAPT, 1998, What ADAPT does and why we do it). Advocates for the able disabled claim current policies protect and serve all persons with disabilities and lobby for additional mandated entitlement programs and services that will facilitate independence and the complete integration of all persons with disabilities into society. As a result, Congress is essentially

unaware that it's response to demands by the advocates for the able disabled has resulted in a trend for disability policy that adversely affects or at times excludes the severely disabled sector of the disabled population.

Advocates for the severely disabled frequently argue that many current policies and proposed policies don't address the needs of the severely disabled. Though advocates for the severely disabled support policy that promotes independence for disabled persons who are capable of living in the community, they oppose policy which may result in reduced services and programs funded for the severely disabled or may put that sector of the population at risk (U.S. Congress. House. 1998, HR 2020 Hearing). This philosophical difference creates contention between disability advocates for different sectors of the disabled population as they compete for Congressional support and scarce federal dollars. Programs and services are being developed alongside established programs with little attempt at coordination or elimination of duplicate services or compounded cost. As a result, disability policy is incoherent, convoluted, complex, and rapidly changing.

Congress, under increasing political pressure from the Republican majority and executive branch to reduce the deficit and gain control of government spending, has succeeded in implementing welfare reform and is currently working on major Social Security, Medicare, and Medicaid reform. All of these activities have, or will have, a major impact on the direction of disability policies and how these policies are implemented. "In the 1996 battle over cutting domestic discretionary spending and entitlement programs, Congressional members pursued 'strategic protection' of individual interest over a more

broadly defined public interest” (Dodd, L.C. & Oppenheimer, B. I., 1997, p. 332). Despite a conservative Republican Congress, disability policy has escaped severe program budget cuts and weakened legislative effort.

Chapter 2 is an introduction to disability policy and presents a historical overview regarding the origins of Congressional actions and intentions for disability policy. A review of disability literature is examined to establish a conceptual framework for the study. The various dynamics affecting the development of disability policy, its inherent problems, and the Congressional intentions, as stated in the legislation, are included in this chapter. Also, included in Chapter 2 is an examination of the historical disability statutes: *Civil Rights Act of 1964*, *Rehabilitation Act of 1973*, and the *Americans with Disabilities Act of 1990 (ADA)*. The philosophies and agendas of various disability special interest groups, particularly those of American Disabled for Attendant Programs Today (ADAPT), United Cerebral Palsy Association (UCPA), and Association for Retarded Citizens (The ARC) are identified in this chapter. The chapter includes a discussion on Congressional behaviors and its bipartisan willingness to continue to expand disability policy while engaging in social policy reforms.

Both Chapters 3 and 4 discuss modern Congressional disability policy activity. Each chapter contains an introduction, comparison and descriptive analysis of two currently proposed service bills and their status; an examination of the positions expressed by special interest groups in Congressional hearings and an overview of stated proposed legislative goals; a review of the expected impact of anticipated consequences of the proposed bills and a forecast of the unintended consequences of the proposed bills for the

target groups; and, policy recommendations. Chapter 3 includes a discussion on continued Congressional commitment to disability policy expansion. Two proposed community-based personal attendant care service bills are discussed in Chapter 3 and two proposed work incentive bills are discussed in Chapter 4.

Chapter 5 describes the major disability service programs which are currently in effect. I will present the complexities of regulatory processes, population protection mechanisms and implementation problems. The analysis addresses implementation, cost and disability level of the populations served in the various programs. The service program evaluation seeks to determine if there is bias in the individual programs for a particular benefit population or if the programs are equally distributed and beneficial over the entire disabled population. Is there a negative relationship between the programs' target population and the effected population? Are the programs cost effective in comparison with the number of target population served? Is there a trend in the focus of policies and programs that excludes the severely disabled?

A discussion of the critiques of proposed policy bills and current programs overview is included in Chapter 6. The effectiveness, impact, and summaries of programs and policies on the populations are included in the discussion. The analysis findings determine that there is a negative impact on the severely disabled population from both the current and proposed program policies.

Results of this study will aid in resolving some of the controversy raised by disability advocates for both primary disabled populations. This study established that there is a disability policy trend that results in a negative effect of disability policy on the

severely disabled population. Disability policy analysis is frequently very narrowly focused and fragmented. This study presents a comprehensive analysis of an array of dynamics that affect the formation and direction of disability policies and their effect on the targeted populations.

Disability Terms and Survey Descriptions

Only for about the last decade has disability policy been broadly studied by political scientists and analysts. This area of policy is changing very rapidly and has an impact on virtually every area of society. Accurate statistics and estimates for the disabled population are difficult to establish. Various sources use a variety of methodologies and criteria for disability data. Definitions regarding the disabled population have been refined and clarified through Federal disability research agencies. Different agencies, however, provide statistics based on different criteria and definitions are often skewed slightly to accommodate different perspectives. Caution must be exercised when using these statistics to ensure reliable results. Reliability requires combining definitions and statistics from various agencies.

Several major national surveys are used in this research to define the disabled populations and the prevalence of certain characteristics. These surveys provide the most current national statistics and estimates from respondent-based information. *The National Health Interview Survey* is a nationwide sampling of the health status of non-institutionalized civilians, conducted by the National Center for Health Statistics (NCHS). For disability purposes, the focus of the survey is on activity limitations and chronic

conditions. The survey is conducted by continuous weekly sampling throughout the year, preventing seasonal bias. Weekly samples are representative of the target population and are added with other weekly samples. Samples are grouped by four geographic regions: Northeast, Midwest, South and West. In 1993, the survey sampled 109,671 persons; 116,179 persons were sampled in 1994. The response rate was approximately 95.6 percent in 1993 and 94.1 percent in 1994, providing a significant representation of the survey sample. The Assistive Device Supplement survey is included once every year in the NCHS survey and uses the following definitions for chronic condition, disability and limitation of activity:

- *Chronic condition* is one noticed for three months or more, or being on the NHCS list of chronic conditions.
- *Disability* refers to any long- or short-term reduction in the respondent's activity as a result of an acute or chronic condition.
- *Limitation of activity* is a person's reduced capacity to perform routine activities associated with the respondent's age group.

The second survey used in this research is *The Survey of Income and Program Participation* (SIPP), a longitudinal household survey of non-institutionalized persons conducted by the Bureau of the Census. The SIPP 1991-1992 reports topical modules including disability status questions. A wave is a cycle of four interviews every four months, covering the entire sample, using the same questionnaire. Data for this report come from the third wave of the 1991 panel and the sixth wave of the 1990 panel. The October 1991 to January 1992 waves' sample size was 34,000 households. The number of individuals surveyed is not available, since this is a household survey. The number of

individuals was estimated, using a formula of 2.5 persons per household, and estimated to be approximately 85,000 persons. Responses to the survey ranged from 81.7 percent in October and 82.3 percent in November. This survey uses the following definitions:

- *Functional limitations* defined from questions that indicate a limitation in performing the basic functional skills of seeing, hearing, understandable speech, carrying, or lifting up to 10 pounds, and walking up a flight of stairs.
- *Activities of daily living (ADLs)* includes the ability to move about inside the home, getting in and out of bed, bathing, dressing, eating, and toileting.
- *Instrumental activities of daily living (IADLs)* includes the ability to move about outside of the home, take care of personal finances, do light housekeeping, prepare meals and use the telephone.
- A person was disabled if they:
 - a) used a wheelchair;
 - b) used a cane or walking aid for more than 6 months;
 - c) had difficulty with a functional activity;
 - d) had difficulty with 1 or more ADL;
 - e) had difficulty with an IADL;
 - f) had an identified developmental, emotional or mental disability;
 - g) had difficulty doing housework and were over 16 years of age;
 - h) were between 16 and 67 years of age and had a condition that limited the kind and amount of work they could do;
 - i) under the age of 21 and had received developmental services, had limitations in usual activities, adapted school curriculum, or limitations in the ability to walk, run or use stairs;

j) were under the age of 65 and covered by Medicare or received SSI.

The Current Population Survey (CPS), March Income Supplement, is a monthly labor force data survey of all household members over the age of 14 and is produced by the Bureau of the Census. The *March Supplement* includes questions regarding income and provides data for characteristics of non-institutionalized persons with a work disability. The sample includes all 50 states and the District of Columbia and is continuously updated. There were 60,500 households eligible, with a response rate of 95.8 percent. The number of individuals is estimated to be 120,000 (using the formula of 2.5 persons per household) and lowers the estimate because the sample only includes ages 14 and above.

The only disability measured by the CPS is work disability:

- *Work disability*: People are classified as having a work disability if they:
 - a) are unable to work or have a limitation in the amount or kind of work;
 - b) retired or left a job for health reasons;
 - c) were unable to do any kind of work during the survey week due to a long-term physical or mental illness or disability;
 - d) did not work during the entire previous year due to illness or disability;
 - e) are under the age of 65 and are covered by Medicare;
 - f) are under the age of 65 and receive SSI; or
 - g) received veteran's disability compensation

The *National Medical Expenditures Survey (NMES)* is a national probability sample of households done for the Agency of Health Care Policy and Research (AHCPR). It queries households and medical providers about medical service and expenditures, sources of payments for health care, and health insurance coverage. Disability is measured by activity limitations and limitations in ADLs. The NMES has a stratified multi-stage area probability sample design which includes the poor and low income, the elderly, persons

with limitations, and minorities. In this survey, 35,000 participants in 14,000 households were interviewed five times between February 1987 and July 1988. This survey uses the following definitions for activity limitations and ADLs:

- *Activity limitations* are defined by age groups:
 - Age 18 and over - If their health prevents or limits employment, doing housework or going to school.
 - Age 5 to 18 - If the child attends or needs to attend special schools or classes due to an impairment or health problem, if health prevents or limits health problem.
 - Under the age of 5 - If health limits or prevents age-appropriate play activities.
- *Activities of daily living (ADLs)* - Includes moving about inside the home, getting into and out of bed or a chair, bathing dressing, eating, and toileting.

Americans with Disabilities

There is currently no source for specific data for institutionalized persons with disabilities regarding specific reasons for institutionalization, prognosis, accurate estimate of capability of living independently if services were available, or what kinds of services would be needed by the individual to facilitate living in the community. The 1990 U.S. Census data does include a count of institutionalized persons (determined to be approximately 3.3 million) but no other census data is gathered on these individuals. Limited data, such as demographics, functional level and mortality rates of institutionalized residents, is available through the American Health Care Association (AHCA).

According to the 1994-1995 Disability, U.S. Census data, the number of non-institutionalized persons with some type of disability rose from 48.9 million in 1990 to 54

million in 1994. Of the 54 million disabled persons, almost 50 percent (or 26 million) have severe disabilities. Also, the likelihood of having a disability and that it will be severe increases with age (McNeil, 1997, Census Brief).

Of the total, non-institutionalized population in the United States:

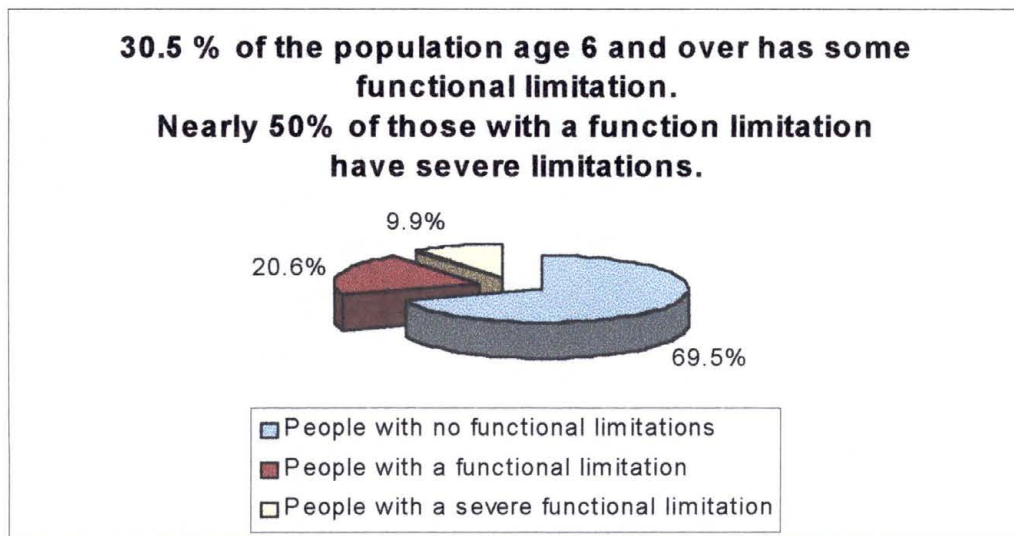


Fig. 1 Source: McNeil, John. M. Census Bureau 170-61. Current Populations Report. Americans with Disabilities: 1994-95.

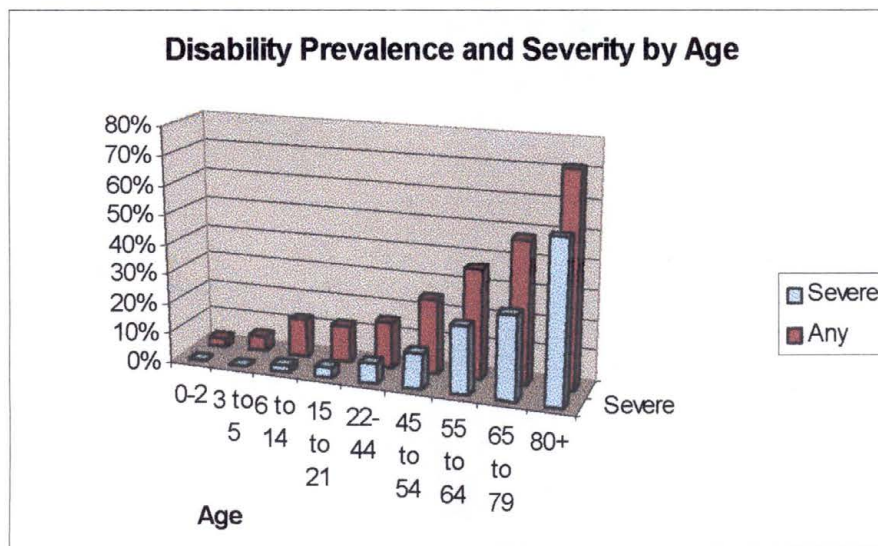


Fig 2 Source: McNeil, John. M. Census Bureau 170-61. Current Populations Report. Americans with Disabilities: 1994.

While there has been some limited form of disability policy for decades, the disability community has made extraordinary progress in the past eight years. By the usual standards applied to politics and policy-making (success being measured in tiny increments and compromise being measured in wide increments) the achievements which have been made in disability policy is a modern phenomenon that has escaped the usual policy pitfalls, made exceptionally quick progress, and yet until very recently remained relatively obscure and unnoticed. Presently, however, there is a profuse amount of research and policy and program analysis being conducted regarding disability issues. A large portion of this research is focused on home and community-based care and client controlled care. The history of disability policy in Chapter 2 illustrates how this area of policy evolved and why it is now in the forefront of health care policy.

CHAPTER 2

HISTORIC OVERVIEW OF DISABILITY POLICY

The Nineteenth Century: Dr. Samuel Howe

Not until the phenomena of the industrial revolution in the United States during the early 1800's, which encouraged society to acquire a higher level of education, were the problems of the disabled addressed by society and the government. As universal education became available, persons with any type of impairment (deaf, blind, mental, or motor) that interfered with the ability to learn or attend school were labeled as “feeble-minded”.

In 1846, the Massachusetts Legislature appointed Dr. Samuel Gridley Howe to study the “feeble-minded” and recommend a policy to assist them. In 1849, Dr. Howe opened the Massachusetts School for Idiot Children and Youth in Boston. Dr. Howe’s contention was that the school would serve as temporary placement wherein the child would become “temperate and industrious...and happier” and then be returned to his or her family. In 1874, when he retired as headmaster of the school, he warned of the dangers of segregating and institutionalizing the feeble-minded and disabled. Dr. Howe’s was the last voice opposing institutionalization of the disabled for the next fifty years.

In the U.S., an institutionalized, residential state school system for disabled children was developed that provided only custodial care. “Segregation of most persons

with disabilities into institutions was the policy answer” (Pheiffer, 1993, p. 726). Residents were required to labor in the facility in order to pay for the cost of their institutionalization (Pheiffer, 1993, p. 725).

Many of the abandoned or unwanted disabled were placed in orphanages. Such facilities were unregulated and by and large their activities were unhampered. Such facilities were generally regarded favorably by society because they took in society’s unwanted members. Residents in these institutions were often exploited for labor, abused, and neglected, an unpleasant subject that society refused to address for decades (Bledsoe, 1993, p.175). When society did express outrage at the conditions and treatment with these facilities in the 1940s and 1950s, focus was given to the more “normal” residents, while ignoring the plight of those with more severe disabilities (Ferster, 1966, p.621).

The medical profession’s attitude regarding disability contributed enormously to the institutionalization of the disabled. For example, prior to the mid 1960s, most Down’s Syndrome children (then called Mongoloids) were routinely institutionalized. Until that time, most medical professionals regarded those with such conditions as Down’s Syndrome and cerebral palsy, two prevalent disability conditions, as incapable of learning and adapting. Families were frequently presumed unable to care for virtually any severely disabled person and institutionalization was strongly encouraged.

The Twentieth Century: An Early Law Enabled Discrimination of the Disabled

Strongly supported by those who were part of the popular eugenics movement, laws allowing involuntary segregation of most disabled persons and involuntary

sterilization of mentally retarded women were approved in *Buck V. Bell*, 274 U.S. 200 (1927), and upheld by the U.S. Supreme Court. In 1938, thirty-three states had a sterilization law, and as late as the 1960's, twenty-three states still had compulsory sterilization laws for the mentally retarded (Scheerenberger, 1987, p.189). In the United States between 1921-1964, 63,000 persons were involuntarily sterilized for “genetically related reasons” (Pfeiffer, 1993, p.726).

In the wake of the civil rights movement in the 1960s and early 1970s, attitudes towards the disabled began to change. As a result, the U.S. Department of Health, Education, and Welfare (HEW) was ordered to cease providing federal funds for compulsory sterilization in 1974 (Scheerenberger, 1987, p.189). At approximately the same time, medical research and technological advances began to escalate dramatically, resulting in a rapid increase in the survival rate for premature or seriously ill infants, the seriously injured, and chronically ill. Medical advances coupled with the changing societal attitudes regarding equal and civil rights led to the realization that ignorance leads to discriminatory statutes that may violate individuals’ civil rights. An understanding began to emerge among the disabled populations that they were also entitled to the same rights as other populations (Fine, 1989).

The Birth of the Disability Movement

The opposition that arose in response to the treatment of the disabled as social outcasts became the initial wave of the disability movement. Advocate, parent, and professional coalition groups sprang up nationwide to address disability issues. Veterans

who were blinded in World War I and others formed the American Foundation for the Blind (AFB), and World War II veterans formed the Paralyzed Veterans of America. Both groups laid the foundation for later accomplishments. Parents of retarded children banded together to protest their children's exclusion from public schools (Pheiffer, 1993, p. 724).

In 1972, both the Boston Center for Independent Living and the Center for Independent Living in Berkeley, the first organized special interest groups that address disability issues in general, were established. While still advocating for the usual need for services, these groups were a new breed of disability organization that was equally focused on the need for equal civil rights for persons with disabilities as well as the need for services (Pheiffer, 1993, p.726).

During the Nixon administration, Congress passed the *Rehabilitation Act in 1973*. The *Act* was created on behalf of veterans and focused on job training for those with the most severe disabilities. Congress almost gratuitously included all disabled persons as beneficiaries of the *Act*. For the first several years, few disabled persons who were not veterans were even aware of the *Rehabilitation Act of 1973* or the programs it provided for them.

Passage of the *Rehabilitation Act*, however, provided national status to the political agenda of developing disability advocate groups. As group organizations improved and their agendas gained momentum, they began to get positive responses from federal agencies and Congress. In May 1977, the Department of Transportation (DOT) publicly promised accessible transportation for the disabled and announced that all new buses purchased with DOT funds had to be handicapped-accessible. The Secretary of

Housing and Urban Development (HUD), announced the establishment of the Office of Independent Living for the Disabled to ensure that all new housing built with federal funds was accessible to the disabled (Shapiro, 1993, p. 34).

In spite of dramatic progress in developing disability policy and rights, public ignorance and the preconceptions regarding persons with disabilities lingered. In June 1989, a Washington, D.C. minister had an epileptic seizure on his way home from work. He was taken by ambulance to a hospital. When he awoke, he got out of bed. Whereupon he was restrained, and forced back in bed and strapped down. When he protested and demanded to see a physician, he was gagged with a surgical mask and informed that because persons with epilepsy were dangerous, he was being forcibly restrained (National Disability Action Center, 1989). Efforts to change the public's negative preconceptions about the disabled continue today.

The advocacy groups sharpened their political skills and, with the passage of the *ADA* in 1990, achieved their strongest and farthest reaching accomplishment. The *ADA* prohibits employment discrimination based on disability and requires employers to make reasonable accommodations for qualified disabled applicants and employees. Enactment of the *ADA* marked a kind of right-of-passage maturation for the disability movement.

"There were new actors to be considered when public policy is being made" (Holbrook & Percy, 1992, p. 213; See also, Lewis & Allee, 1992, p. 392; Watson, 1993b, p. 52).

Disability advocates were homogenous in their agendas and finally had powerful pressure groups on the national, state, and [some] local levels. Disability policy now engages the attention of decision makers in a way it did not in the past (Litvak, 1992, p. 97).

Special Interest Politics: Development and Role in Policy-Making

The tactics of disability special interest groups is a pivotal component in the development of disability policy. Wilson's Topology of Policy Situations (Fig. 3) demonstrates the different types of political situations involved in policy-making, and how and why the public and politicians may respond to special interest groups in certain ways. Disability advocates often rely on a "mobilization model of agenda setting," to stimulate public concern. Using Wilson's topology, a special interest group can hypothesize whether an issue is ripe for policy expansion and what actions are necessary to achieve special interest policy goals, based upon the prevailing public opinions and the ability to strategically manipulate the public's opinion on the issue. Wilson's Model also reveals circumstances that can lead to the creation of special interest groups. Disability advocacy groups must use constraint in their approach to mobilize public opinion and concerns. The public often ignores, or is negatively influenced by, groups that are viewed as having a too narrowly focused self-interest (Page, Shapiro, & Dempsey, 1987, p. 32). Wilson's model illustrates how special interest groups gain support for their issues and demands.

Wilson's topology model allows the researcher to develop hypotheses by specifying the issue stakes and the relationship between the organized interest and the government agencies involved. Identifying the stake issues and the agencies' relationship aids in determining whether the conditions are ripe for efforts to expand issues. Wilson defines client politics as a situation, such as disability policy in general, in which a special interest group enjoys concentrated benefits while the costs are spread broadly over

society. Interest group politics is a result of two or more organized interests having different or conflicting issue stakes and where both benefits and costs are concentrated, as is the case for disability policy which targets a subset of the disabled population.

Special Interest Political Theory

WILSON'S TOPOLOGY OF POLICY SITUATIONS

Costs of Proposed Policy		Concentrated	Diffuse
		<hr/>	
		I. Client Politics	IV. Majoritarian Politics
Diffuse	Dominant interest group	No important interest group	
	favorable to agency goals	continuously active	
		<hr/>	
		II. Interest Group Politics	III. Entrepreneurial Politics
Concentrated	Two or more interest groups	Dominant interest hostile	
	in conflict over agency goals	to agency goals	
		<hr/>	

Fig. 3 Source: Adapted from James Q. Wilson, *Bureaucracy*, 1989. (76-78).

In entrepreneurial politics, for example, strong opposition to policy expansion exists from those who bear the concentrated cost; however, diffused beneficiaries have no incentive for an organized push for the policy. Therefore, a policy entrepreneur must mobilize the silent beneficiaries in order to overcome the organized opposition. Public

sentiments regarding the issue are dormant unless the entrepreneur activates them. This method allows for the hypothesis that:

H1: In entrepreneurial politics, issue salience in the mass public will be initially low, but will escalate.

In cases of majoritarian politics, politicians are responding to mass public concern rather than mobilizing a response to issue expansion. Majoritarian politics is a type of “outside initiative” model of agenda setting. Hence:

H2: In majoritarian politics, mass public issue salience will be high prior to the introduction of the issue on the government agenda.

Cases of client politics, efforts to expand issues and mobilize mass public sentiments, occur least often. Costs are diffused so there is little opposition to the issue based on cost. Beneficiaries are concentrated and have little incentive to draw attention to or arouse controversy around the issue. Client politics is an example of the “inside access” model of agenda setting and it can be hypothesized that:

H3: In client politics, mass public issue salience will be low before and during the government action on the issue.

Interest group politics, however is more complex and must be more sensitive to public sentiment. Expansion of controversy regarding an issue is not to the advantage of the interest group if the mass public is unlikely to favor the issue (Page, Shapiro, and Dempsey, 1987, p. 38) or if the interest group itself is likely to create negative responses from the public (Kolman, 1992). Interest group issue expansion is contingent upon the current direction of public opinion. Therefore:

H4 : Interest group politics will mobilize issue salience provided that current public opinion is hospitable to one or more of the contending groups.

Disability policy expansion offers an interesting contrast to most other areas of policy expansion such as defense and environment policy. An examination of the historical expansion and timing of disability policy indicates that there have been no salient divisions of mass public opinions and sentiment concerning policy for the disabled during the entire modern twenty years of policy development. Additionally, as seen in the historical and modern legislative process for disability policy, there has only been moderate opposition from those organized interests that have or will bear the cost concentration from disability issue expansion.

Disability Special Interest Groups

Overview

Disability advocate groups no longer have homogenous populations or agendas. Since the ADA, two distinct groups have developed: those who advocate for the “normal except for a disability”, who are often referred to as the “able disabled,” and those who advocate for the “severely disabled.” The disabled population is stratified, with the hierarchical status of issues and the agendas for the two groups being very different. Competition for scarce federal dollars for services and programs have often made the groups adversarial. This conflict is seldom understood by politicians, as advocates for the able disabled are far more numerous and organized than the advocates for the severely disabled. Not only are several advocate organizations for the able disabled population independently well organized and politicized, but they have joined together in powerful coalitions in support of common goals and agendas.

The severely disabled population must generally rely on someone else to advocate for them. The advocate organizations for the severely disabled are fragmented, many representing small subset populations with specific disabilities or those whose disabilities are secondary to a primary disease or condition. Most of these organizations have not yet joined into large, formal coalitions or affiliations to promote common agendas. Most are loosely organized grass-root organizations, with limited resources, seeking to benefit small subset populations. Additionally, the narrowly focused, specialized needs for these various small groups may make it difficult for the groups to realize a common political agenda. There are national organizations, such as The Voice of the Retarded, American Health Care Association and the National Alliance for the Disabled, which advocate for the severely disabled, but their memberships are far fewer than those of the able disabled advocacy groups and promotion of the organizations to the severely disabled community is poor.

The answer to the obvious question of why these two groups would oppose each other's agendas is fairly simple. The able disabled want to live independently in the community, not in nursing facilities or other institutions (ADAPT, 1998, What ADAPT does and why we do it). However, many require personal attendant assistance with daily living skills such as dressing, feeding, and toileting in order to be able to live independently. These are the disabled who had experienced years of few community services and were many were forced into dependency on income supplements or forced to reside in inappropriate settings. Increased activity by disability special interest groups, combined with the passage of the *ADA*, improved awareness of service needs for the

disabled and resulted in an increase in community-based services. Many persons with disabilities found new “normal” freedom due to *ADA* mandated accessibility to public places. They are intensely fearful of the possibility that reductions in funding of their home and community-based services and programs for funding of institutionalized services for the most severe physically and/or mentally disabled will result in the loss of their freedoms, choices, and independent living services. The services that do exist are fragmented and scarce in some areas. The able disabled fear that loss of *any* of these services could force them back into nursing homes. As a result, their agenda reflects these concerns as they adamantly campaign that *all* persons with disabilities have the right to live independently within the community, regardless of the level of their disabilities. They exert an enormous amount of tenacity and energy defending and protecting their right to an independent, self-determining lifestyle. Not only do the able disabled far exceed the severely disabled in number, but they are usually able to physically advocate for themselves. The ability to self-advocate increases their sheer political number and political voice dramatically, thus giving the able disabled population a distinct political advantage over the severely disabled population.

The able disabled group is composed primarily of working age people who are cognitively sound but with physical disabilities; they are vehemently opposed to institutionalization of the disabled, regardless of their level of severity. Their agenda is to obtain public funds for services that will provide personal attendant care for daily living activities and the right to control selection, hiring, and firing of personal attendants without agency interference (ADAPT, 1998, E. P. Burke’s letter). The able disabled

agenda also includes securing technical assistance services, independent handicapped accessible housing, employment assistance, and periodic medical needs services (i.e., home care, a visiting nurse). These services are needed by this population to enable them to live independently in the community. Advocacy for all of the needs and services for this population is organized under the “Independent Living” and “Community-based Care” agenda. To achieve their agenda, their legislative goal is to secure the transfer of Medicaid and Social Security service funding from what they claim is “an outdated institutionally biased medical model” to community-based services based on a new individual-focused model.

The able disabled community and their advocates continue to attempt to improve their status in the community, gain protection from employment discrimination and change society’s perception of them from “disabled” to “normal except for a disability,” in addition to their service and independent living agenda. At advocates’ urging, Congress intentionally altered in the *ADA* the phrase “disabled persons” to “persons with disabilities” (U.S. Congress. House. 1990, *ADA Legislative History*, Note 23) in an effort to alter social attitudes and perceptions of people who have a disability. Society equates “disabled” with “unable.” By changing the phrase, the focus is now not on the disability but on the person. Albeit slowly, the *Act* is altering the society’s negative perception that persons with disabilities are “incapable” and “unable.” However, the severely disabled, who will never be capable of independence, are seldom acknowledged by the able disabled community and have become the new “invisible class.”

The concerns of the severely disabled differ from those of the able disabled population. The severely disabled populations are frequently unable to undertake employment. This population includes the profoundly brain-damaged, chronically ill/ medically fragile, and the physically/ mentally incapacitated disabled who may require residential placements in state institutions or nursing facilities when adequate family support is unable to sustain the general well-being or health stability of these persons. Advocates for the severely disabled are concerned that modern disability legislation and proposed bills for disability policy do not address the needs of the severely disabled (U.S. Congress. House. 1998, March 12, HR 2020 Hearing). Many of the severely disabled populations that require 24-hour constant medical care and/or attendant services in all aspects of their lives and are cognitively incapable of making decisions or living independently to any degree. Advocates for the severely disabled are concerned that the policy advocated by the able disabled population, intended to apply to all segments of the disabled population, will place some severely disabled at risk of losing current funding for institutional long-term care services, thereby placing the health and general well being of this population at risk. Advocates for the able disabled purport to advocate for all members of the disabled population. It is, however, the all-inclusive nature of narrowly focused policy demands of some able disabled advocacy groups that creates tension with the severely disabled advocacy groups.

While there are dozens of politically active advocates and organizations for the able disabled sector of the disabled population, three of the most influential and active advocacy organizations include: The United Cerebral Palsy Association (UCPA), The

ARC (formerly Association for Retarded Citizens), and American Disabled for Attendant Programs Today (ADAPT). All three organizations work tirelessly at building the coalition membership of individuals, agencies, companies, and other compatible advocacy groups as well as lobbying for the creation and passage of bills that support their agenda. UCPA, The ARC, and ADAPT advocacy organizations have become increasingly powerful and influential. Each has a national office, nationwide affiliations and coalitions and full-time salaried lobbyists. With well-developed alliances with Congress, each has become a pivotal advocacy organization for disability policy. Together, these three organizations have unified the representation of three different sectors of the disabled population: UCPA advocates for persons with cerebral palsy and other disabilities; The ARC advocates for the disabled who are retarded; ADAPT advocates for community-based services, de-institutionalization, and civil rights for all disabled persons, regardless of the severity of the disability.

United Cerebral Palsy Association

Established more than 45 years ago, United Cerebral Palsy Association (UCPA), located in Washington, D.C., is a national organization with a nationwide network of 153 affiliates that strives to ensure the inclusion of persons with disabilities in every facet of society.

As the second largest health charity in America, United Cerebral Palsy's mission is to advance the independence, productivity and full citizenship of people with cerebral palsy and other disabilities, through our commitment to the principles of independence, inclusion and self-determination. UCPA's national office serves people with disabilities and others through the development of forward-thinking programs, an information and referral service, legislative advocacy, technology

initiatives and research. UCPA affiliates, represented in 43 states, serve more than 30,000 children and adults with disabilities and their families every day through programs such as therapy, assistive technology training, early intervention programs, individual and family support, social and recreation programs, community living, state and local referrals, employment assistance and advocacy. Each affiliate offers a range of services tailored to its community's needs, 65% of people served by UCPA have disabilities other than cerebral palsy. (UCPA, 1998, Index).

The UCPA and its local affiliations share the following mission:

“To advance the independence, productivity and full citizenship of persons with cerebral palsy and other disabilities”(UCPA, 1998, Mission Statement).

The organizational philosophy of UCPA, thus stated, is that every adult or child with a disability has the fundamental right to receive a free and appropriate public education that will prepare that person to live independently. Each person has the desire and ability to shape his or her own destination and the right and responsibility to be active in the decision-making processes for policy, decision, and service planning of organizations that directly affect his or her life. The organization supports the philosophy that the disabled population has the right to live in a family or in a living arrangement of choice and works diligently to change “attitudes and policies that permit the warehousing of persons with disabilities in institutions, nursing homes, and other unnecessarily restrictive facilities and programs.”(UCPA, 1998, Index). As a non-profit organization for the disabled, their primary purpose is to “work with public officials to implement and enforce the Americans with Disabilities Act and other federal policies at the local, state and national levels” (UCPA, 1998, Index). Their purpose is “to assure full opportunities for early intervention, education, employment and integrated community living and effectively influence the passage of laws and the allocation of public and private resources

at the local, state and national levels in order to enable persons with disabilities to become more productive, independent and integrated into community life”(UPCA, 1998, Index).

UCPA provides a web page called the *Washington Watch* which contains information on the organization’s position and analysis of pending legislation and the Congressional activity and status of those bills. Included in the site are recommendations for or against support of various bills, amendment recommendations, instructions and addressees for contacting congressmen, the president, and relevant committee members regarding each bill (UCPA, 1998, Webpage).

The ARC

The ARC is a national advocacy organization on mental retardation. The first convention of the "National Association of Parents and Friends of Mentally Retarded Children" was held in 1950 in Minnesota. In 1993, the organization’s 150 local and state chapters, following the lead of The ARC of the United States, changed its name from the Association for Retarded Citizens to The ARC (The ARC, 1996, Milestones). The mission statement for The ARC is:

The ARC, a national organization on mental retardation, is committed to securing for all people with mental retardation the opportunities to choose and realize their goals of where and how they learn, live, work and play.

The ARC is further committed to reducing the incidence and limiting the consequence of mental retardation through education, research, advocacy and the support of families, friends and community.

Through the successful pursuit of quality and justice, The ARC will provide leadership in the field of mental retardation and develop necessary human and financial resources to attain its goals. (The ARC, 1998, Mission Statement).

The ARC contends that the fundamental rights of people with mental retardation have not yet been fully acknowledged or secured. Their organizational philosophy states that people with mental retardation have the same legal, civil, and human rights as other citizens. The ARC advocates for needed supports, services and protection that will ensure the mentally retarded the opportunities to exercise their rights. A key difference in The ARC and other advocate organizations is that The ARC also serves the disabled population in a protector role. The focus for the organization as a protector of persons with mental retardation is to protect the rights, safety, desires and choices of the individual above and beyond that of agencies, institutional or family caretakers. If The ARC determines that decisions made by parents or guardians are not in the disabled persons' best interest or threaten their health, safety, lives or general well being, they "will assist in pursuing all legal mechanisms---constitutional, legislative, administrative, and judicial---intended or developed to protect the mentally retarded," (The ARC, 1996, Positions).

The philosophical beliefs of The ARC regarding the quality of supports and services for the mentally retarded are that they should be designed for maximum control and choice by the disabled person, allowing for maximum self-determination and self-responsibility. Supports and services should be individualized and flexible for changing needs and adequately funded in order to develop maximum independence for the mentally retarded, (The ARC, 1996, Positions). Services should promote in-home supports and inclusion in the community and use community resources with a community-based support network to assure services for mentally retarded citizens without families. The ARC

advocates that local, state, and national disability policy should be family-centered while promoting the individual. (The ARC, 1996, Positions).

A priority for The ARC is to achieve adequate federal and state policy and funding to promote employability for the mentally retarded. The ARC believes that support, funding, training, and technical assistance must be made available to service vendors in order to convert traditional services to the provision of competitive employment in the community for persons with mental retardation. They are advocates for “flexible and individualized supports including, but not limited to, transportation, on-the-job support and assistance, assistive technology, financial planning, retraining and compensation of at least minimum wages based on job requirements and production commensurate with wages paid co-workers without disabilities.” (The ARC, 1996, Positions).

The ARC is most ardent in its policy positions regarding inclusion, self-determination, and community-based residency of persons with mental retardation. They are adamantly against any form of segregation or institutionalization. The ARC believes that persons with mental retardation have the right and should have the opportunity to live in a home in the community like those without disabilities, have maximum control over their own lives and be “encouraged to make their own decisions regardless of the type or level of disability.” The ARC argues that institutionalization of persons with mental retardation has been and still is a result of lack of services available in the community. Public policy has not kept pace with the movement by these individuals into community, hindering the development of family and individual supports and services that would

enable the disabled individual to thrive in the community. The ARC strongly advocates that funding for supports and services must follow the individual and not be tied to a facility or agency. “Large congregate facilities are no longer necessary for anyone, regardless of the type or severity of their disabilities” (The ARC, 1996, Positions).

American Disabled for Attendant Programs Today

The American Disabled for Attendant Programs Today (ADAPT) is a national advocacy group that organizes and trains the able disabled community in self-advocacy. It uses civil disobedience and other non-violent “direct action tactics” to achieve its agenda goals (ADAPT, 1998, We Will Ride!). They provide training and support for ADAPT organizations at the local level throughout the U.S. ADAPT began a national campaign in 1983 as the American Disabled for Accessible Public Transit, blocking city buses across the nation over a period of seven years to raise awareness of the need for disability access to public transportation. ADAPT played a pivotal role in the accessible transit requirements included in the ADA. After the passage of the ADA, which included accessible transportation mandates, ADAPT changed its name to American Disabled for Attendant Programs Today in order to reflect its new agenda of retaining national mandated attendant programs. The primary present goal of ADAPT’s agenda is to secure 25% of Medicaid long term care funding to be redirected to national mandated attendant care services to prevent “warehousing people with disabilities in institutions and nursing homes.” The organization’s philosophy is diametrically opposed to the institutionalization of any person due to a disability (ADAPT, 1998, What ADAPT does and why we do it).

ADAPT's civil disobedience approach to institute change in disability policy has gained it a great deal of media attention as well as a reputation as a somewhat radical group. The language of its literature is intentionally dramatic and, unfortunately, sometimes exaggerated and inaccurate. For example, ADAPT views and declares all nursing homes as "filthy hell holes with deplorable care where even the most severely disabled are held hostage in an outdated service system that is favorably biased towards the medical model institutions" (U.S. Congress. House. 1998, March 12, HR 2020 Hearing).

ADAPT's organizational philosophy refuses to allow even the acknowledgment that some quality nursing facilities do exist, and for some severely disabled persons a quality nursing facility is the most appropriate and least restrictive environment. Many of ADAPT's members would quite literally rather die than be in a nursing facility. According to ADAPT literature, nursing facilities dehumanize some for the profits of others. While this may be true for some nursing facilities, it is not true of all, or even a majority, of nursing facilities. ADAPT believes the system is "institutionally biased" in its funding for health care service delivery (U.S. Congress. House. 1998, March 12, HR 2020 Hearing). To ADAPT, the failure to adopt its provided resolutions and agendas clearly indicates that the institution, facility or individual is an "enemy" of its targeted population. The literatures from ADAPT has a concentration of critiques of testimonies from agencies and individuals of other organizations and lobby groups. Comments generally praise those who fully support ADAPT's position and chastise those who do not as testifying with "the usual fear mongering with mortality rates" or "the usual nursing home lobbyist line of how

some facilities are very good and there's a need for them" (ADAPT, 1998, MiCASA Hearing).

ADAPT's inflexibility and their tone of advocacy has weakened the organization in relation to their political and organizational credibility and respect in the health industry and policy making arena (U.S. Congress. House. 1998, March 12, HR 2020 Hearing). Where The ARC, UCPA, and many other advocacy organizations have developed community focused educational and assistance programs and services for the disability population, ADAPT's programs are limited to training persons with disabilities to self-advocate through civil disobedience and a periodical newsletter called *Incitement*.

History of Congressional Actions on Disability Issues

Initial Congressional acts addressing rehabilitation service needs for the disabled, limited those services to injured veterans only and did not address the rehabilitation service needs of the disabled community as a whole. It was not until 1973 that Congress provided rehabilitation services to the disabled in general. Even though *Section 504 of the 1973 Rehabilitation Act* prohibits discrimination on the basis of a disabling condition in any federally funded program (Rehabilitation Act of 1973 § 504), services were limited under the *ACT* to those with severe disabilities and subject to availability. Not until 1990, with the passage of the *ADA* did disabled persons have a "right" to services.

The Rehabilitation Acts

A series of vocational rehabilitation acts from 1914-1992 were initially implemented to assist wounded and disabled World War I veterans so they could return to

civilian life. The *Vocational Rehabilitation Act of 1920* was the first national policy to address the needs of a disabled population, although the language in the act was targeted towards veterans' needs, not the disabled in general (Scotch, 1984, p. 46-49). This study relies on research by Scotch, a primary researcher of the Rehabilitation Acts and author of *From Good Will to Rights: Transforming Federal Disability Policy*, for policy development in the *Rehabilitation Acts*.

The *Rehabilitation Act of 1973* broadened the definition of who could receive benefits and services from rehabilitation. This legislation was the first that specifically targeted the disabled population in general. Section 503 required holders of federal contracts over a set dollar amount to implement affirmative action programs to hire persons who were disabled and Section 504 prohibited discrimination on the basis of a disabling condition in any federally funded program (Rehabilitation Act of 1973 §§ 503, 504).

The initial phase of policy-making providing services that targeted the disabled involved the enactment of *Section 504* in the *Rehabilitation Act of 1973*. Scotch states in his case study of the *Rehabilitation Act of 1973*, that the *Act* initially targeted only the service needs of disabled veterans and did not include language or provisions for the disabled in general (Scotch, 1984, p.53-54). Organized special interest groups representing the disabled were fragmented and not yet politicized. These groups had not yet developed coalitions and affiliations for support and independently represented an array of specific disabilities; neither had disability special interest groups yet defined civil

rights for the disabled as an agenda goal. Disability rights were never discussed in any of the *Rehabilitation Act* hearings.

The legislative foundation for future disability rights occurred quietly behind the scenes without special interest disability groups being aware of its inclusion in the act. According to Scotch, "Rather, the section was conceived by Senate Committee staff members and added to the bill at a relatively late point in the legislative process" as a challenge by a liberal Congress to President Nixon (Scotch, 1984, p.79-80). Consistent with Wilson's typography of majoritarian politics, both cost and benefits of Section 504 were considered diffused at the time of the *Act*. Disability special interest groups only became aware of Section 504 after the first rulemaking draft in 1975 (Scotch, 1984, p.79-80). Beneficiaries of disability rights were considered a concentrated group because there were no active special interest groups attempting to initiate expansion of the issue. Scotch found that "the legislative history of this provision contains only passing references to Section 504 and there is no statement:

...providing any rationale or predicting any impact...it appears that most members of Congress either were unaware that Section 504 was included in the act or saw the section as little more than a platitude, a statement of a desired goal with little potential for causing institutional change." (Scotch, 1984, p.53-54).

The disability issues added by Senate Committee staff members expanded program objectives to include rehabilitation services that would increase the employability of the disabled and promote independence. Emphasis focused on providing services for the most severely disabled. The *Act* contains eight titles that also expanded the scope of beneficiaries and services:

- Title I - expands State assistance with coordination and program development.
- Title II - expands research, demonstration projects, and training activities to assure full inclusion of the disabled.
- Title III - addresses grants and contracts for services.
- Title IV - establishes the President's National Council on Disability to promote programs, procedures, and equal opportunities for the disabled.
- Title V - establishes the architectural and Transportation Barriers Compliance Board.
- Title VI- creates the Equal Opportunities for Individuals with Disabilities Board that promotes employment and business opportunities for persons with disabilities.
- Title VII - establishes the Independent Living Services, Centers for Independent Living, and statewide Independent Living Council to maximize empowerment, independence, and productivity of persons with disabilities.
- Title VIII - creates a Special Demonstrations and Training Project that address grants available to states, public, non-profit, and educational organizations (*Rehabilitation Act of 1973*).

The potential for Section 504 to institute change came when Secretary Weinberger of the Department of Health, Education and Welfare (HEW) assigned

responsibility for administering Section 504 to the Office of Civil Rights (OCR) within HEW in 1973. This assignment proved to be critical to both the interpretation of Section 504 and the future development of disability policy. Secretary Weinberger placed the interpretation of Section 504 in an organization whose entire history had been devoted to efforts to fight racial discrimination “often in the face of opposition by uncooperative or hostile public officials and community leaders,” (Scotch, 1984, p. 63). The OCR viewed most federal fund recipients as adversaries and was keenly aware that its interpretation of Section 504, which included special accommodations for the disabled, would impose highly concentrated cost on these organizations (Scotch, 1984, p.63). Through the rulemaking process in the OCR, the *Rehabilitation Act* had transitioned from Wilson’s topology model of majoritarian politics to entrepreneurial politics. Cost of Section 504 had, by OCR’s interpretation, become concentrated for organizations that received federal funding. Benefits however still remained diffuse because special interest organizations were not yet involved in the policy’s process.

The Emergence of Disability Special Interest Groups

By 1975, disability special interest groups, which had previously been unaware of Section 504, had organized into the American Coalition of Citizens with Disabilities (ACCD) and increased political activities. David Mathews, the new Secretary of HEW, had repeatedly stalled publication of the *Rehabilitation Act* due to concerns regarding the controversial draft regulations produced by OCR. The OCR had increasingly been in contact with the disability advocates concerning the potential of Section 504 to provide

rights for the disabled and the status of the stalled regulation. Mathews replacement, Secretary Califano, also refused to release the draft regulations due to “political and financial implications,” (Scotch, 1984, p.108). Instead, in 1977, Secretary Califano created a task force committee in to review the proposed regulation. The committee met with 45 “organizations representing disabled people” and “a somewhat smaller number of recipients of federal funding,” (Scotch, 1984, p.108). The disability advocates issued an ultimatum to President Carter that if Califano did not sign the regulations by April 4, 1977, ACCD would hold protest at HEW headquarters as well as at every HEW office in the region. When Califano stated in the April 4, 1977 meeting that he would not sign the regulations, disability advocates walked out of the meeting while 300 disabled people “staged a sit-in Califano’s office, and demonstrations were held in each of the ten HEW regional offices,” (Scotch, 1984, p.111). On April 28, 1977, Califano signed the regulation draft without any modifications to the original interpretation of Section 504 that had been drafted by OCR. The disability advocates were clearly victorious.

In May 1977, the Department of Transportation (DOT) publicly promised accessible transportation for the disabled and announced that all new buses purchased with DOT funds had to be handicapped accessible. The DOT rulemaking for Section 504 involved eight years of controversy. In 1978, DOT issued regulations calling for nationwide accessibility to the disabled for all public transportation. Strong opposition existed from organizations that would bear the concentrated cost of the regulation, such as the American Public Transit Association (APTA). Final regulations were issued by DOT without modification except for an increase in the time frame that authorities would have

to come into compliance (Percy, 1989, p.144). Attempts by Congress to “limit the impact of DOT’S regulations” failed as Congress never passed the mass transportation act that would include the compromise (Percy, 1989, p.144). In 1981, Congress passed an amendment to the *Surface Transportation Assistance Act* that ended the full accessibility requirement and required DOT to establish a minimum service criteria for designing services for the elderly and handicapped populations (Percy, 1984, p.148). Advocates were initially successful in achieving the scope of public transportation policy demanded. The ultimate amendment, however, diminished their accomplishment.

Also in 1981, the Department of Housing and Urban Development (HUD), announced the establishment of the Office of Independent Living for the Disabled to ensure that all new housing built with federal funds was accessible for the disabled (Shapiro, 1993, p. 33).

The *Rehabilitation Acts of 1986 and 1992* were watershed legislation that emphasized an intentional effort by Congress not only to expand services for the disabled but to include persons with disabilities in the decision-making process for disability issues. The *1992 Act* strongly emphasized consumer involvement in the policies and procedures of state rehabilitation agencies and in the development of mandated Individual Work Rehabilitation Programs (IWRP). Congress mandated state rehabilitation agencies to establish rehabilitation advisory councils with the majority of members being individuals with disabilities. The importance of empowering people with disabilities was emphasized by fully involving the consumer in the construction and annual review of their IWRP. State agencies were required to respond with eligibility decisions within sixty days of receiving

an application for services and mandated to increase interagency collaboration through formal agreements. Congress states the following purpose of the *Act*:

Policies shall have respect for individual dignity, personal responsibility, self determination, and pursuit of meaningful careers, based on the informed choice of individuals with disabilities; respect for privacy, rights, and equal access of individuals with disabilities; inclusion, integration, and full participation of individuals with disabilities; support for the involvement of the family, advocates or authorized representatives, if desired or requested by the individual with disability; and support for individual and systemic advocacy and community involvement.

The purposes are to empower individuals with disabilities to maximize their employment, economic self-sufficiency, independence, and inclusion and integration into society, and to ensure that the Federal Government plays a leadership role in promoting the meaningful and gainful employment and the independent living of individuals with disabilities, and assists states and providers of services in their efforts in this regard (U.S. Congress. Senate. 1990, ADA Legislative History, Note 23).

The Congressional provisions for employability training, technical and support services, and independent living programs, which were designed to move the disabled person into the work force, necessitated Congressional protection from employment discrimination for persons with disabilities. A series of acts had been enacted by Congress for the general public in an effort to eradicate discrimination in the workplace. *The Equal Pay Act of 1963* prohibited discrimination on the basis of sex (*Equal Pay Act*, 1968). Acts that protect persons with disabilities from employment discrimination are hinged on the *Civil Rights Act of 1964*, which prohibited discrimination based on race, color, sex, national origin, and religion (*Civil Rights Act of 1964*). The *ADA* was the landmark piece of legislation that not only prohibited employment discrimination for persons with disabilities but mandated public accessibility to public entities, transportation, and housing.

This *Act* impacts most of the society and mandates reasonable accommodation for employment and public accessibility for persons with disabilities.

The Americans with Disabilities Act of 1990

The *Americans with Disabilities Act of 1990* (*Americans with Disabilities Act of 1990*), was authored by Senator Tom Harkin (D-IA) and strongly supported by Majority Leader Bob Dole (R-KS) and President George Bush. Disability special interest groups were fully aware of the potential the ADA held to mandate nondiscrimination, civil rights, and accessibility for the disabled. Well aware of the beneficiary concentration of the *ADA*, advocates formed unified coalitions that created a homogenous population and a strong and influential political voice.

There were two schools of thought on the *ADA*. Opposition to the bill was limited almost exclusively to business lobbyists, particularly those representing small businesses, who were concerned about cost concentration for businesses required to comply with the *ADA*. The *ADA* 1990 required compliance by all businesses with 25 or more employees; in 1994, an *ADA* amendment required compliance by businesses with 15 or more employees. Those who opposed the *Act* contended that it was an ineffective law that was complicated by vague definitions and very expensive to implement. They claimed the definition of “disability” was vague and would clog the courts with legal manipulation of the business community and lawsuits without merit by thousands who should not be included under the *Act*. Opponents argued that the *Act* would not even be of much benefit to the group it was intended to help, if the definition of disability was changed to

accurately reflect who should qualify as disabled, because the valid targeted group would be too small to warrant the expense of accommodation and regulation. Accommodation requirements were also vague, broad, and expensive. The *Act* did not clearly indicate the meaning of “reasonable accommodation.” Lobbyists argued that businesses would be forced to provide horrendously expensive accommodations that would be underutilized.

Supporters of the *ADA* maintained that it would allow persons with disabilities to be main-streamed into daily social and business activities and opportunities. Disabled persons would gain autonomy, independence, and a voice in policy choices. Advocates argued that the *ADA* was a civil rights act that protected millions of disabled people, and to deny them protection would be unconstitutional. The Congressional intention for the *ADA* was to prohibit employment discrimination and physical barriers that would prevent the disabled from exercising the same rights afforded to other populations.

A 1989 Senate conference report on the bill, which passed by Senate Vote No. 152, 91-6 (100% Democrats, 86% Republicans) voting yea. The conference report, in part, explains the purpose and Congressional intention of the *ADA*:

S 933 prohibits discrimination on the basis of disability in employment, public services, public accommodations, and telecommunications relay services.

--mandates compliance by employers with 25 or more employees;

--defines “disability” as a physical or mental impairment that substantially limits one or more of the major life activities of an individual;

--prohibits discrimination on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, and accommodations at any place of public accommodation...All public accommodations, irrespective of the number of people they employ, are covered under the Act;

--allows an employer to discharge a worker who is illegally using drugs, but protects those who have enrolled in or have completed, drug rehabilitation programs from adverse job actions (U.S. Congress. Senate. 1989, Conference Report, p. 933).

Subchapter I, Title I [Section 101] of the ADA addresses discrimination of employment on the basis of disability and establishes the Equal Employment Opportunity Commission (EEOC) by Section 2000e-4 of this title as the regulatory agency for enforcement of non-discriminatory employment practices regarding the disabled (*Americans with Disabilities Act of 1990*, § 2000e-4).

The conference report also makes accessibility mandates for each type of public transportation with compliance time requirements. Authority of regulations and enforcement is assigned to the Secretary of Transportation. Authority over mandated compliance for telecommunications accessibility is delegated to the FCC. Congressmen who favored final passage of the conference report stated:

For far too long we have wasted the valuable resources disabled Americans possess. This conference report to the ADA bill is a final proclamation that the disabled will never again be excluded or treated by law as second-class citizens. We are proving that we will no longer subject persons with disabilities to isolation. By passing this conference report we are unlocking these resources and bringing individuals with disabilities into the mainstream of the economic structure of our country. In employment, public accommodations, transportation, and communications services--all of which many of us take for granted--we will not tolerate the exclusion of the disabled because of ignorance, fear, or intolerance (U.S. Congress. Senate. 1989, Conference Report, p. 933).

Senate bill 933 passed without great opposition by a 76-8 majority vote on September 7, 1989, with the following amendments:

--Requires a judge to consider if a defendant who is accused of discrimination on the basis of disability has acted in good faith;

--Excludes an employee or applicant who is currently using illegal drugs from the definition of “qualified individual with a disability”;

--Provides that the term “disabled” or “disability” shall not apply to an individual solely because of...sexual behavior disorders;

-- to invoke the sweep of congressional authority, including the power to enforce the fourteenth amendment and to regulate commerce, in day-to-day activities by people with disabilities (U.S. Congress. Senate. 1989, August 7, Senate Vote Analysis).

The *ADA* also specifically prohibits employers from:

...(1) limiting, segregating, or classifying a job applicant or employee in a way that adversely affects the opportunities or status of such applicant or employee because of the disability...

...(3) utilizing standards, criteria, or methods of administration -(A) that have the effect of discrimination on the basis of disability or (B) that perpetuate the discrimination of others who are subject of common administrative control...

...(5) (A) not making reasonable accommodations to the known physical or mental limitations of an otherwise qualified individual with a disability, who is an applicant or employee, unless such covered entity can demonstrate that the accommodation would impose an undue hardship on the operation of business...(*Americans with Disabilities Act of 1990* § 12101).

The *ADA* has provided protection from discrimination in a variety of arenas for persons with disabilities where there was none. It is important to note that disability policies do not provide any additional rights or privileges to persons with disabilities (U.S. Congress. Senate. 1989, Conference Report, p. 933). Persons with disabilities became a legally recognized class that was entitled by law to protection from discrimination. Prior to the *ADA*, persons with disabilities were an “invisible” class of people who had no legal right to a personal choice of their mode of transportation, whether they had a job, or

where to shop, eat, or go to school. The *Act* has had an immense positive impact on the scope of activities and choices available for persons with disabilities.

The *ADA* has not resulted in the wildfire litigation that was predicted by its opponents. Carla Walworth, partner with Day, Berry & Howard of Stamford, Connecticut, says, “Fear of litigation and the expenses associated with fighting a battle for years cause the employers to make an effort to comply [with the law] and to resolve disputes before litigation” (Stansky, 1996, p.67). Civil litigation is not the only recourse provided by the *ADA* to resolve legitimate claims. The EEOC rules do not allow the Department of Justice (DOJ) or a complainant to file a lawsuit unless it has first unsuccessfully exhausted all administrative avenues in an attempt to settle the dispute through negotiations (Stansky, 1996, p.67). A complainant must receive a “right to sue” letter issued by the EEOC before a suit can be filed. This provision appears to be successfully resolving disputes without involving the courts.

The number of lawsuits that have actually gone to court has been very small in consideration of the scope of the *ADA*. These suits have improved compliance, with few suits seeking to broaden the scope of the *ADA*. The few lawsuits that have been frivolous or have sought to broaden the scope seems to be anomaly (Shapiro, 1993, p.35).

Much of the criticism of the *Americans with Disabilities Act* has centered around the breadth (some contend a vagueness) of its terminology. The term “disability” has raised difficult issues for the courts and those employers who are required to comply with the *ADA* (Americans with Disabilities Act of 1990 § 12111, A5).

The terms used prior to the enactment of *ADA* to identify the disabled were overlaid with stereotypes, patronizing attitudes and mis-perceptions. During the formation of the *ADA*, advocates encouraged Congress to adopt the more appropriate and accepted term “person with a disability” rather than “handicapped person,” so that legislation would align with the sensibilities of most Americans with disabilities. The use of the term “person with a disability” is preferable to the “disabled” or “handicapped” because it emphasizes the individual not the condition (U.S. Congress. House. 1990, *ADA Legislative History*, Note 2, p. 33).

The term “disability” as it applies to the individual, is defined in the *ADA of 1994* as:

- (A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual;
- (B) a record of such an impairment; or
- (C) being regarded as having such an impairment (Americans with Disabilities Act of 1990 § 12111, A5).

The three alternatives for the definition of disability target the various ways persons with disabilities face barriers in employment and services (U.S. Congress. Senate. 1990, *ADA Legislative History*, Note 23, p.120). The first part of the definition accounts for most conditions that are thought of as disabilities, such as learning disabilities, blindness, physical impairment, and certain diseases (U.S. Congress. Senate. 1990, *ADA Legislative History*, Note 23, p.120). The second part covers those who might experience residual discrimination when a disability no longer exists, such as cancer survivors who are treated as though they still have cancer (U.S. Congress. Senate. 1990, *ADA Legislative History*, Note 23, p.120). The third part targets stereotypes and biases that result in the

person being perceived and discriminated against as disabled, although the person has no disability or when the person has an “impairment” of some type but it does not, as required in the *ADA*, “substantially limit one or more life activities,” such as the perception of a burn victim with severe scars as disabled although he has no disability. This three-part definition is essentially the same definition applied in the *Rehabilitation Act of 1973* (U.S. Congress. Senate. 1990, *ADA Legislative History*, Note 23, p.120). Congress incorporated both the *Rehabilitation Act of 1973* as well as case law interpreting the *Rehabilitation Act* into the *ADA* in such a way that this case law is binding on courts seeking to interpret the *ADA*’s terms and definitions. The court’s are bound by precedent interpretations of the term “handicap” as used in the *Rehabilitation Act* (U.S. Congress. Senate. 1990, *ADA Legislative History*, Note 23, p.120). Jurisprudence in the *Rehabilitation Act* is incorporated into the *ADA* because Congress viewed the *Rehabilitation Act*’s protections as the foundation for the *ADA*’s protections (*Americans with Disabilities Act of 1990*). Although, it is not stated in the *ADA*, Congress expected that the *Rehabilitation Act* regulations would be a binding authority in interpreting the *ADA*’s definition of “disability”(U.S. Congress. Senate. 1990, *ADA Legislative History*, Note 23, p. 467).

The definition of disability as “. . . a physical or mental impairment that substantially limits one or more of the major life activities of an individual” (*Americans with Disabilities Act of 1990* § 12101 et seq.) was indeed initially troublesome. The court has determined major life activities to be: seeing, hearing, walking, and caring for one’s self (*Pacourek v Inland Steel Co.*, 1996) and has provided opinions regarding who does

and who does not qualify as disabled. These are expensive opinions, however, and must be determined through the courts on a case-by-case basis. Occasional lawsuits that seek to broaden impairments that can be included in the definition of “disability” continue to be filed. The court has rejected the argument that infertility is a disability since child bearing is a major life activity and should be included under the *ADA* (Epstein, 1997, p.A4). The Supreme Court issued an opinion in July 1998, that persons who are asymptomatic HIV positive are to be included under the *ADA* as a person with disabilities (*Bragdon v Sidney Abbot*, 1998). The court’s ruling could result in a dramatic increase in lawsuits seeking to include various other diseases under the current definition of disability.

The courts have attempted to clarify what is considered a “reasonable accommodation.” Court opinions have also limited how far an employer must go to accommodate employees. “The number of employees, annual revenues of the entity, and the impact of the cost to accommodate are considered when determining whether a request for accommodation is reasonable” (Stansky, 1996, p. 67). The courts’ consistency in opinions regarding reasonable accommodation has protected the business community from the “bankrupting” compliance requirements that the opposition argues the *Act* imposes. According to a survey by the Job Accommodation Network, a federally funded organization that provides information to employers and the disabled, the cost of 19 percent of the changes made was \$0; 50 percent of respondents reported that accommodation cost ranged between \$1 and \$500 (Stansky, 1996, p.69).

Kenneth Morse, liaison attorney with the Equal Employment Opportunity Commission (EEOC) Office of General Counsel in Washington, D.C., reports that as of

September 30, 1995, 40 percent of all *ADA* claims filed with the agency were dismissed for having “no reasonable cause.” Another 43 percent were closed for administrative reasons. Back problems, mental disorders, and neurological illnesses comprised 40 percent of all remaining complaints with the majority regarding dismissal issues, not accommodation. HIV infection represents only 1.8 percent of charges filed but roughly one-third of the 89 suits filed since the *ADA* was passed. However, Reginald Welch, a spokesman for the agency, stated the EEOC had a backlog of 24,800 cases due to staff and budget constraints. (Stansky, 1996, p. 69).

Businesses have reaped benefits from hiring the disabled by tapping into an otherwise wasted resource of skill and talent. The disabled have provided businesses with an entirely new market to target that had previously been overlooked. New product and service development and technological advances such as speech recognition for computers can be attributed to this market. It was for these reasons that there was unexpectedly little opposition from the business community toward the *ADA*. A 1996 survey by the National Organization on Disability showed that only a small percentage of employers reported increased litigation cost due to the *ADA*, 70% of the businessmen surveyed said that the *ADA* accommodates the disabled in the workplace, and only 12 percent of American businesses were in favor of weakening or repeal of the *ADA* (*Architectural Record*, 1996, p. 37).

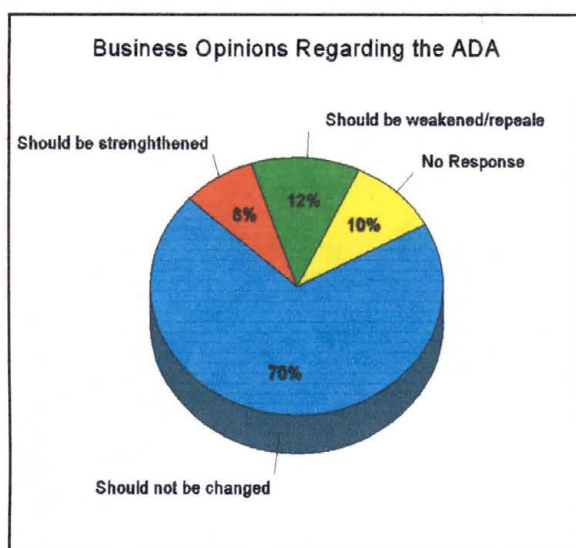


Fig. 4

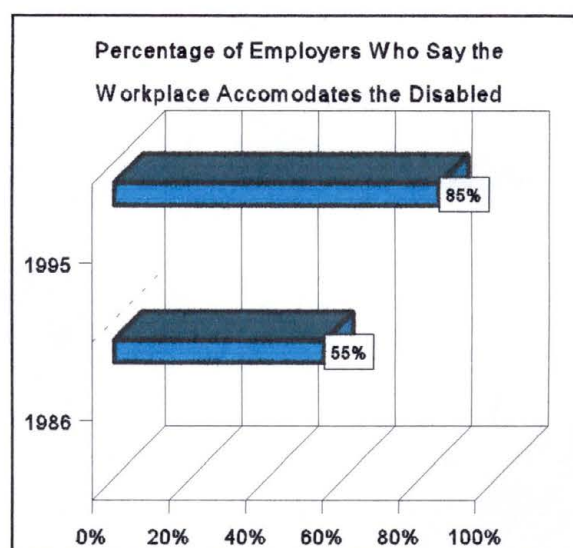


Fig. 5

The *ADA* manifests unintended consequences toward those with mental disabilities with the inclusion of two provisions: 1) the direct threat exclusion and 2) employers obligation to accommodate only the known disabilities of an employee or applicant. Most of society perceives the mentally impaired as volatile, unstable, and potentially violent. Mental illness carries the most negative stigma even within the disabled community. Congressional attempts to balance the rights of persons with disabilities and the public's right to protect itself from harm with the direct threat standard have resulted in untended negative impact on those with mental disabilities. The inclusion of these two provisions exposes the person with mental disabilities to unwanted scrutiny and psychiatric stigmas. The requirement to disclose a mental disability exposes the disabled person to the stigma, and the widespread acceptance of the cultural stereotype of the mentally ill as dangerous and violent, and often exposes them to discrimination that the *Act* was intended to prevent. A number of studies show that employers have a strong negative impression of

persons known or thought to have a mental illness (Colbert, Kalish, & Chang, 1973, p.196). The two provisions that work against the mentally disabled are nonetheless necessary to include in order to provide fairness to the employer regarding accommodations and to have regard for the employer's liability to protect others in his charge. Disability special interest advocates argue that separate is not equal and the goal of social equity can only be accomplished by community integration.

While the act is no more likely to completely eliminate the myths, fears, and discrimination faced by people with disabilities than earlier civil rights laws eliminated discrimination based on race, the new legislation will nonetheless contribute to the enormous education effort needed to combat widespread misinformations and stereotypes about disabilities (Haimowitz, 1991, p. 24).

The benefits of the *ADA* for the physically disabled persons have been substantial, but the benefits for persons with mental disabilities have not been as significant. There are very few occasions when the meaning of reasonable accommodation for this group has been addressed. The EEOC has no specific guidelines for mental disabilities and no funds to expand guidelines at this time.

The last major unintended consequence of the *ADA* has become known as the "Catch 22." Many disabled individuals who were closed out of the workforce prior to the *ADA* had to rely on Social Security Disability Income assistance (SSDI). In order to qualify for SSDI the applicant had to declare themselves permanently "unemployable" due to disability. After the *ADA* was enacted those who were already employed or who became employed and later filed a complaint with the EEOC discovered that they were not protected under the law because they had accepted income assistance through a program that required them to be unable to work. They could not be both "unemployable" and "a

qualified employee.” This issue was finally resolved in June 1997, when the U.S. District Court of Appeals for the District of Washington held in *Swanks v Washington Metropolitan Area Transit Authority*, that “an application for Social Security Disability Income (SSDI) does not automatically bar *ADA* claims because the Social Security does not consider reasonable accommodation in determining whether an individual is able to work,” (*Harvard Law Review*, 1992, p.1608). This ruling removed a major barrier for most disabled employees who sought protection from discrimination through the *ADA*.

CHAPTER 3

CURRENT CONGRESSIONAL ACTIVITY FOR PERSONAL ATTENDANT SERVICES LEGISLATION

Modern Congressional Activity and Policies

Post-*ADA* legislative and federal agency activities regarding disability policy have primarily focused on clarification and mandates for compliance with the *ADA*. Recent significant disability advocate activities for additional policies address a three-prong agenda:

- 1) continued emphasis on de-institutionalization,
- 2) the need for home and community-based services which are necessary in order for the disabled to secure and maintain residency in the community and/or employment, and
- 3) and personal attendant services, which are generally an employment or independence related issue.

The 1994 elections resulted in a Republican-controlled Congress for the first time in decades. President Clinton had failed to get Congressional support for his national health care program. Acting on the Republican platform that was centered on the deconstruction of “big government” and devolution to state control, Congress began to

redirect public health objectives towards education and prevention programs that addressed behavior induced illnesses as mechanisms to control rising health care costs. Public health education programs focus on diet, exercise, sexual behaviors, smoking, drug and alcohol usage. Preventive health care includes programs such as mammograms and wellness clinics. These health education and prevention programs supported the Republican social policy philosophy that the public should exercise self-responsibility and self-determination by changing behaviors that can impair one's health. These types of programs, however, can only be effective for persons whose behaviors may result in illness or disease; they do not necessarily affect the disabled community. Only those members of the disabled populations who are at risk of behavioral-induced illness would benefit from these programs.

Since the passage of the *Rehabilitation Act of 1973*, with a Democratic-controlled Congress, disability policy expanded dramatically. Early childhood intervention programs, special education programs, and a multitude of rehabilitation and habilitation programs funded by federal grants and under the implementation of state agencies have been developed. There has been little interagency association or attempt at interagency coordination and control of overlapping or duplicated services. Additionally, only recently has there been an attempt to develop a system to track program recipients who may be enrolled in duplicate programs through multiple agencies or private health care services, and thus may be receiving duplicate services. As all grant-funded programs are limited in the number of recipients they can serve, recipients who are receiving duplicate services through multiple agencies compound the problem of some potential recipients being

placed on waiting lists for months and sometimes years without receiving needed services.

The Democratic Party favors social public policy and subscribes to the philosophy that the federal government must assist or subsidize assistance to those who are unable to help themselves. In contrast, the Republican Party believes that “less government is better government” and states that the public should be as self-governing and self-responsible as possible. Since 1994, the Republican-controlled Congress has, through reforms and agency consolidation or restructuring, addressed what it considers a wasteful glut of social programs. Congress has also transferred control of many social programs to the states through the use of block grants and allows states the option of implementing federally mandated programs if federal funding is not provided for program development and implementation.

Is it incongruent, then, that a Republican-controlled Congress that has used reform and decentralization to reduce social programs has remained willing to expand disability programs? There is great public and private cost associated with disability policy. However, in some ways, support for disability policy is an almost perfect political platform, regardless of the political orientation. Passage of the ADA has resulted in an awareness by Congress of a myriad of other disability issues, such as housing, employment, technical assistance, and accessible transportation, and a willingness to address and resolve those issues. *The 1994 U.S. Census: Disability and Program Participation Data* indicates there are 54 million Americans with some type of disability (McNeil, 1997, December, Census Brief). It is politically risky to oppose policy that would potentially enable 54 million people with disabilities to be independent. The general

public is supportive of disability policy expansion because it is viewed as a means for helping those who are dependent on society to become independent and productive, even though this is not always the case. Additionally, many members of Congress either know someone personally or have family members of their own who have a disability. Many Congressmen are sympathetic to, or may personally benefit from, expansion of disability policies. The Republican Congress has been particularly receptive to able disabled advocates' demands for disability policy that promotes autonomy, self-responsibility, and self determination; Congress is responding to this new disability agenda with several highly significant new bills. Because advocates' agendas, as well federal and state programs and policies, are moving toward the restructuring of health care services from a medical model to a consumer-oriented model, this study focuses on four bills that illustrate this trend. *HR 2020* and *S 879* are both community personal attendant services bills. *HR 3433* and *S 1858* are work incentive bills that include personal attendant services. The purpose of all four bills is to promote independence, autonomy and self-direction for the disabled populations in a home or community setting.

H.R. 2020

H.R. 2020, the *Medicaid Community Attendant Services Act of 1997* (CASA), was introduced to the 95th Congress by the House Speaker Newt Gingrich (R-GA) and cosponsored by Minority Leader Dick Gephardt (D-MO) on June 24, 1997 (U.S. Congress. House. 1997. Summary). This bill presents an unusual occurrence of mutual cooperation and support for a public program by senior members of both the Republican

and Democratic parties. The *Act* amends the title XIX of the *Social Security Act*, which mandates Medicaid services, to include a mandate for states to provide qualified home and community-based personal attendant services to all individuals who qualify for services in a nursing facility or in an intermediate care facility for the mentally retarded (ICF-MR).

The services included in the bill are limited to those furnished in the home or a community-based setting and specifically exclude services in nursing homes, ICFs-MR, or other institutionalized settings. Currently available funding for nursing or ICF-MR services would “follow” the individual and be used to fund Qualified Home and Community-Based Services (QHCBS), not to exceed in a fiscal year the amount that would have been used for the individual’s care in an institutional setting. The recipient would have the right to both choose and self- direct all services; including the right to select, hire, terminate, and direct the provider. The recipient would serve as the provider’s employer and would choose an agency to serve as the payroll agent.

HR 2020 directs the Secretary of Health and Human Services to:

- 1) review existing Medicaid regulations for home health services and other services in home and community-based settings ;
- 2) report to the Congress on how excessive overutilization of medical services can be reduced under Medicaid by using qualified community-based attendant services;
- 3) develop a functional needs assessment instrument with respect to an individual’s need for such services; and
- 4) establish a task force to examine appropriate methods for financing long-term care services (U.S. Congress. House. 1997. Summary).

HR 2020 also:

1. Amends the *Social Security Act’s title XIX* to allow States to waive certain income limitations with respect to Medicaid payments to

individuals eligible for medical assistance who are also eligible for or already receiving State supplementary payment.

2. Allows such a waiver in such cases as the State finds the potential for employment opportunities would be enhanced through the provision of qualified community-based attendant services.
3. Allows the State, in the case of such an individual, made eligible for medical assistance because of such a waiver, to impose a premium based on a sliding scale relating to income (U.S. Congress. House. 1997. Summary).

This bill was read twice and then referred to the House Committee on Commerce and to the Subcommittee on Health and Environment. Sponsored by both the majority and minority party leaders, the bill has been well received, and as of October 1, 1998, has seventy-six cosponsors. Of the seventy-six cosponsors, fifty-one are Democrats and twenty-five are Republicans (U.S. Congress. 1998, October. Congressional Record). No other activity was generated on this bill during the 105th Congress.

S. 879

On June 11, 1997, two weeks prior to the introduction of *HR 2020* by House Speaker Gingrich, Senator Feingold (D-WI) introduced his competing bill for home and community-based services entitled *The Long-Term Care Reform & Deficit Reduction Act* and it was referred to the Committee on Finance the same day. Senate bill 879 seeks to give states the flexibility to establish “consumer-oriented, consumer-directed home and community-based long-term care for disabled persons of any age,” (U.S. Congress. Senate. 1997, Statements). Feingold’s bill is based on the Wisconsin Community Options Program (COP), a keystone of Wisconsin’s long-term care reforms. *S 879*, entirely optional for states, is a plan for four core services: assessment, recipient care planning,

personal assistance services, and case management. Even though States choosing to participate in the program have the flexibility of deciding what, if any, other services are provided, participating state plans must include personal attendant services. Unlike *HR 2020*, Feingold's bill allows the types of services offered by participating states to be optional; provisions for enrollment limitations are included, and only personal attendant services could be self-directed and controlled by the recipient. This bill provides some initial funding and directs the Secretary of Health and Human Services to submit to Congress a proposal by which states could retain 75 percent of the federal Medicaid long-term care savings they generate by participation in the program. As of October 1, 1998, there are no cosponsors, and there has been no other Congressional activity on this bill.

Comparison of *HR 2020* and *S 879* Bills

The primary difference between *HR 2020* and *S 879* is that *S 879* is a completely optional state plan, which does not attempt to amend Title XIX of the *Social Security Act* (Medicaid). Thus, states which choose not to participate in the plan retain the status quo. States that choose to have a plan under this legislation also have the option of which services it offers. Feingold's bill clearly states "Title I 101(b) . . . that nothing in this title shall be construed to create a right to services." On the other hand, *HR 2020* creates a new service, referred to as "Qualified Community-Based Services" (QCBS) by amending Title XIX Medicaid state mandates, in which consumers have the option of participation. This bill requires each state to develop a long-term care services transition plan with optional program participation for all persons with a disability. The State Independent

Living Council, the State Developmental Disabilities Council, and the Councils on Aging are required to participate in the development of the long-term care service transition plans which must include specific action steps and timetables to increase the proportion of home and community-based services provided in the state. Information in the following comparison (Fig. 6) of *HR 2020* and *S 879* is derived from a comparison report produced by the Topeka Independent Living Resource Center (Topeka Independent Living Resource Center. *Feingold/Casa Comparison, 1997*).

S 879

Plans must specify how services will be allotted across the 5 eligible groups listed above. The plan shall attempt to meet the needs of eligible recipients within the limits of available funding. Consumer choice of services shall be provided *to the extent feasible*.

HR 2020

Money for services would follow the individual and be used for services of the individual's choice.

S 879**SERVICES:**

HCBS are optional.

Possible services mentioned in the bill are:

1. Personal care services.
 2. Optional HCBS offered by the state could include:
 - a) homemaker services,
 - b) home modifications,
 - c) respite,
 - d) habilitation and rehabilitation,
 - e) adult day care,
 - f) supported employment,
 - g) home health
 - h) transportation and/or
 - i) other service options to be determined by the state.
 3. HCBS to functionally disabled persons.
 4. Community supported living.
 5. Services provided in a nursing facility, ICF-MR, or other institutional setting.
 6. Services can be provided in a range of *community residential arrangements* (undefined).
 7. Determination of disability and care plans.
Reviewed every 6 months.
-

HR 2020**SERVICES:**

QHCBS would become mandatory under an amended Title XIX of the Social Security Act.

1. Mandated attendant services would be provided:
 - a) on an as-needed basis,
 - b) in a home or community-based setting,
 - c) through an agency provider,
 - d) as services selected and controlled by the recipient,
 - e) and health related services which could be delegated, or assigned to and performed by an unlicensed attendant.
 2. Includes those services listed opposite (a-h) as HCBS optional Medicaid services in addition to:
 - a) voluntary training on selection and management of attendants,
 - b) emergency attendant services,
 3. Services can be provided in the home or a community-based setting including school, workplace, recreation or religious facility. This bill specifically *excludes* a nursing facility, ICF-MR or other institutional facility as a setting for providing services.
 4. Care plans as provided for under Current law.
-

S 879**SERVICE PROVIDERS:**

The State shall contract with an agency to serve as the employer of the home care service provider, including both agency-administered and recipient directed personal assistant services, but can not limit benefits to services provided by professional providers.

The State may specify requirements for provider participation but can not require any kind of certification or license not specified as necessary for health and safety by the Secretary.

The recipient has the right to select, hire, terminate, and direct the provider.

The State must provide a single point of access to apply for the program, except the State may designate separate points of access for certain classes of individuals (such as MR).

PA services are mandatory in The State Plan and are the only self-directed services. The agency in charge of "Care Management" directs all other services. After 2005, no more than 10 percent of program funding can be used by providers for administrative cost.

HR 2020**SERVICE PROVIDERS:**

The recipient will be the attendant employer and can choose an agency to serve as the payroll agent.

Health-related task may be assigned to, delegated to, or performed by un-licensed personal attendants.

The recipient retains control of the provider and a continuum of options to self direct.

The program will use points of access which are currently available.

Attendant services are mandatory. The recipient has the option to self-direct all services.

S 879**PAYMENT AND COST SHARING:**

The State can provide vouchers, cash to individuals, capitalized payments to health plans, and payment to providers in their plan.

States may impose cost sharing and/or annual deductible.

HR 2020**PAYMENT AND COST SHARING:**

Any service under CASA Medicaid could be self directed vouchers or direct cash payments. Fiscal agents and agency providers are delivery options in CASA.

States may impose a spend down and/or an annual deductible.

Current Medicaid income limitations may be waived by the State if it is determined that services could result in increased potential for employment.

QUALITY ASSURANCE:

States will establish a plan to monitor quality which includes:

- a) consumer input and surveys,
 - b) optional training on how to hire, fire and manage personal attendants,
 - c) minimum competency requirements for agency provider employees who provide direct services,
 - d) minimum standards for providers,
 - e) grievance procedures and appeal procedure for eligibility denials,
 - f) other components determined by the state.
-

QUALITY ASSURANCE:

Public hearings must be held prior to developing the program. The State established and maintained program must be based on customer satisfaction and include:

- a) minimum qualification standards for providers,
 - b) financial operating standards,
 - c) and a process for consumer grievance.
-

S 879**SAFEGUARDS:**

The State Plan will establish a Client Advocacy Office for this program.

Rights of Consumers must include:

- a) the right to be fully informed in advance, orally and in writing, of any changes in the provision of care (guardians of incompetent individuals will be notified)
 - b) and, the right to participate in The Care Plan process or any changes in The Care Plan,
 - c) instructions on how to file grievances,
 - d) the right to voice grievances without reprisals,
 - e) and prompt resolution to grievances.
-

ADVISORY GROUPS

A federal advisory group will be established composed of people with disabilities and their representatives. Each state will also establish an advisory group composed of political appointees, and people with disabilities and their representative. This advisory group would establish The State Plan.

HR 2020**SAFEGUARDS:**

Each state's advocacy & protection offices which are currently in place, as well as the Council for Independent Living and other state and federal organizations would monitor the program. State monitoring boards would include consumers, parents, providers and neighbors. Safeguards already in place for community service living arrangements (CSLA) would apply.

The consumer rights listed opposite (a-e) are currently contained in long-term care Rights of Consumers.

ADVISORY GROUPS:

Groups which are currently in place, specifically including representatives from Independent Living Centers, Developmental Disability Councils and Councils on Aging will be included in the Advisory Committee to develop The State Plan.

S 879**FUNDING:**

Changes in funding would be established for nursing facilities that care for persons with disabilities with high service level needs.

Starting in 1999, new federal funding would be phased in over 9 years, totaling 5.5 billion dollars in 2007.

Participating State Programs & Administrations would receive ½ of 1 percent for advocacy services.

HOSPITAL LINKAGE PROGRAMS:

Grants would be made to discharge planning entities who will ensure that HCBS options are available to those leaving acute care/rehabilitation settings rather than discharge planning only to nursing home facilities.

HR 2020**FUNDING:**

When an individual chooses to utilize QHCBS instead of institutional long-term care, funding currently available for institutional care would follow the individual and be used for QHCBS.

The federal government would appropriate an additional 2 billion dollars over 6 years to assist states transition from institutional to community-based services.

Funding for State Programs & Administration would remain unchanged.

Recipients who qualify for institutional care may choose QHCBS, so long as aggregate federal expenditures for an individual in a fiscal year do not exceed the total that would have been expended in a fiscal year for institutional care for the individual.

TRANSITION TO HOME SETTING

To encourage transition from nursing facilities or ICFs-MR to home and community-based settings, expenditures may be made for rent and utility deposits, first month's rent and utilities, basic kitchen supplies, bedding, and other required necessities.

Fig. 6 Comparison of *S 879* and *HR 2020*

Feingold's proposal requires extensive new and expanded state administration, and states have incentive through funding to develop HCBS, the regulatory and administrative burden is a disincentive to participate. Senate bill 879 is not as popular as *HR 2020* with the advocates for the able disabled because it is optional to the states. Advocates for the able disabled are, however, supportive of the bill because it includes mandatory personal attendant services for participating state's plans. Other points of contention for the advocates are that, for participating states, all services in The State Plan are optional except personal attendant care and only personal attendant services may be self-directed by the recipient. Therefore, the scope, availability or level of services provided are at the discretion of each state. This destroys the possibility of nationwide program and service consistency. Many provisions of the bill, as stated in the comparison, already exist.

HR 2020, on the other hand, has received intense vocal support and lobbying efforts from advocates for the able disabled and group coalitions for developmental disabilities (including ADAPT, the National and Local Independent Living Centers and UCPA). It is opposed, however, by special interest groups which advocate for people with mental retardation, nursing facility special interest groups, and the National Alliance of the Disabled (a cross-disability advocacy organization).

HR 2020 CASA Hearing

In March, 1998, the Health and Environment Subcommittee of the Commerce Committee held a public hearing entitled *The Hearing on Community-Based Care for*

Americans with Disabilities. Presented below are excerpts from the testimony transcripts from the HR 2020 hearing to illustrate the complexity of the issues, and sometimes adversarial tone often associated with the development of disability policy (U.S. Congress. House. 1998, March 12, HR 2020 Hearing).

Speaker Newt Gingrich and cosponsor, Minority Leader Dick Gephardt, both testified at the hearing in a rare bi-partisan effort to promote support for a bill. Speaker Gingrich begins the testimony by outlining to the committee the following goal for this legislation,

Our goal should be to replace the caretaker dependency model with a model of empowerment and independent living. While the dependency model is better than the previous model of simply ignoring these problems, it should now be superceded by individual independence and empowerment (U.S. Congress. House. 1998, March 12, HR 2020 Hearing).

Minority Leader Dick Gephardt's testimony was also supportive of the bill, but he also acknowledged a need for institutionalized long-term care. He made reference to the bi-partisan support of *HR 2020*:

It's interesting to note today that you have the leader of the Republican Party in the House, the leader of the Democratic Party in the House, we disagree on most things. We don't disagree on this (U.S. Congress. House. 1998, March 12, HR 2020 Hearing).

Representative Frank Pallone (D-NJ) stated to Speaker Gingrich that while he was in favor of changing Medicaid to provide more home and community based attendant care services, he was concerned that funds used to provide HCBS could take away from funds that are currently available for institutional care (U.S. Congress. House. 1998, March 12, HR 2020 Hearing). Rep. Sherrod Brown (D-OH) also expressed these

concerns and stated that, in her district, many parents of mentally retarded children and adults are concerned that leadership's, including Speaker Gingrich, repeated attempts to cut Medicaid dollars will result in fewer resources being available for those who require institutional assistance. Her constituents are also concerned that *HR 2020's* efforts to expand access to assisted living services could unintentionally allow less qualified health workers to care for individuals with physical and mental disabilities under the Medicaid program (U.S. Congress. House. 1998, March 12, HR 2020 Hearing). Rep. Gene Green (D-TX) (cosponsor) added his concern that reductions in spending for nursing home and intermediate care facilities could cause the care in these facilities to deteriorate. He stated the committee needed to include some parameters for care providers because the bill would allow consumers to choose their attendant regardless of training or qualifications (U.S. Congress, *Community-Based Care for Americans with Disabilities: H.R. 2020 Hearing*, 12 March 1998). Speaker Gingrich replied to Rep. Pallone's concerns:

Rather than have a long fight over funding, et cetera, *let's get things started and see what happens in the real world as opposed to the scoring theories of the Congressional Budget Office (CBO) or what have you . . . 49 of the 50 states, have had a dramatic increase in spending per family under welfare reform . . . I think at some point we should sit down with governors and say, 'Is there a pot of money here that is available?' . . . At some place in there, there is a chance, I think, for us to look to find some more money. Many of the groups I have met within trying to work this out . . . believe that in fact in the long-run, as we design the right systems, independent living and community services will be less expensive than full-time nursing home services* But I think our primary interest here should be the patient and the individual citizen, not the institutions that . . . want to protect the past because they happen to have figured out how to make money out of it (U.S. Congress. House. 1998, March 12, HR 2020 Hearing).

Speaker Gingrich's comment regarding the Congressional Budget Office (CBO) is in reference to a letter to him in October 1997, from CBO Director June O'Neill. The

letter presents the results of the *Analysis of the Congressional Budget Office Regarding the Estimated Cost of HR 2020* (U.S. Congressional Budget Office, 1997, Letter to Speaker of the House), requested by Speaker Gingrich. The CBO (1997) analysis concluded that even though “any estimates of cost are highly uncertain . . . there are no reliable estimates of the number of individuals receiving non-institutional long-term care services.” The 1997 CBO analysis assumes the figure of 8 million low-income persons living in the community [who] cannot perform 1 or more ADLs as the basis for its estimates. The analysis also concludes that *HR 2020* provisions “establish a new mandatory Medicaid benefits for essentially unlimited community-based attendant care services would be very expensive,” and “could cost the federal government \$10 billion to \$20 billion a year. Expenditures for HCBS attendant care services are projected by the CBO to total \$8 billion in 1998 and increase in excess of 10% per year. The cost per person, in the analysis is based on the experiences of several states which currently provide attendant care services under Medicaid HCBS waivers. Experience in these state programs indicate that services, subject to limitations such as maximum hours per week and age of recipient, range from \$8,000 - \$16,000 per person annually. In states that offer services other than attendant care, costs are higher. One state, which pays attendants \$8 per hour for a 40- hour week and pays \$4,500 to make any home modifications needed for provision of attendant care, has cost of \$20,500 per recipient annually. The analysis summary from the CBO goes on to say:

Net Increase in Medicaid Spending:

The simple multiplication: 2 million users, the cost per user, and the average federal matching assistance percentage (57 percent) indicates significant new Medicaid cost for the federal government. Total cost would be higher because in addition to the costs of attendant care services, the federal government would also incur cost for some people who would not otherwise have been enrolled in the Medicaid program, but who would now be eligible for the full Medicaid benefit package. Second, cost would be partially offset by savings associated with providing attendant care to people who would otherwise have entered nursing facilities. The potential for savings from nursing facility diversions is limited, however, because only a small fraction of long-term nursing home residents could be diverted to home and community settings and their places would likely be filled by new residents. Finally, the bill makes grants to states for transitional assistance. These grants total \$2 billion over the 1998-2003 period (U.S. Congressional Budget Office, 1997, Letter to Speaker of the House).

It is true that reliability of the CBO cost estimate analysis is uncertain due to the inability to determine how many people would utilize the program and the inability to determine how many and what kind of services the individuals would require. Hence, it can also be assumed that disability advocates' adamant claims that QHCBS provided under *HR 2020* are significantly less expensive than nursing facilities or ICFs-MR is equally unreliable for the same reasons.

Rep. Stupak (D-MI) asked Sally Richardson, Director of Medicaid, and Dr. Hamburg, Assistant Secretary of Health and Human Services, whether they agreed with the CBO cost estimate for *HR 2020* and what costs averaged for nursing home care. Mrs. Richardson estimated the average cost of institutional care to be between \$20 and \$30 thousand a year. Both Richardson and Hamburg discussed the consequences of implementing a bill with undeterminable program participation and the need to have support infrastructures in place (U.S. Congress. House. 1998, March 12, *HR 2020*

Hearing). Ms. Richardson responded:

... the scoring includes an estimate of additional individuals who would use the benefit. . . you're worried about the bill...because of the cost . . . it's not just a matter of de-institutionalizing people. It becomes a matter of a whole bunch of folks who are already at home with developmental disabilities who aren't claiming a benefit. Whose families are taking care of them, suddenly claiming benefits, and jacking up the cost (U.S. Congress. House. 1998, March 12, HR 2020 Hearing).

Dr. Hamburg added:

... we also need to factor in the transitional services . . . an infrastructure...to provide the home and community based services. That does mean that over time there won't be approaching the cost neutrality that you were siding for . . . we don't know enough about the true costs, and we need to look at that.

[In N.Y.] we faced a very serious epidemic of tuberculosis . . . in large part the result of de-institutionalizing individuals with tuberculosis. But not insuring that the appropriate system for community based and home based care for TB patients was in place, we ended up spending lots more money building that infrastructure to fight an epidemic that was already in place, than had those services been put in place in the first place (U.S. Congress. House. 1998, March 12, HR 2020 Hearing).

Rep. Brown asked Sally Richardson if, for home health care, more [regulatory] effort was needed for oversight because it was more difficult to measure and guarantee quality due to the fact that institutions are easier to visit. Ms. Richardson responded “, . . . it is the state's survey agencies that, who actually do these surveys and certifications of a whole variety of health care provider organizations . . . ” (U.S. Congress. House. 1998, March 12, HR 2020 Hearing) but did not address the question of a need for more regulatory effort for home health care to provide quality assurance.

Rep Greenwood questioned the need to require state Medicaid waivers and suggested that devolution to the states might be more appropriate:

39 states have waivers . . . why don't we get over the notion of us here at Washington granting waivers to states and just say look, let's give you carte blanche

to do this yourselves. And trust them to run these programs without having to run to Uncle Sam and beg permission to do it and show that they do it well (Applause)

Ms. Richardson: Well, that would take a legislative...

Rep. Greenwood: Yeah, we know that, that's what we are. (Laughter.)

Ms. Richardson: . . . what we're finding is that the states, while they like the freedom and flexibility of the State Plan Amendment options, they are still wanting to use the waivers as well (U.S. Congress. House. 1998, March 12, HR 2020 Hearing).

Several ADAPT advocates and Congressional supporters of ADAPT testified in support of *HR 2020*. Rep. Stupak pointed out that due to changes in the Balanced Budget Act, some providers were now claiming that they may no longer serve recipients who received home aid services through Medicare. “These individuals who have received home aid services are very afraid they will be placed in nursing homes”(U.S. Congress. House. 1998, March 12, HR 2020 Hearing). Rep. Lazio (R-NY) challenged the committee to recommit to the “empowerment model” by authorizing “whatever program we have to unleash the shackles, to break out of the mold of warehousing, to insure that we move away from the custodial model . . .”(U.S. Congress. House. 1998, March 12, HR 2020 Hearing). Rep. Degette (D-CO) called for government intervention for the “millions of thousands of people who are still locked up in institutions without due process of law” (U.S. Congress. House. 1998, March 12, HR 2020 Hearing). A representative, unidentified in the testimony transcript, complained that as the sponsor of the bill, Gingrich testified like a “sort of knight in shining armor about how great *2020* is . . . and then played one group off of another” (U.S. Congress. House. 1998, March 12, HR 2020 Hearing). . . Mike Auberger, a national organizer for ADAPT, testified:

. . . this bill would begin to really be pulling people in the direction of community based services instead of institutions. We have got states out there that have been doing this for 16 years, and doing it right (U.S. Congress. House. 1998, March 12, HR 2020 Hearing).

Rep. Bilirakis (R-FL): Is that how many more years are we going to be studying this while people don't have a choice, and dying in institutions unneedlessly (U.S. Congress. House. 1998, March 12, HR 2020 Hearing)

Mr. Auberger:...we need some kind of intelligent long term care system to deal with the issues...until that happens we will be pitted against each other...we need to start somewhere to change this bias from institution to community . . . (U.S. Congress. House. 1998, March 12, HR 2020 Hearing).

Analysis of *HR 2020* CASA Bill:

My analysis of *HR 2020* is based on a set of five minimum requirements for responsible personal attendant care legislation. The concerns repeatedly stated in organizational literature, advocate agendas and Congressional hearings by the advocates for individuals with severe and non-severe disabilities demonstrate that there are five minimum requirements by which one could judge *HR 2020*. The five minimum requirements are eligibility, choice, fiscal considerations, quality assurance and consumer input.

Eligibility:

HR 2020 does not provide additional services to all persons with disabilities. Those persons with profound cognitive disabilities and/or severe medical needs requiring daily, skilled nursing services are small subsets of the developmentally disabled population. Their needs are generally addressed through ICF-MR and nursing facility services. Most of the people represented by ADAPT, UCPA, and other advocates for the able disabled do

not have daily skilled medical care needs and are not severely cognitively impaired. *HR 2020*, which purports to legislate services for all persons with disabilities, fails to recognize legitimate differences in ability or support requirements among the various disabled populations. If community-based services are to be successfully tailored to meet the needs of all persons with disabilities, differences in related conditions and service needs (which may be outside of the scope of personal attendant services) must be recognized.

Eligible recipient subset populations must not be isolated from needed supports. Rep. Bilirakis poses the emotionally charged question in the *HR 2020* committee hearing testimony of "...how many more years are we going to be studying this while people don't have a choice, and [are] dying in institutions needlessly?" (U.S. Congress. House. 1998, March 12, *HR 2020* Hearing). The fact of the matter is that living in an institution, in and of itself, does not result in needless death any more than living at home or the community can prolong life. It is also a matter of fact that many people are in nursing facility institutions because they have serious, progressive medical impairments and they are dying.

HR 2020, as a mandated program, does not allow for limitation of program participants. "As written, eligibility includes individuals receiving care in ICFs-MR (129,449) or nursing facilities (1,028,842); individuals receiving HCBS waiver services (190,000); individuals waiting for HCBS (number is unknown) or ICF-MR placements (200,000), or nursing facility placements (number is unknown); and eligible individuals who have never applied for any services, but would be induced to do so" (ADAPT, 1998, MiCASA Hearing) when the new entitlement program becomes available.

Choice:

HR 2020 exhibits a bias against institutional care settings for severely disabled persons. The bill is openly biased against institutional settings and implies, if it does not forthrightly state, that all residents of ICFs-MR or nursing facilities want to leave those settings. The Medicaid HCBS waiver already provides this option, however, most of these individuals and their families have not opted to leave the institutional setting (ADAPT, 1998, MiCASA Hearing, p.8). Transfer grants are made available by *HR 2020* to states that establish specific action steps and timetables to increase the proportion of long-term care HCBS. States must include aggressive downsizing, with a goal of eventual elimination, of supports and services in institutional settings (U.S. Congress. House. 1997, Bill Text). It is likely that due to *HR 2020's* implementation cost, ICFs-MR, nursing facility, and waiver options will be incrementally abolished. Choice of service settings for the severely disabled population would be severely diminished and ultimately eliminated. Elimination of supports and services in an institutional setting also eliminates the choice of an institutional setting. The result of *HR 2020* would be to impose the personal attendant care model on all disabled people without regard to professional advice or the individual's personal choice. The legislation does not provide for service need differences for this subset population. 80 percent of ICFs-MR residents have profound mental limitations, and related medical and/or behavioral conditions, and the vast majority of nursing facility residents need daily skilled nursing care. Without support services for the severely medically involved and retarded disabled population, the severely disabled could not

choose HCBS without isolating themselves from needed services. Continuity of services is critical to ensure quality of life for individuals with daily skilled nursing care needs and/or severe mental impairment.

Quality Assurance:

HR 2020 lacks basic quality assurance and adequate safeguards. The bill only provides for a plan to develop a plan at some unspecified future date. The bill allows for a delivery model that includes direct cash payment or a fiscal agent to assist in obtaining services. Past Medicaid and Medicare practice with this model has shown it to be highly susceptible to fraud and abuse.

As written, the bill disregards medical need, age, and disability as a basis for eligibility. Of critical importance, this legislation allows for Medicaid payment for health-related tasks to be assigned, delegated, or provided by unlicensed or non-certified attendants without requiring oversight. Even a minimum requirement that attendants be CPR-certified is omitted. Without required oversight, non-certified and unlicensed attendants caring for severely medically involved beneficiaries is a potentially deadly combination. Many severely disabled individuals are unable to communicate pain or illness symptoms. Their condition fluctuates frequently and often suddenly. Oversight in the context of a nursing facility annual survey, which assures compliance with nursing facility regulations, generally includes a nutritionist, pharmacist, registered nurse, social worker, and a generalist. While a RN can fulfill the functions of all of these, none of the others can fulfill the RN function. Skilled nursing care oversight assures facility personnel are

qualified and can recognize adverse changes in medical conditions at the onset so the condition can be treated before it becomes serious. Adequate quality assurance mechanisms and qualified oversight of medical and health-related services are unequivocally essential for stabilization and the well-being of severely medically involved disabled individuals.

“With the economy booming and unemployment at a 20-year low, it is harder than ever to recruit and retain quality direct workers,” (Larson, 1997). Beneficiaries must be able to access a pool of properly and adequately trained attendants who are subject to independent monitoring. HR 2020, however, allows program participants to select, interview and hire non-certified, unlicensed personal attendants to provide health related services. A primary reason advocates for the disabled have insisted on inclusion of this provision is that it allows the disabled person to “hire” a family member as their personal attendant. The provision is potentially dangerous for those disabled persons who do not have available family members to act as their attendants and may hire unqualified “outsiders” as their attendants.

HR 2020 needs to include some qualification parameters for home health care providers. The failure of *HR 2020* to include quality assurance mechanisms places eligible beneficiaries at risk. Failure to ensure access to appropriate supports, including skilled medical care, may lead to increased risks of abuse, neglect and mortality for persons with disabilities in the community. “The mortality rate, for individuals with severe cognitive disabilities, is 72% higher in the community settings than in institutions” (Strauss, 1996, p.30). Mortality rate comparison of developmentally disabled, after transfer into

community care, with comparable persons in institutions revealed that, “risk- adjusted mortality rates for movers exceeded institutional rates by 51%, $p < .05$. After removal of cancer deaths in both groups, this increased to 67%” (Strauss, 1995). According to a study by The College of Education and Human Development, University of Minnesota, the high turnover rate in residential support staff has affected service quality and consumer satisfaction for those who receive home health care. The report states:

- Average turnover rates of staff in private community residential settings range from 57% to 71% per year.
- Annually, an estimated 190,000 direct support staff members in the U.S. leave their positions in residential settings alone.
- The turnover in residential support staff, and those experienced in educational, vocational, and health services, has affected the quality of services to citizens with developmental disabilities.
- High turnover rates in residential support staff have affected service quality and decreased productivity and consumer satisfaction.

Uniform quality assurance standards for community-based programs and personal attendant programs do not presently exist (Hewitt, 1997).

There are no provisions or directions to the states on how to provide housing, transportation, or employment for the institutionalized disabled population once they return to the community. Currently, community services are at a premium or non-existent. “The majority of cities currently have a waiting list of 12-24 months for accessible housing”(U.S. Congress.House. 1998, March 12, HR 2020 Hearing).

HR 2020 provides no definition or direction to states regarding The State Plan for implementation. There are no criteria provided for a timetable for compliance, nor for who will establish the determination of functional need for eligibility. There are no criteria stating what services will be available as attendant care services. There are no provisions or directions to the states regarding respite, adult day services, supported employment, or employment transportation. Substantial cost savings under *HR 2020* are anticipated by Congress because it is presumed that many eligible beneficiaries will enter the workforce as a result of the increase in attendant care services. Other services not defined or mandated in *HR 2020* will be essential for this to occur.

HR 2020 allows for eligible beneficiaries to choose to either self-direct services or to choose and appoint an agency to direct services. The bill only provides for “optional training” for those who choose to self-direct, presuming beneficiaries have the adequate skills and knowledge to do so effectively. Training for the self-direction by consumers should be mandatory as a consumer protection mechanism.

Fiscal Considerations:

HR 2020 creates new mandatory entitlements that will impact existing optional programs and escalate Medicaid cost. The CBO estimates the implementation costs to be \$10-20 billion annually, assuming that only two million of the eight million eligible citizens (U.S. Congress. House. 1998, March 12, HR 2020 Hearing) will request services and receive an average of 8 hours of attendant care services per day. The CBO admits that cost estimates for *HR 2020* are likely underestimated (U.S. Congressional Budget Office,

1997, Letter to Speaker). *HR 2020* eligibility is based on ICF-MR and nursing facility eligibility. Many eligible beneficiaries will require 24-hour attendant services. 83 percent of individuals receiving care in ICFs-MR, due to significant physical, mental and behavioral disabilities, require 24-hour support (Strauss, 1996, p.28). Based on figures from the 1997 Census Brief, the CBO estimate may account for as little as 24 percent of the services that will be required by the majority of eligible mentally retarded beneficiaries alone (McNeil, J. M., 1997, *Americans with Disabilities*). Additionally, most nursing facility eligible beneficiaries need 24-hour skilled nursing care or 24-hour attendant services due to physical impairments and/or medical conditions. The CBO estimates only allow for a maximum of 40 hours of attendant care per week. The severely disabled cannot be left unattended for 16 hours a day. The CBO estimate does not include the cost of services for severe skilled medical needs which are more costly than uncertified and unlicensed attendant services.

The high turnover rate of residential support staff has increased administrative and service costs. "The estimated cost in 1993 of recruiting, orienting, training, and supervising replacement staff in residential settings alone was estimated at \$80 to 100 million dollars annually" (Hewitt, 1997).

When questioned about funding sources in the *HR 2020* CASA Hearing, House Speaker Gingrich encouraged the passage and implementation of *HR 2020's* community attendant care programs, yet he had no concrete answer regarding long-term funding. Instead, he suggested vaguely that at some point in the future, "Some place...there is a chance, I think, for us to look to find some more money... *in the long-run*, as we design

the right systems, independent living and *community services will be less expensive than full-time nursing home services*"(U.S. Congress. House. 1998, March 12, HR 2020 Hearing). Advocate and *HR 2020* cosponsors have consistently claimed that community attendant care services are less expensive than current institutional care. However, there is no documentation available at this time that can confirm this claim. In the meantime, passage of *HR 2020* will require federal long-term commitment to substantial additional public funding for this program. Passage of this legislation without verified, committed long-term funding initiatives in place is unconscionable.

The limited reduction in institutional care would be more than offset by the increased demand for new community-based services. A primary problem with controlling implementation costs for *HR 2020* are the provisions that allow a recipient who qualifies for institutional care to choose QHCBS, so long as aggregate federal expenditures for the individual in a fiscal year do not exceed the total that would have been expended in a fiscal year for institutional care for the individual. This limit will be difficult to apply. While the average costs for attendant care services per individual could be less than costs for nursing facilities, many of the eligible beneficiaries for attendant care services would have never entered a nursing facility or ICF-MR. The annual costs of institutional care for such individuals are unknown. Home and community-based waiver services can be limited by states by imposing a waiting list. Nursing facility services are constrained by capacity limitations. Attendant care services under *HR 2020* do not allow for limitation of the number of program participants because the program is mandatory and is not constrained by the number of available providers or facilities. As a result, *HR 2020* is open-ended, with

the states incapable of controlling costs. Due to the cost implications of mandatory entitlements under *HR 2020*, passage of this legislation would necessitate states to transfer public funds from optional state programs. Medicaid-funded services such as ICFs-MR and HCBS Medicaid waiver programs serving those with profound mental retardation and/or severe skilled medical service needs would be jeopardized. Disabled individuals who experience profound mental retardation and/or severe medical impairment represent the populations' most needy. Hence, these are the most costly individuals to serve. To compensate for unlimited program enrollment, states would be forced to reduce services to this sub-population. Isolation from essential services would put individuals in this group at risk of their lives.

Consumer Input:

HR 2020 states that no federal financial participation will be available to a state unless the state establishes and maintains a quality assurance program, after public hearings, that is based on customer satisfaction (U.S. Congress. House. 1997, Bill Text, §2 (a) (2) (ii)). The State Plan is to be developed with participation of the State Independent Living Council, the State Developmental Council and the Council on Aging (U.S. Congress. House. Bill Text, §2 (a) (2) (ii)). There is no direction to the state on policy direction, principles, or specific plan components. No provision has been made for direct consumer participation in the actual development of The State plan. The three councils specified to participate in formulating The State Plan are able disabled advocate councils. There is no direction to the state to include advice from medical or institutional

councils regarding the transition back into the community of institutionalized profoundly mentally retarded and/or severely medically needy beneficiaries. This sub-population is extremely fragile with frequent adverse reactions to changes in their environment. Underrepresentation in this process may put them at serious risk.

CHAPTER 4

CURRENT CONGRESSIONAL ACTIVITY FOR DISABILITY WORK INCENTIVES POLICY

Current Congressional activity for personal attendant services potentially affects the able disabled population in the community and severely disabled population who currently reside in institutions but wish to live in the community. Current Congressional activity for disability work incentives, however, only addresses the policy needs of people with disabilities which live in the community and wish to work. This chapter continues the evaluation of proposed disability policy.

The 1994-1995 Disabilities, Current Population Report, released in August 1997, indicates that among the 145.9 million people 16 to 64 years old, 29,056,330 have a disability; 12,507,300 have a severe disability. Of this population, 17.4 million have a work disability (McNeil, 1997, Census Brief, p.1). Several members of Congress have inquired about the reasons for the gross increase in the working age populations that have disabilities. While a verifiable reason has not yet been presented, it is likely attributable in part, to the broad and generalized line of questioning regarding physical ability limitations in the Census's survey and the expansive scope of impairments and conditions which by definition constitute a disability and/or a work disability.

People are classified as having a work disability if they:

- a) are unable to work or have a limitation in the amount or kind of work;
- b) retired or left a job for health reasons;
- c) were unable to do any kind of work during the survey week due to a long-term physical or mental illness or disability;
- d) did not work during the entire previous year due to illness or disability;
- e) are under the age of 65 and are covered by Medicare;
- f) are under the age of 65 and receive SSI; and
- g) received veteran's disability compensation (U.S. Congress. House. 1998, Bill Summary& Status: HR 3433).

History of Social Security Insurance and Social Security Disability Insurance:

Between 1985 and 1995, the number of working age persons with a disability, aged 24 -65, who participate in Social Security Disability Insurance (SSDI) and/or Social Security Insurance (SSI) increased from 4.0 to 6.6 million and continues to rise sharply (U.S. General Accounting Office, 1995, March, Social Security, p. 97).

SSDI and SSI are administered by the Social Security Administration (SSA) and

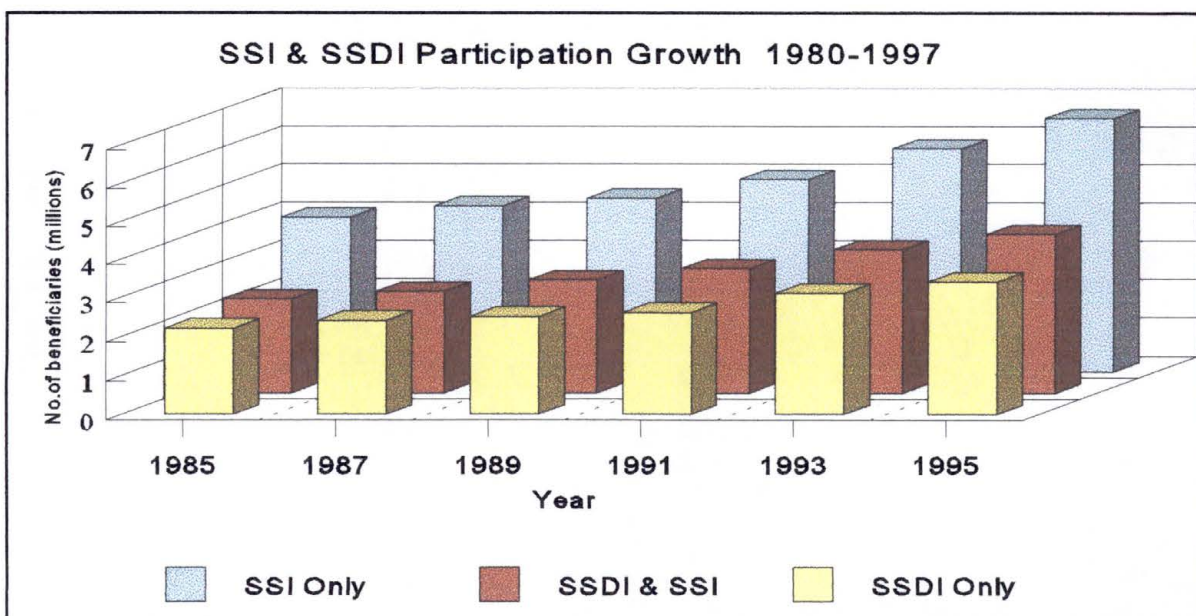


Fig.7 Source: General Accounting Office (1996). Social Security Administration (1996).

the state Disability Determination Service (DDS) offices. SSDI and SSI are the two largest federal cash and medical assistance programs for the disabled populations. Eligibility for either program requires an adult to be unable to work at any substantial gainful activity because of a medically determinable physical or mental impairment. The impairment must be expected to result in death, or has lasted or is expected to last one year or longer. Not only must the impairment be so severe as to prevent the person from performing their previous work, but it must also prevent him or her from doing any other kind of substantial work.

SSDI was established in 1956, and is funded by SS payroll taxes. It benefits those who have worked long enough and recently enough to be eligible and have lost the ability to work. Beneficiaries are not eligible for Medicare until they have received SSDI cash benefits for 24 months. In 1995, approximately 4.2 million beneficiaries, aged 18 to 64, received \$36.6 billion in DI cash benefits. Included in the 4.2 million beneficiaries, are 694,000 people who are low income and dually eligible for SSI disability benefits (U.S. General Accounting Office, 1995, March, Social Security, p. 97).

SSI was established in 1972 to provide income assistance for low income disabled, blind and aged individuals, regardless of their history in the labor force. In 1995, SSI paid \$20.6 billion in benefits to about 2.4 million beneficiaries of all ages, who were disabled and/or blind, excluding those who are dually eligible for SSI and SSDI (U.S. General Accounting Office, 1995, March, Social Security, p. 97).

HR 3433, Ticket to Work and Self-Sufficiency Act of 1998

HR 3433, entitled the *Ticket to Work and Self-Sufficiency Act of 1998*, was sponsored and introduced to the House by the House Ways and Means Social Security Subcommittee Chairman, Jim Bunning (R-KY) in March 1998. The bill was assigned to the House Committee on Ways and Means and House Subcommittee on Social Security (U.S. Congress. House. 1998, Bill Summary & Status: HR 3433). The bill would:

Amend part A, of title XI of the *Social Security Act* (SSA) to establish a Ticket to Work and Self-Sufficiency Program (TWSSP) under which SSI or OASDI programs disabled beneficiaries may use a ticket to work issued by the Commissioner, to obtain employment services, vocational rehabilitation services, or other support services from an employment network of the beneficiary's choice pursuant to an appropriate individual work plan (U.S. Congress. House. 1998, Bill Summary & Status: HR 3433).

HR 3433 is a bipartisan bill that proposes to remove some of the barriers that discourage people with disabilities who receive SSI or SSDI from entering the workforce. The bill provides a "ticket" that can be used to obtain rehabilitation, employment, or other community-based support services from the private and public providers. Currently, Medicare beneficiaries who begin transition into the workforce may retain their Medicare coverage for up to four years. The committee bill provides Medicare health coverage for an additional two years after employment begins (U.S. Congress. House. 1998, Bill Summary & Status: HR 3433).

Under current law, beneficiaries who earn more than the allowed \$500-per-month-income threshold lose their SSDI cash benefits. This bill requires a pilot program to determine the feasibility of a \$1 reduction in SSI payments for every \$2 earned above a

certain level of income instead of the current maximum allowable income cut-off for SSDI benefits. *HR 3433* would eliminate the disincentive for people with disabilities to enter the workforce because they fear losing needed benefits.

Disability advocacy groups were successful in achieving minor clarifications and wording that strengthened consumer choice and consumer rights for people with disabilities of where they receive support services. However, they failed to convince the committee to specify the program as a mandated rather than an optional state program or to include a tax credit up to \$5000 annually for impairment related work expenses (UCPA, 1998, Ticket to Work and Self-Sufficiency Act of 1998, p. 7).

House bill *HR 3433* cleared the House on June 4, 1998, by an impressive Yeas-Nays Vote: 410-1 (U.S. Congress. House. 1998, Bill Summary & Status: HR 3433). “The one dissenting vote was a symbolic protest against the lack of coverage for prescription drugs” (UCPA, 1998, June, Washington Watch, p.6). On June 5, 1998, the bill was received and read in the Senate and placed on the Senate Calendar No. 403 on June 9, 1998 (U.S. Congress. House. 1998, Bill Summary & Status: HR 3433).

S 1858, Work Incentives Improvement Act of 1998

S 1858 was introduced to the Senate in March 1998, by Senator Jeffords (R-VT) as the Work Incentives Improvement Act of 1998 and is the companion Senate bill for HR 3433. The bill has ten cosponsors. It was read twice and assigned to the Senate Finance Committee and the Senate Subcommittee on Social Security and Family Policy on the day it was introduced. The Subcommittee on Social Security of the House Committee on

Ways and Means hearing on S 1858, entitled *Barriers Preventing Social Security Disability Recipients from Returning to Work* was held on July 29, 1997. There has been no further action by Congress on this bill (U.S. Congress. Senate. 1997, Bill Text: S 1858).

S 1858 Hearing, July 1997:

The statement of Jane Ross, Director, Income Security Issues, Health, Education and Human Services, GAO:

Each week, the Social Security Administration (SSA) pays over \$1 billion in cash payments to SSDI and SSI beneficiaries. Fewer than 1 percent of SSDI beneficiaries, and few SSI beneficiaries, leave the rolls to return to work each year. Relatively small improvements in return-to-work outcomes offer the potential for significant savings in program outlays. If an additional 1 percent of the 6.6 million working-age SSI and SSDI beneficiaries were to leave SSA's disability rolls by returning to work, lifetime cash benefits would be reduced by an estimated \$3 billion (U.S. Congress. Senate. 1997, July 29, S 1858 Hearing, Ross, p.1).

Ross states that research by Health, Education & Human Services, GAO, demonstrates that redesigning disability programs will require a multi-faceted approach that includes earlier intervention, return-to-work supports and assistance, and benefits to encourage beneficiaries to return to work. Efforts to estimate the net effect on caseloads and taxpayer costs are done so with a high degree of uncertainty because measures of changes in work incentives and return-to-work rates are unknown (U.S. Congress. Senate. 1997, July 29, S 1858 Hearing, Ross, p.1). Ross's testimony focuses on "trade-offs" involved in the redesign of disability programs. In the testimony, she strongly advises the testing and evaluating alternatives for best practice strategies to develop the work potential of beneficiaries without jeopardizing benefits for those who cannot work (U.S.

Congress. Senate. 1997, July 29, S 1858 Hearing, Ross, p.3).

The GAO proposes an SSI vocational rehabilitation system that emphasizes provider choice. The proposed plan calls for SSA to develop a comprehensive, integrated return-to-work strategy that includes:

- earlier intervention,
- structuring benefits in such a way that encourages the recipient to return to work,
- provision of return-to-work supports and assistance,
- simplification of rules to promote understanding by both the provider and the recipients,
- testing of various different types of vocational rehabilitation service delivery systems by SSA for outcomes,
- a work incentive program that allow for provider payment for both beneficiary achievement milestones and outcome,
- a work incentive program that allows the recipient to participate in both full-time and part-time employment, and
- provides sufficient work incentives to overcome the prospect of a reduction in income for those employed in low-wage work (U.S. Congress.

Senate. 1997, July 29, S 1858 Hearing, Ross, p.2-5).

SSA needs to develop strategies to intervene earlier in the application process to help applicants better assess their ability to remain in the workplace and perhaps postpone their application for benefits (U.S. Congress. Senate. 1997, July 29, S 1858 Hearing,

Ross, p.2). Even part time work could reduce their dependence on benefits.

Vocational rehabilitation services can promote independence by improving the beneficiary's marketable skills. "By returning to work, a beneficiary trades guaranteed monthly income and premium-free medical coverage for the uncertainties of employment" (U.S. Congress. Senate. 1997, July 29, S 1858 Hearing, Ross, p.3). Work incentives such as retaining access to medical coverage and a portion of the cash benefits will make return to the workforce more financially attractive (U.S. Congress. Senate. 1997, July 29, S 1858 Hearing, Ross, p.3).

The work incentive program's rules for SSDI and SSI differ significantly. First, SSDI cash benefits end after a certain period of time if the beneficiary's earnings exceed \$500 per month (U.S. Congress. Senate. 1997, July 29, S 1858 Hearing, Ross, p.3). If SSI cash benefits are reduced gradually, \$1 for every \$2 the beneficiary earns, the transition back to work will be easier. Secondly, SSDI and SSI rules also differ in respect to health care insurance coverage. DI beneficiaries can purchase Medicare coverage after premium-free coverage ends, although it may prove to be too expensive for low-wage earners. On the other hand, SSI beneficiaries lose Medicaid and cannot purchase coverage once they reach a certain level of income (U.S. Congress. Senate. 1997, July 29, S 1858 Hearing, Ross, p.3).

Even though changes in the work incentive program may produce an increase in the number of beneficiaries that return to work, a net increase in beneficiary work effort may not be realized. Allowing beneficiaries to retain more of their earnings will make the program more generous and may cause those who are not currently program participants

to enter the program for the first time. The total work effort may be decreased by those who reduce work effort in order to become eligible for the program. Additionally, improving work incentives and allowing beneficiaries to keep more earnings could cause some, who may otherwise have left, to remain in the program. How much program entries and exits occur will determine how much the program will cost to implement and maintain (U.S. Congress. Senate. 1997, July 29, S 1858 Hearing, Ross, p.7).

The statement of Richard C. Baron, Director of the Matrix Research Institute and Training Center on Vocational Rehabilitation Services for Persons with Mental Illness on Behalf of the International Association of Psycho-social Rehabilitation Services (U.S. Congress. Senate. 1997, July 29, S 1858 Hearing, Baron):

The largest group of SSA recipients, who rely on both DI and SSDI for cash assistance and medical coverage, are individuals who experience a serious mental illness. 90 percent of this sub-population is unemployed and, is most likely to remain unemployed and on the rolls for their entire adult lives (U.S. Congress. Senate. 1997, July 29, S 1858 Hearing, Baron, p. 1) While symptoms of serious mental illnesses are a definite barrier to effective job performance, a number of transition and rehabilitation programs have proven to be dramatically effective in helping this sub-population return to work. Unfortunately, these programs are scarce.

The focus of current public policy is “getting people off the SSA rolls.” “What we need instead is a new legislation focus that encourages more people to work at their individual capacity as frequently and as often as they can, even if that employment is less than full-time or is only intermittent” (U.S. Congress. Senate. 1997, July 29, S 1858 Hearing, Baron, p. 1). Legislation needs to address both those who can return to work

full-time and those who are only capable of maintaining intermittent or part-time employment.

The current work incentive provisions are largely misunderstood by provider professionals and underutilized by most consumers. “Any future changes to incentives must be accompanied by a financial commitment to provide expertise, at the local level, that consumers need to manage these complicated systems” (U.S. Congress. Senate. 1997, July 29, S 1858 Hearing, Baron, p. 2).

The statement of Virginia P. Reno, Director of Research, National Academy of Social Insurance (U.S. Congress. Senate. 1997, July 29, S 1858 Hearing, Reno):

The Panel was asked to answer to three basic questions:

- 1) Do disability cash benefits provide a strong deterrent to Work?
- 2) Can an emphasis on rehabilitation be built into the SSDI program without greatly expanding costs or weakening the right to benefits?
- 3) Are there ways to restructure disability income policy to better promote work?

The short answers are no, yes and yes. The reasons for these answers and the Panel’s recommendations follow (U.S. Congress. Senate. 1997, July 29, S 1858 Hearing, Reno, p.2).

The Panel determined that current benefits are not a strong deterrent for disabled individuals to work. The SSDI and SSI programs use the strictest test for disability than any other public or private disability programs in the United States. SSDI benefits require a 5-month waiting period from the onset of disability before benefits are paid. Beneficiaries must wait an additional 24-month waiting period before qualifying for Medicare coverage. Almost all U.S. private systems assure short-term benefits before long-term benefits are paid, and pay health care cost before and after disability. SSDI

replacement rate benefits are modest. SSDI pays replacement rates ranging from 43 percent for incomes of \$25,000 to about 26 percent for incomes of \$60,000. Incomes below \$25,000 are paid at a 50 percent replacement rate, but are still below the poverty threshold (U.S. Congress. Senate. 1997, July 29, S 1858 Hearing, Reno, p. 3).

SSI benefits are even more modest and are paid by the same strict test of disability as SSDI benefit requirements. In 1997, the maximum federal SSI benefit is \$484 a month, or 70 percent of the poverty level. While some states opt to supplement the federal benefits, total benefits remain below the poverty level and do not serve as a strong deterrent for an individual who is capable of re-entering the workforce and earning living wages (U.S. Congress. Senate. 1997, July 29, S 1858 Hearing, Reno, p. 3).

The replacement rates for SS are also modest and reflect the expectation that the beneficiary will supplement his or her income with pensions or savings. However, because disability erodes savings and interrupts pension and savings plans, disabled workers have significantly smaller asset holdings than do retirees (U.S. Congress. Senate. 1997, July 29, S 1858 Hearing, Reno, p. 3).

Constraints on access to health care, however, can be a significant deterrent to work for the disabled (U.S. Congress. Senate. 1997, July 29, S 1858 Hearing, Reno, p. 4). The subset of the disabled population that has a chronic health condition frequently cannot secure health care coverage in the private insurance market. Those who do, often do not have sufficient coverage for the range of services or long-term supports they need to live independently. In 1988, the number of uninsured for working-aged populations, including the disabled was 2.3 million; in 1993, this number had increased to 2.9 million (U.S.

Congress. Senate. 1997, July 29, S 1858 Hearing, Reno, p. 4). For members of the disabled population who have chronic health conditions, Medicare and Medicaid are crucial supports.

The Panel Determined that emphasis on rehabilitation can be built into the SSDI program without greatly expanding costs or weakening the right to benefits. The Panel concluded that a “radical” new market approach, incorporating beneficiary choice, innovation, and payment for outcome for rehabilitation services, will achieve the desired return-to-work results while controlling for cost. Beneficiaries will receive a Return-To-Work (RTW) ticket that they can use for rehabilitation or RTW services from either private or public providers. Once a provider accepts the ticket from the beneficiary, SSA is obligated to pay the provider. The provider, however, is only paid after the beneficiary returns to work and has left the benefit rolls. Each year, the provider receives a fraction of the benefit savings that accrue to the SS trust funds because the provider’s client is now working and no longer receiving SSA benefits (U.S. Congress. Senate. 1997, July 29, S 1858 Hearing, Reno, p. 4).

The Panel recommends restructuring disability income policy with wage subsidies and personal assistance tax credits, and improving how existing work incentives are implemented, to encourage beneficiaries to return to work. First, a wage subsidy for low-income disabled workers will be provided in the form of a Disabled Worker Tax Credit (DWTC). “It would be paid to low-income persons, not because they are unable to work, but because they work despite their impairments” (U.S. Congress. Senate. 1997, July 29, S 1858 Hearing, Reno, p. 5). The DWTC targets three populations: 1) the older worker

who works fewer hours or for lower wages due to progressive impairments, 2) young developmentally disabled individuals entering the workforce, and 3) disabled individuals who return to work and leave the SSI or SSDI rolls. “The wage subsidy would ease the ‘income cliff’ that SSDI beneficiaries now face” (U.S. Congress. Senate. 1997, July 29, S 1858 Hearing, Reno, p. 5). Secondly, a personal assistance tax credit will be provided to compensate for a portion of the cost of personal assistance services which are needed in order to be able to work. Disabled workers who are able to work in the competitive market successfully are usually disqualified from receiving publicly funded services but do not make enough to pay for needed services on their own (U.S. Congress. Senate. 1997, July 29, S 1858 Hearing, Reno, p. 5).

The Panel suggested two ways to improve the implementation of existing work incentives: 1) Work incentive programs are complex and beneficiaries who return to work need assistance in understanding and complying with the rules. Service providers need to understand the rules and, as part of their program’s service obligations, be able to assist clients in understanding and complying with the rules. 2) The SSA needs to restructure the administration process so that earnings reports and benefits are promptly adjusted as the beneficiaries circumstances change. The Panel concluded “that disability income policy must strive for balance—between improving secure and dignified income benefits to those who are unable to work . . . while providing realistic opportunities and supports for those who have the capacity to work” (U.S. Congress. Senate. 1997, July 29, S 1858 Hearing, Reno, p. 5).

Analysis of *S 1858*, Work Incentives Bill:

My analysis of *S 1858* concludes that the bill presents a constructive and creative effort by Congress to control and reduce SSA entitlement program expenditures while attempting to satisfy disability advocates' demands. *S. 1858* is attractive to Congress because it is perceived as a way to reduce SSA beneficiary rolls and program expenditures and control for program cost through provider payment methods without reducing access to services. Most disability advocates are attracted to the bill because it increases the disposable income for beneficiaries while increasing employability and acquisition of appropriate job placements. However, in my opinion, there are several inherent problems in the bill which must be resolved before passage, through careful analysis and application of implementation best practices, if the expected outcome is to be achieved.

Of the 17.4 million people who have a work disability. Only 33.1 percent (5.7 million) of the population with a work disability is in the labor force, and the unemployment rate among those in the labor force is 13.6 percent. In contrast, of the 153.2 million people with no work disability, 81.9 percent (125.5 million) are in the labor force, and the unemployment rate for this subset population is only 5.3 percent (McNeil, 1997, *Americans with Disabilities*).

Employment Status for Those With and Without a Work Disability

	Work Disability		No Work Disability	
	Number	% of Total	Number	% of Total
Not in labor force	11,655,318	66.9%	27,732,096	18.1%
In labor force	5,766,682	33.1%	125,483,904	81.9%
Employed	4,982,692	28.6%	11,895,561	77.6%
Unemployed	783,990	4.5%	6,588,288	4.3%
Total	17,422,000	100%	153,216,000	100%
Unemployment Rate		13.6%		5.3%

Fig. 8 Source: U.S. Bureau of the Census Website, Table 297.
Survey: CPS 1997. (<http://www.census.gov/hhes/www/disable/cps>).

There is often an erosion of motivation to work during the lengthy disability determination and application process. When applying for SSA entitlements, the application process requires an applicant to emphasize his or her inability to work due to impairment (Ross, 1998, p.2). SSA needs to address the issue of the applicant's

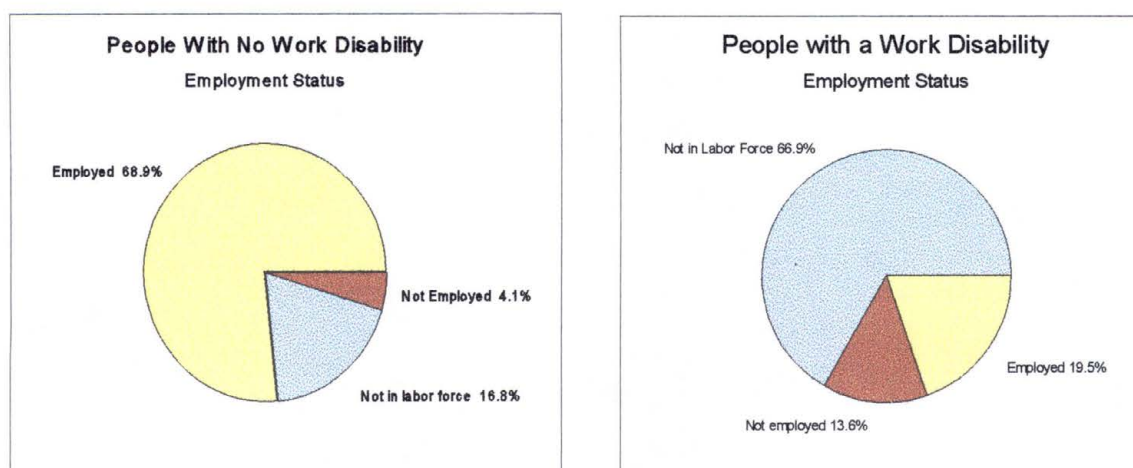


Fig. 9

employability and referral to the return-to-work incentive program from the onset of the disability. Earlier dependency intervention in the initial application process will encourage the applicant to retain or regain employment.

S. 1858 attempts to design work incentives that will encourage the disabled to return to work and become independent and restricted provider payment methods that will increase the providers' incentive to place the client in a position as quickly as possible. In the present system, there is no assurance that training in a vocational rehabilitation center will actually result in a job.

Based on the 1994 Harris survey information (Fig. 10), vocational rehabilitation centers have not been assertive in finding job placements for clients. SSA does not appear to aggressively monitored state vocational rehabilitation providers' progress of an individual's employment placement. Fewer than 1 percent of SSDI beneficiaries leave the rolls each year because they have returned to work, those who do are primarily nonsevere disabled persons (U.S. Congress. Senate. 1997, July 29, S 1858 Hearing, Ross, p.1).

There are three nonseverely disabled people employed for every employed person with a severe disability (McNeil, 1997, Census Brief, p. 2). SSA needs to restructure oversight of the work incentive program to include actively monitoring the providers' progress of employment placements.

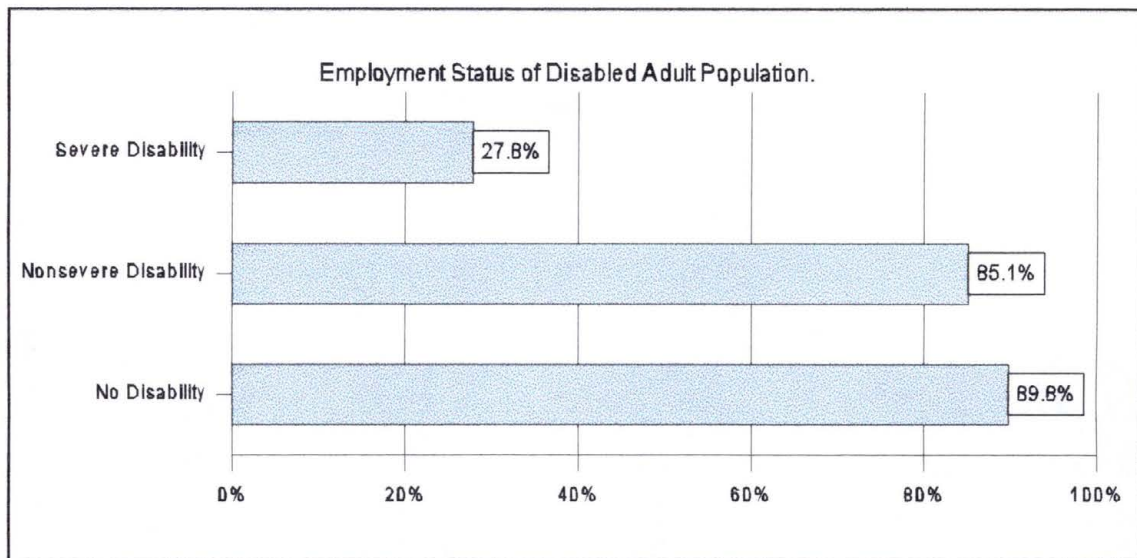


Fig. 10 Source: McNeil, 1997, Americans with Disabilities: 1994-95
Survey: SIPP, 1994-95

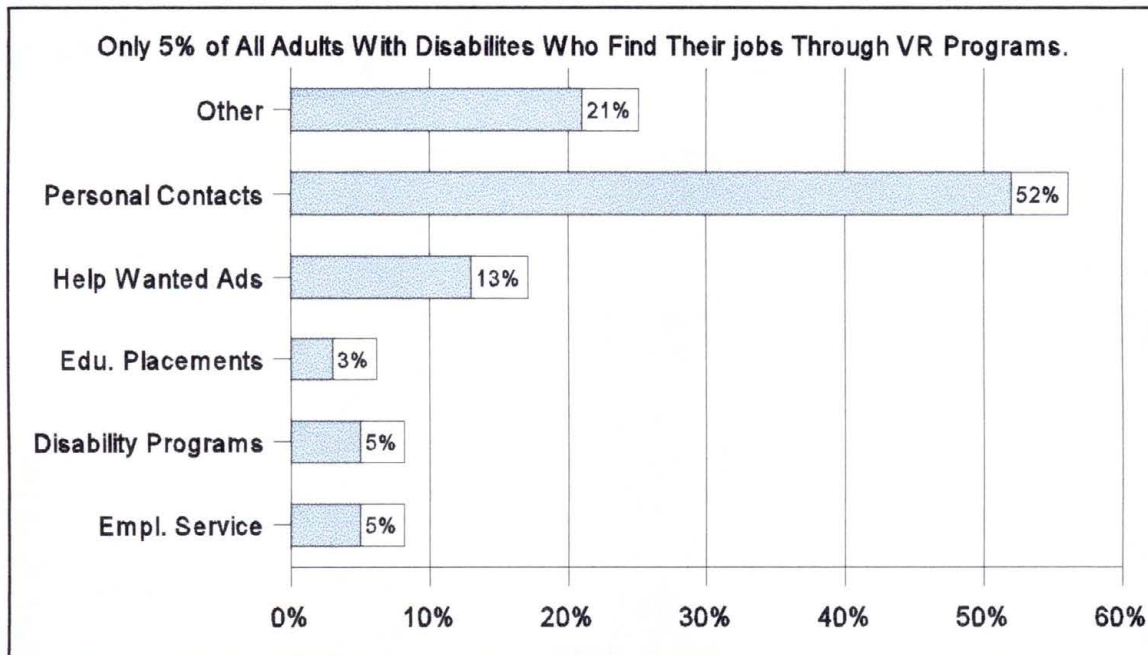


Fig. 11 Source: NOD/Harris Survey of Americans with Disabilities (1994).
Survey: Louis Harris and Associates, Inc.

The attempt by rehabilitation professionals to determine at the outset which beneficiaries have a capacity for employment and which do not, will result in initially eliminating all but the highest functioning beneficiaries. It is not clear that vocational rehabilitation providers who may create a work incentive training program, as a result of this legislation, will have the skills or tools available to accurately make that determination. Providers must receive sufficient training by SSA in program rules and the client evaluation process.

New approaches should encourage each client to achieve his or her personal employment potential. There are many individuals with disabilities in the community who are capable of successfully working in a part-time position but are not capable of working full-time. Work incentive policy that concentrates only on a limited number of select people who have the capacity to return to full-time jobs may eliminate program participation by the majority of beneficiaries. SSI savings to the government are realized even if the beneficiary only works part time. An increase in SSI savings and an increase in employment for the disabled could be realized by assuring the program is open to both full-time and part-time employable beneficiaries.

Policy rules concerning SSI and SSDI entitlements need to be adjusted so that SSI and SSDI entitlements are treated in the same manner. SSDI beneficiaries can purchase Medicare coverage after premium-free coverage ends. An SSI beneficiary will lose Medicaid, with no provision to allow purchase of further coverage, once he or she exceeds a \$500 per month level of income. Buy-in coverage protection needs to be provided to both classes of beneficiaries. The potential loss of Medicaid coverage will

serve as a disincentive to returning to work for SSI beneficiaries.

S 1858 authorizes a demonstration to explore the feasibility of decreasing SSI benefits \$1 for every \$2 earned by the beneficiary. SSI savings to the government are realized even if the beneficiary only works part time because entitlement payments are offset by an incremental reduction as the beneficiary's income increases. SSDI beneficiaries do not yield program savings unless they leave the rolls because their benefits are not offset. Provisions which also allow SSDI benefits to incrementally decrease as the beneficiary's income increases will provide additional government program savings from offset benefits. Abruptly stopping SSDI benefits at a \$500 a monthly income level creates an "income cliff" and a work disincentive for SSDI beneficiaries. The "income cliff" can be avoided and the transition into the workforce will be eased if both SSDI and SSI benefits are gradually reduced.

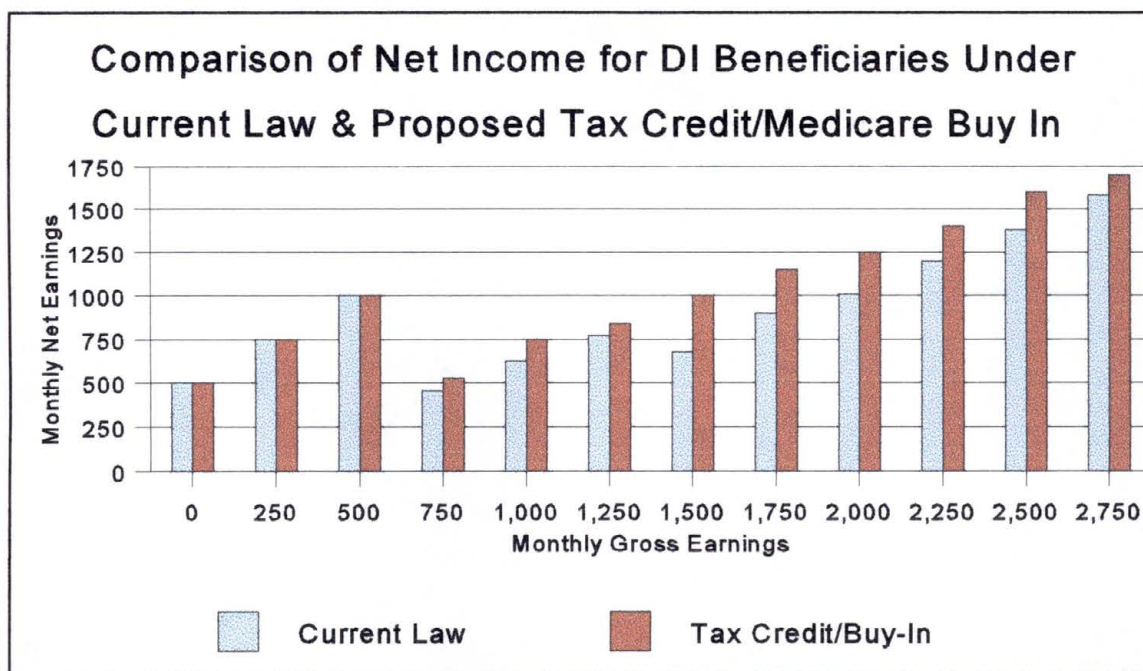


Fig. 12 Source: Employment Support Institute, Virginia Commonwealth University.

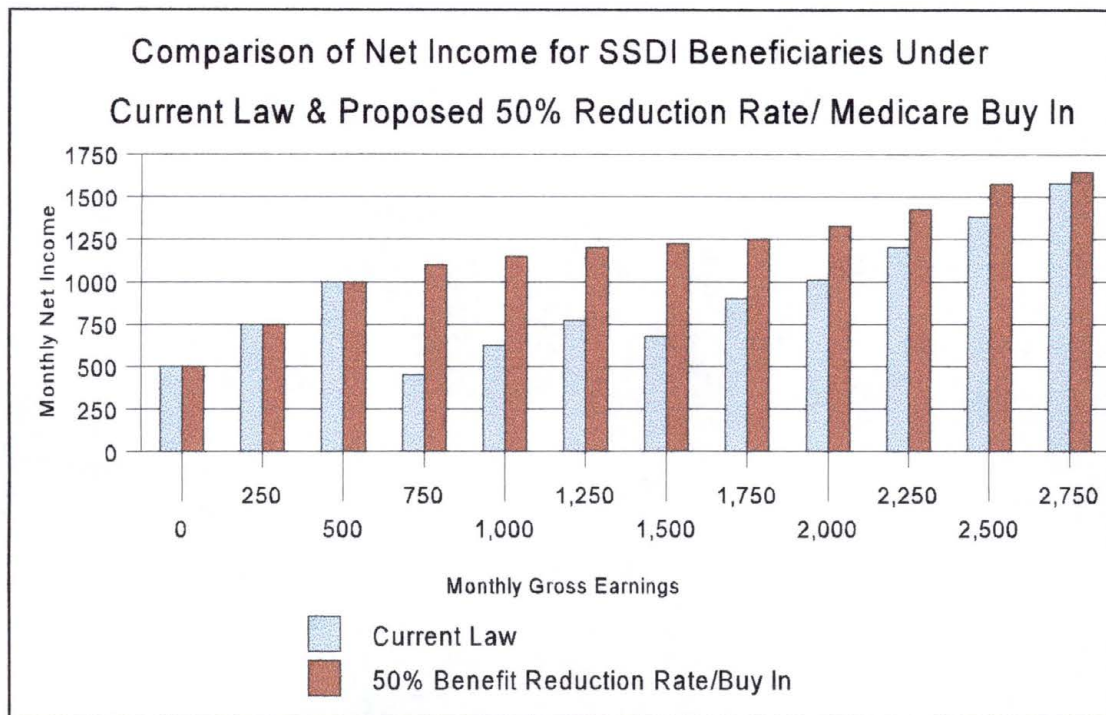


Fig. 13 Source: Employment Support Institute, Virginia Commonwealth University

S 1858 actually creates a barrier by assuming that the vocational rehabilitation is a straight line process. Many beneficiaries will attempt to return to work and fail, possibly repeatedly. Care must be taken to ensure that *S. 1858* does not offer a one-point-in-time opportunity to reenter the workforce or impose arbitrary time limits on beneficiaries. A provision for automatic re-entitlement of benefits for program beneficiaries that fail to remain in the workforce will prevent the need for program participants to reapply and reduce program administration cost. The program must be structured in a way that does not discourage beneficiaries from attempting to re-enter the workplace. Notwithstanding, the program must also be structured to not encourage benefit dependency for those who are capable of re-entering and remaining in the workplace. The evaluation process should include identifiers that will distinguish this sub-group of program participants. The work

incentive program should include safeguards that would prevent this sub-group from unnecessary benefit dependency. “Current law provision that imposes benefit deductions for refusal to accept vocational rehabilitation services is repealed upon enactment” (UCPA, 1998, May 26, Washington Watch, p.4). Repeal of benefit deductions for refusal to accept vocational rehabilitation services should be reserved for those who are determined in the evaluation process to be incapable of achieving and retaining work, due to impairments. To include those who are capable of working encourages unnecessary benefit dependency.

As written, the S 1858 work incentive program could potentially become an open-ended program because beneficiary program participation is entirely optional. Beneficiaries, who are capable of working, may stay in the program for long periods of time without achieving and retaining full-time employment or decrease work effort in order to qualify for the program and take advantage of new incentives that allow a higher retention of benefits. “Current law provision that authorizes priority referral of recipients by SSA to state vocational rehabilitation agencies will be repealed on a gradual basis as states are phased into the new program”(UCPA, 1998, May 26, Washington Watch, p.4). Repeal of priority referral entirely will decrease the potential for program savings. Rather than repeal the practice of priority referral of recipients to state vocational rehabilitation agencies, the provision should be amended to include priority referrals to the entire provider network for those who are determined to be capable sustaining full-time or part-time work. The program is open to all SSI and SSDI beneficiaries as well as all as those who are not currently in the program. A possible unintended consequence of S 1858 is

that it may actually encourage many to reduce work effort in order to qualify for the program and retain an increased amount of benefits. Additionally, in order to retain an increased portion of the benefits, many may choose to remain in the program instead of entering the work force.

Of primary concern, is *S 1858*'s restricted provider payment methods. *S 1858* allows State vocational agencies which do not choose to participate in the new program to continue to be reimbursed under the current rule of provider payment after the recipient completes nine months of gainful employment. For providers who choose to participate in the new program, as written, *S 1858* authorizes SSA is to provide payment to providers under one of two payment systems: an outcome payment system; or an outcome-milestone payment system. Providers who choose the outcome payment method system receive 40 percent of the average disability benefit for each month the recipient does not receive a benefit payment due to work activity, not to exceed sixty months. Providers who choose the outcome-milestone payment method receive payment based on a combination of: 1) achieving one or more "milestones" (undefined) directed toward the beneficiary achieving permanent employment; and 2) payment of 40 percent of the average disability benefit for each month the recipient does not receive a benefit payment due to work activity, not to exceed sixty months.

The restricted provider payment provision is intended to act as a program cost control mechanism whereby providers only receive payments based on results. The intention of the restriction is to provide incentive for providers to both adequately train and engage the beneficiary in permanent gainful employment as quickly as possible. The

practice of setting operational policy in such a way that allows service to the higher functioning, less impaired members of a population and/or provide a less intensive service package, while declining to service the more severely disabled population members is known in the industry as “cherry picking.” The operational policy allows programs or facilities “pick” the “best” residents, through the use of restrictive admissions criteria or an evaluation process, whose disabilities or impairments are less involved and less costly to service. This system not only encourages, but virtually requires providers to engage in “cherry picking” of the clients served. Providers will serve only those beneficiaries who are higher functioning and represent the “best bet” for achieving gainful employment. As written, *S. 1858* will only benefit the able disabled who are capable of achieving and retaining long-term, full-time employment. Those with severe physical limitations, acute medical needs, profound mental retardation, or severe mental illnesses will likely be turned away due to provider limitation of the number of beneficiaries who can be served or placed on interminable waiting lists for services. Excluded from the program will be those who complete training and return to the workforce but cannot or do not retain employment long-term. Additionally, only providers who accept tickets for vocational rehabilitation services from “best bet” candidates will benefit from participation in the program. Payment is based on benefits no longer received by the beneficiary due to employment. Provisions for intermittent provider payment based on pre-determined milestones or other service provision criterion must be included in order to retain private provider participation. Otherwise, the program will not be beneficial to private providers and those who cannot make a profit or recuperate spent resources will discontinue

program participation. If this occurs, provider choice provision in *S 1859* will become null with only state agencies providing rehabilitation/work incentive services, as is presently the case. Additionally, *S 1859*'s provision of optional program participation by states could result in the unintended consequence of reducing rather than expanding work incentive services to beneficiaries. As a result, a significant reduction in SSA rolls and a significant increase in program savings would not occur.

The accuracy of any attempt to estimate or project the net program effect on work effort and program cost is highly suspect and uncertain. Information that is not currently available is required to simulate beneficiaries work effort changes, or describe how beneficiaries work efforts change when income levels change, in response to program changes. Information on the number of beneficiaries who will enter the work incentive program as a result of legislation and the number who will leave the program and SSA rolls as a result of employment (enter and exit effects) is unavailable, making accurate estimation of costs of program reforms and estimated program costs impossible to determine with any degree of certainty.

Under current Congressional rules, any bill that cost money must "pay for" itself by either increasing revenues or decreasing expenditures. Congress is not authorized to raise taxes to cover cost created by *S 1858*. While costs for the work incentive program are estimated by the CBO to be approximately 1.9 billion (UCPA, 1998, May 16, Washington Watch, p.5). Memorandum, 1998), accuracy of the estimated cost of the work incentive program is highly suspect and how to pay for costs is problematic. The primary "pay for" provided for in the bill is a provision that requires prisons to report to

SSA when a person who receives SSI or SSDI is incarcerated. Prisoners are not eligible for cash benefits while incarcerated, but few report prison entry to SSA. Savings from discontinuing eligibility of incarcerated beneficiaries will be realized, although the amount that would be saved is unknown. The amount saved in benefits for recipients that return to work is also unknown. *S 1859* authorizes the Director of Social Security to transfer funds from SSA title II, Old Age, Survivors and Disability Insurance (OASDI) and to use appropriations authorized for the SSA under SSA title XVI to fund the work incentive program (U.S. Congress. House. 1998, Bill Summary and Status: HR 3433). The impact of transferring funds from OASDI to pay for *S 1859* on the beneficiaries of programs provided by OASDI is unknown.

CHAPTER 5

HOME AND COMMUNITY- BASED SERVICES

The majority of current disability policy issues, agency research and analysis reports, advocate demands, and Congressional activities center on the issue of home and community-based service for the disabled populations. Many federal agencies have produced dozens of research products concerning home and community-based care which can be used for guidance by Congress in the formulation of policies, states in the development of programs, funding sources, and implementation aspects, and advocates for agenda strategy.

The trend of disability policy is toward changing the service delivery system from an institutionally biased medical-model system to a home and community-based, client-oriented system. Home and community-based services are provided by state agencies through Medicare, SSI, SSDI, Medicaid, Medicaid waivers and federal/state grant funds. For most of the HCBS and programs participation by the states is voluntary. Availability of services and programs vary from state to state. Both federal and state governments are supporting the alternative to nursing homes for residents who require personal care and routine scheduled nursing care by creating home and community-based resident services that are client oriented. States perceive services provided in community-based settings to

be less expensive than those provided in institutional settings. As a result, states are providing assisted living alternatives for non-institutional settings to produce savings as well as in response to lobbyist and advocate demands for community-based services.

Assisted Living

“Assisted living” refers to residential settings for people with disabilities which provide both housing and personal assistant services within a homelike or noninstitutional environment. Unlike nursing facilities which provide 24-hour skilled nursing care, most assisted living facilities only provide scheduled, routine nursing care. The average nursing facility resident needs assistance with 4 of 5 ADLs (AHCA, 1997, *The Looming Crisis: Nursing Facility Residents*).

The typical assisted living resident is an 82-year-old woman who is mobile, but needs assistance with one or two personal activities. . .29 percent are male. (AHCA, 1997, *The Looming Crisis: Assisted Living Resident*).

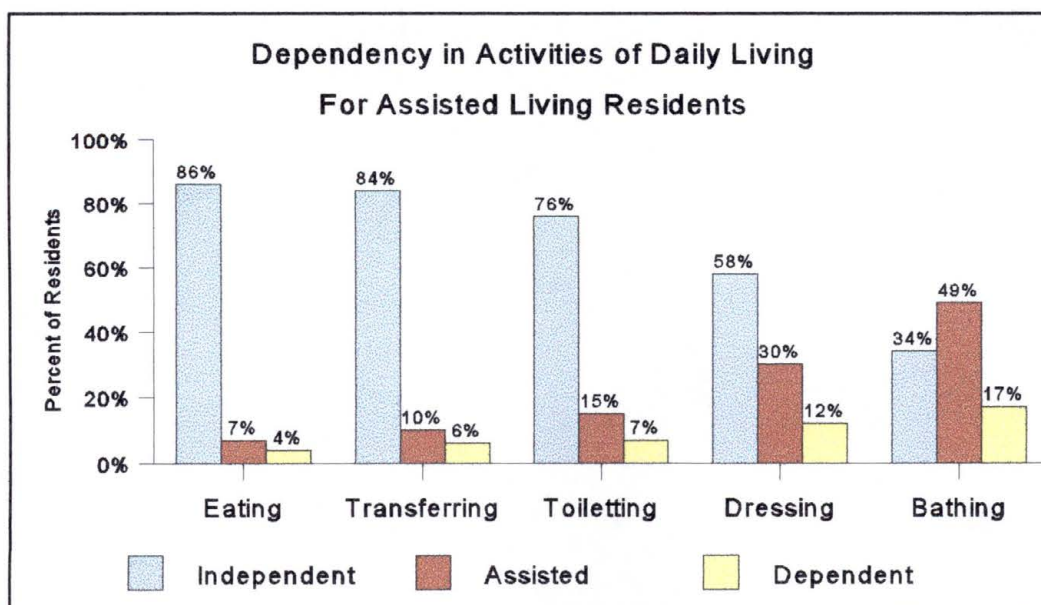


Fig. 14 Source: AHCA, *Survey of Assisted Living Facilities*, 1996.

Steve Mollica, from The Office of Disability, Aging and Long Term Care Policy recently released a study titled *State Assisted Living Policy: 1996* (Mollica, 1996, State Assisted Living Policy: 1996). This study reviewed the assisted living, personal care, and board and cares policies in each of the fifty states. All three categories of community-based residential settings are synonymous in the study. Although there is no common definition for assisted living, state approaches to assisted living policies share common characteristics. Twenty-seven states either do, or plan to, reimburse assisted living as a Medicaid service. Some states that do so, do not have a licensure category for assisted living. Six states provide Medicaid reimbursement specified as board and care services. Twenty-two states either have, or are developing, licensure regulations for assisted living facilities and thirteen states have created a task force for the development of assisted living rules. Policies in fourteen of the twenty-seven states that have assisted living services include “a statement of philosophy that describes assisted living as a model which emphasizes consumer or resident independence, autonomy, dignity, privacy and decision making” (Mollica, 1996, State Assisted Living Policy: 1996, p.1).

These assisted living policies precisely reflect the agenda and demands of the able disabled advocates. Representatives for the able disabled have advocated since the 1980s, and more recently through a nationwide campaign called “No Place Like Home”, for community-based residential services to promote independence, autonomy, dignity and decision-making for the disabled. They argue these benefits cannot be achieved in nursing homes, which they label as inappropriate and unnecessarily restrictive. However, in 1996, only 14% of those moving into assisted living centers came from a nursing facility and

only 59% came from their home (AHCA, 1996, Survey of Assisted Living Facilities).

The fundamental argument of disability advocates is that, compared to the cost of nursing homes, community-based services can be provided for the disabled population at a substantial savings to the state. Costs for assisted living settings vary greatly, depending on the size, location and services offered. According to the AHCA *Survey of Assisted Living Facilities*, in 1996 costs ranged from, \$1000 to \$3000 a month and 90 percent of the facilities were private-pay (AHCA, 1997, *The Looming Crisis: Assisted Living*

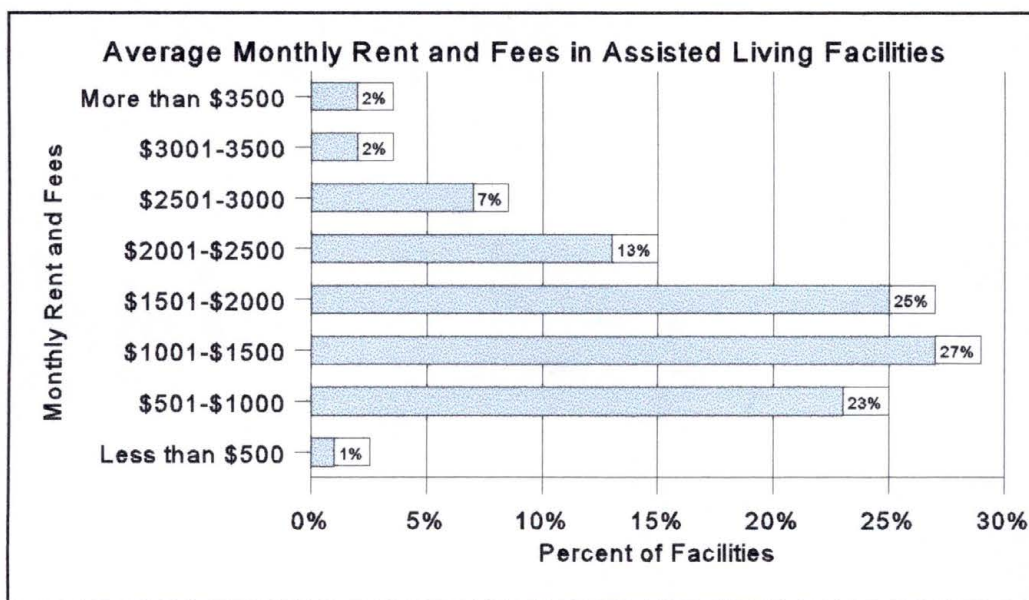


Fig.15 Source: AHCA, Survey of Assisted Living Facilities, 1996.

Resident). Based on the *1990 Census*, 12.7 million disabled individuals (29.7% of all disabled and 5% of entire population) need long-term-care and of those 2.4 million live in institutions (U.S. Department of Commerce Economics and Statistics Administration, 1990, U.S. Census. Disability, Table 3). The 1994-95 Census Brief states there are approximately 9 million individuals whose disability is so severe that they need assistance

with ADLs (McNeil, 1997, Americans with Disabilities: 1994-1995). The acting Deputy Director of the Office of Medicaid Policy testified before the Senate Labor and Human Resources Subcommittee that:

A disproportionate percentage of Medicaid's resources are being absorbed in institutional long-term care. A number of studies documented that at least one-third of those living in Medicaid-funded nursing facilities were capable of living in home or community settings if additional community-based options were provided (U.S. Congress. Senate. 1994, Hearing on Medicaid Home and Community-Based Waivers).

Mollica states in his report that:

In creating a new model, either through licensure or Medicaid, states are supporting an alternative to nursing homes for *elderly* (emphasis added) recipients who need personal care and routine, scheduled nursing services.

In 1993, Medicaid recipients who were disabled made up 5.5 % of the caseload and 37 % of the spending. Elderly recipients accounted for 11.5 % of total recipients and just under 32 % of the spending (Mollica, 1996, State Assisted Living Policy: 1996, p.2).

1993 Medicaid Enrollment and Expenditures		
	<i>% of Caseload</i>	<i>% of Expenditure</i>
<i>Elderly</i>	11.5	32.0
<i>Disabled</i>	5.5	37.0

Fig. 16

In 1993, there were more than twice as many elderly receiving Medicaid benefits than disabled, but the disabled consumed a higher proportion of Medicaid spending than the elderly. While the disabled recipients account for higher total spending, spending per capita was less than for the elderly. The disabled advocates' claim that states will save

1993 Per Capita Medicaid Expenditures for Long Term Care				
	<i>Total</i>	<i>Acute</i>	<i>Nursing</i>	<i>Other</i>
<i>Elderly</i>	\$9300	\$2365	\$5800	\$1135
<i>Disabled</i>	\$7900	\$4500	\$ 924	\$2476

Fig. 17

Medicaid dollars by utilizing community-based services appear only to hold true regarding the elderly population. The disabled recipient utilizes 56.9 percent of Medicaid expenditures per capita on acute care services but only 11.6 percent on nursing facilities. These patterns emphasize the need for states to address long-term care spending for the elderly and acute care spending for disabled recipients to reduce Medicaid spending.

According to the HCFA, 1997 Medicaid Data, Medicaid expenditures are proportionately distributed between

nursing facility and home health care. A “disproportionate percentage” of Medicaid expenditures do go to nursing facilities, however, due to the increase in number of aged in nursing facilities and the increased level of care required by those recipients. It is estimated that one-third of the 2.4 million recipients living

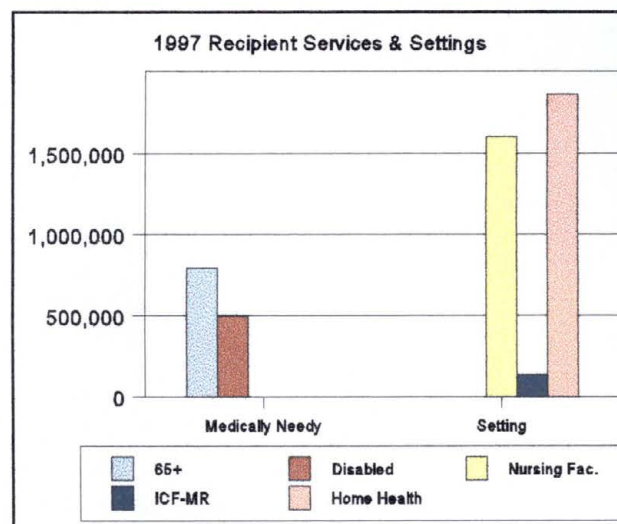


Fig. 18 Source: HCFA, 1997 Medicaid Data.

nursing facilities could be moved to HCBS (U.S.Congress. Senate. 1994, Hearing on Medicaid Home and Community-Based Waivers), this move would result in a change of

service setting for 800,000 recipients. The average cost of nursing facility care is 20-30 thousand dollars a year, which includes nursing care and board. The average cost of Assisted living (averaging \$2000 per month) (AHCA, Survey of Assisted Living Facilities, 1996) plus undetermined health care costs for this subset population would not produce Medicaid cost savings. And, in many cases, could result in increased care cost for beneficiaries.

Notwithstanding, as assisted living options multiply, a challenge facing the federal and state governments, particularly if public funds are used to reimburse cost, is how to regulate such arrangements and balance consumer protection concerns with resident rights for self-direction, taking risks and maintaining accustomed lifestyles. Many of the state policy makers interviewed in Mollica's study discussed the limits of regulations to ensure safety and quality of care (Mollica, 1996, State Assisted Living Policy: 1996). Findings from a study recently released by the Research Triangle Institute indicates that relying on market forces and minimum regulatory standards to produce quality of care may not be a sufficient approach for assisted living facilities. This study found that residents in assisted living settings are presently significantly older and more frail than was true a decade ago, as many are utilizing Medicaid waivers for community-based long-term care. The resident mix of physically frail and cognitively impaired elderly, those who experience mental illness or retardation, and those who have developmental disabilities, presents a complex care giving challenge. The study identified several factors that suggest that appropriate regulations and licensure requirements result in homes that are better prepared to cope with this challenge and provide:

- 1) greater availability of supportive services in licensed homes;
- 2) greater operator training in the care of the elderly and disabled; and
- 3) lower use of psychotropic drugs and medications contraindicated for use in the elderly in homes in extensively regulated states.

Licensed homes were more likely to have in place a wider array of the safety features and supportive devices considered important to the well-being of residents (Hawes, 1995).

The acting Deputy Director of Medicaid Policy testified before the Committee on Labor and Human Resources Subcommittee on Aging that one could not be certain that quality services were being provided by reliance on mechanisms associated with institutional care, such as surveys, facility inspections and state regulations. Whom would one survey? A person being maintained in his or her home may have a variety of both paid and unpaid caregivers during different time frames. Moreover, because the individual has the choice of who provides the care, reliance on the individual to determine quality of care is more practical (U.S. Congress. Senate. 1994, Hearing on Medicaid Home and Community-Based Waivers).

Mollica found in his study that instead of relying on regulation of facilities to ensure safety and quality of care, many states reflect in their policy approach to assisted living an attempt to combine minimum regulatory standards with market forces to produce quality of care. While the regulations set the parameters of minimum standards for assisted living, the owners/operators define the practice (Mollica, 1996, State Assisted Living Policy: 1996, p.1).

In Mollica's study, two major issues addressed in state policies for assisted living settings were the admission/retention criteria and the level of services. New Jersey and

Oregon have the broadest admission/retention requirements for assisted living facilities. New Jersey's rules require, within three years of licensure, that 20 percent of the program participant residents qualify for nursing home level of care. Despite regulations that may allow a higher level of care, facilities themselves may set their admission/retention policy to care for less-impaired residents that the rules allow and provide a less intensive service package than allowed (Mollica, 1996, State Assisted Living Policy: 1996, p.1).

States typically either require that residents have stable medical conditions and do not need 24-hour skilled nursing care, or the policy list a series of conditions that residents may or may not have to be served. The services that facilities provide parallel the admission/ retention criteria allowed (Mollica, 1996, State Assisted Living Policy: 1996, p.1).

The practice of setting operational policy in such a way allows the facility to "cherry pick." Facilities can, through the use of restrictive admissions criteria, serve higher functioning, less impaired populations than regulations require and provide a less intensive service package than regulations require. Fewer than 1 percent of assisted living facilities have specialized medical care units other than Alzheimer units (Mollica, 1996, State Assisted Living Policy: 1996, p.2). Therefore, less than 250 of the approximately 25,000 assisted living facilities are available to the disabled who require extensive nursing care or personal assistance (AHCA, 1997, Facts & Trends: Long Term Health Care, p.2).

The vast majority of assisted living facilities are not required to service the cognitively impaired disabled population who are medically involved. Intermediate Care Facilities for the Mentally Retarded (ICFs-MR) traditionally provide institutional and community based residential settings for the cognitively impaired disabled population. However, ICFs-MR do not generally provide intensive medical care. Additionally, an

extremely limited number of ICFs-MR are level VI facilities which serve the severe/profound cognitively impaired. “Cherry picking” is also common in this portion of the industry. A vast number of mentally impaired persons developed the mental condition as a result of disease, accident or illness resulting in neurological damage to the brain. Cognitive impairment is often the secondary condition. Residual and often chronic or severe medical conditions are common for this population. “Of those with 3 or more ADL disabilities, between 33.1 percent and 41.7 percent are also cognitively impaired,” (U.S. Department of Commerce Economics and Statistics Administration, 1997, Census Brief, p.2). ICF-MRs often also use admission/retention restrictions or limited availability of level VI beds to screen out those beneficiaries who are severely cognitively impaired or have a high level of medical involvement.

Mollica predicts that even though strong market demand for community residential settings supports the practice of “cherry picking,” changes are likely over time as the number of facilities expands, residents age in place, and providers adjust to maintain high occupancy rates. A more likely scenario: Because the vast majority of community-based residential facilities are proprietary, for-profit facilities, profit margins are the primary consideration when determining who the facility will service. Beneficiaries who are more “involved” require a higher staff ratio and additional therapeutic or medical equipment and are therefore more expensive to care for. “Residents of assisted living facilities stay an average of 3.3 years, and leave the facility when a higher level of medical care is needed (ACHA, 1997, The Looming Crisis: Assisted Living Resident). Residents who become medically unstable or severely cognitively impaired will no longer meet the

resident requirements provided by most states and most operators/owners, and will be discharged. If sufficient family resources and supports are unavailable, those residents will probably be transferred to a nursing facility.

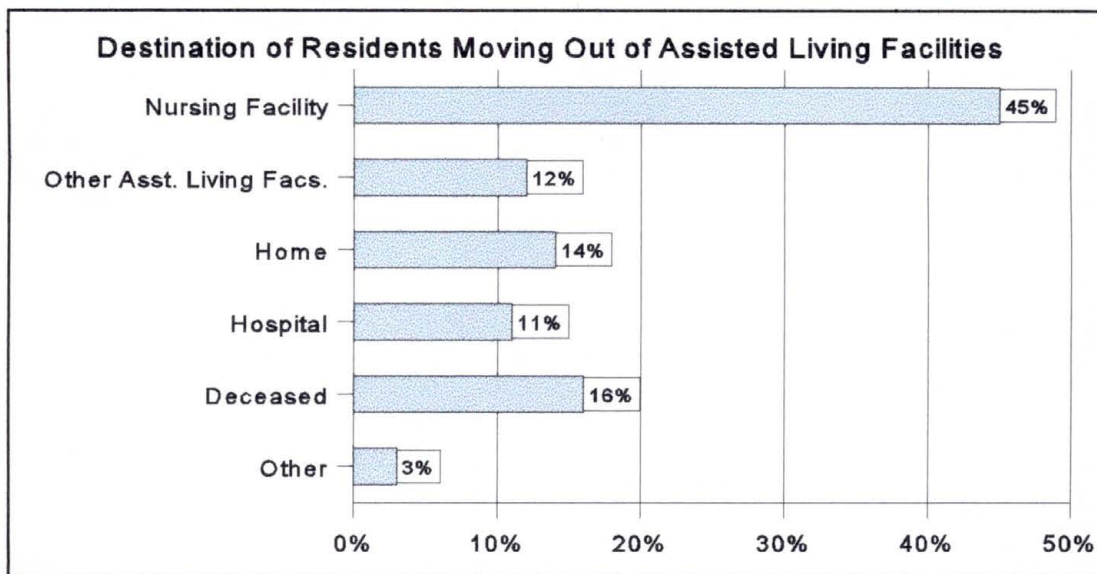


Fig. 19 Source: AHCA, Survey of Assisted Living Facilities, 1996.

Medicaid Home and Community Based Services

States are amending Medicaid reimbursement methodologies to pay for assisted living. Twenty-seven states provide Medicaid reimbursement for assisted living settings, most with Medicaid Home and Community-based Service waivers. "Rate components were developed for nursing services, operations (including personal care and other service costs) and capital cost. Newly constructed facilities also receive a capital add-on" (Mollica, 1996, State Assisted Living Policy: 1996, p.2). The Texas and New Jersey variable rates are based on type of setting. All other states have set a flat rate for the time

being, but plan to develop a tiered or case mix-adjusted rates for assisted living settings in the future. Only one state provides Medicaid reimbursement to providers of Medicaid home and community-based services on a fee-for-service basis (Mollica, 1996, State Assisted Living Policy: 1996, p.2).

Non-Medicaid Community Care Services

These services are funded by federal/state grants and are provided by the state through contracts with community-based provider agencies. While they are considered to be non-Medicaid HCBS, these services are also provided to Medicaid and Medicaid waiver qualified beneficiaries. Non-Medicaid HCBS include:

Family Care Services: meal preparation, housekeeping and escort services

Home Delivered Meals

Special Services to Persons with Disabilities: habilitative and rehabilitative services for maximum independence

Emergency Response Systems: a 24-hour monitoring system for functionally impaired elderly or disabled adults

Adult Foster Care: a 24-hour residential care setting

Day Activity and Health Services: rehabilitative, nutrition and supportive services through licensed adult day care facilities

Residential Care: licensed facilities that provide 24-hour access to services but not daily nursing intervention

Client Managed Attendant Services: Targets the adult with disabilities who is

capable of self-directing their attendant care. The client interviews, hires, trains, and supervises the attendant

Respite Care: Short-term services for elderly or adults with disabilities in order to provide temporary relief to the primary care giver (Texas Department of Human Services Commission, 1998, Medicaid Facts, p.1-2).

Non-Waiver Medicaid Funded Services

As of July 1, 1991, Section 1929 of the Social Security Act allows persons of all ages who meet the Medical Assistance Only (MAO) financial criteria for nursing home care to be financially eligible for Primary Home Care Services (PHCS). Title XIX provides nursing services, physical rehabilitation, nutrition and supportive services in state licensed and certified adult day care centers (U.S. Congress Senate. 1994, Hearing on Medicaid Home and Community-Based Waivers). Primary Home Care Services (PHCS) are non-technical medical services which must be prescribed by a physician and supervised by a nurse for all eligible Medicaid clients whose chronic health problems impair their daily living activities (Texas Department of Human Service Commission, 1998, Medicaid Facts, p.1). Again, daily living activities are defined as routine activities such as eating, bathing, toileting, walking and meal preparation.

Medicaid Waiver Programs

In 1994, 116 waivers were approved by HCFA for 49 states which operated 194 Medicaid-waiver funded community-based programs. In 1996, more than 2.5 million beneficiaries received HCBS through Medicare and 250,000 Medicaid waiver beneficiaries

received HCBS for long-term care (U.S. Congress. Senate. 1996, Hearing on Long-Term Care Options, p.2).

Community-Based Alternatives Program (CBA)

Community-Based Alternatives Program (CBA) is a 1915(c) waiver program that provides home and community-based services to aged and disabled adults as cost-effective alternatives to institutional care in nursing facilities. Services include adult foster care, assisted living/residential care, nursing, rehabilitative therapies, respite care, emergency response, etc.

Community Living Assistance and Support Services (CLASS)

Community Living Assistance and Support Services (CLASS) provides, through a 1915(c) waiver, home and community-based services to people with related conditions as a cost-effective alternative to ICF-MR/RC institutional placement. People with related conditions are people who have a disability other than mental retardation which originated before age 22 and which affects their ability to function in daily life. Services include respite care, rehabilitative therapies, habilitation, adaptive aids, ect (Texas Department of Human Service Commission, 1998, Medicaid Facts, p.2).

The current eligibility rules for CLASS require a medical need for services (Texas Department of Human Service Commission, 1998, Medicaid Facts, p.2) preventing many people with mental retardation or developmental disabilities from qualifying for services. Passage of HR 2020 would result in amendment of this rule to require only a functional need for services.

Cost Control Mechanisms for Medicaid Programs

While the variety of services provided in Medicaid and Medicaid waiver programs appears to be broad and sufficient, accessibility to these services is extremely limited. A report produced by the department of Health and Human Services in 1992,

outlines state cost control mechanisms in programs funded through Medicaid. States limit program participation by using age, types and degrees of functional disability, and income/assets levels in various combinations as eligibility restrictions. States limit program cost by limiting the types and number of services offered through the programs and cost capitation for maximum service expenditures. Beneficiary program participation is also controlled by imposing cost-sharing by all states except Arkansas (Mollica, 1996, State Assisted Living Policy: 1996, p.2). The two additional findings from the HHS study of particular importance are that cost for waiver clients are higher because those clients require more and higher skilled care than non-waiver clients; and the amount of time required to establish medicaid eligibility and extensive waiting lists due to cost control mechanisms imposed by the states often force some individuals who wish to remain in the community into nursing homes or ICFs-MR (U.S. Department of Health and Human Services, 1992).

It should be noted that the Medicaid waiver CLASS program, which serves as a cost-effective alternative to ICFs-MR, requires the beneficiary to have a related condition *other* than mental retardation, which results in a need for assistance with ADLs in order to be eligible. Persons with mental retardation or mental illness who do not require assistance with ADLs do not qualify for the CLASS program, but may be eligible as a Medicaid beneficiary who is at risk of placement in an ICF-MR (Texas Department of Human Service Commission, 1998, Medicaid Facts). Advocates and agencies that serve the mentally retarded are concerned about the trend of closing institutions for the MR/MI population and replacing those services with alternative community based services which

may be inappropriate for those who qualify and non-existent for those who do not. A

Richmond Times Dispatch news article in November 1997, entitled "Not Quite Home,"

expresses these concerns:

Advocates and home owners agree that finding the right place for people with medical and mental problems is going to become even harder as the state tries to discharge longtime patients from institutions . . . 'The guys we're seeing at Central State are very ill, very chronic, and their needs can't be met by an adult home, no matter how good it is,' said Tara Burton, a clinician and licensed social worker at the behavioral health authority. She will have to find places for them. Patients coming out of state hospitals often choose to stay in adult homes and receive treatment from private doctors, who sometimes also own the homes.

'We lose them at that point,' said Felecia M. Jones, supervisor for the behavioral health authority's hospital and community liaison unit. 'We can't go in and provide services that the staff has not requested and the client has not requested.'

'There was a huge discrepancy between a 25-year-old psychiatric patient ...and your 85-year-old little old lady,' said Levy, who began working with mental patients at Kensington Gardens in 1994. Both need care, but they need different kinds of care. And adult homes never were intended to provide care - only housing, food, and basic supervision (Martz, 1997).

Long-Term Care Nursing Facilities

There are numerous reports available which discuss the increasing numbers of elderly and the aging of the "baby boomers" in this country and their impending impact on beneficiary rolls for SSI, SSDI, Medicare and Medicaid. Poor quality of care in some nursing homes has generated a great deal of publicity, with constituents demanding tougher state regulations and oversight of facilities to protect residents from abuse and neglect. Bad publicity for the nursing home industry coupled with the increased development of home and community-based health care explains, in part, the results of the 1995 National Nursing Home Survey. According to a January 23, 1997 news release, from

the National Center for Health Statistics (NCHS), Americans are less likely to use nursing homes today:

Despite the growth in the number of elderly, who make up the largest proportion of nursing home residents, there has been only a slight increase in the number of residents and an actual decline in the occupancy rates (National Center for Health Statistics, 1997, p.1).

Americans who need long-term care have more choices today. Many more are able to stay in their homes and still receive the care they need...this shift is attributed to the rapid growth in home health care...that permit people to postpone institutional care... Since 1985, the number of nursing homes decrease by 13 percent while the number of beds increased by 9 percent. The number of nursing home residents was up only 4 percent between 1985 and 1995, despite an 18 percent increase in the population aged 65 years and over. Prior to the 1995 survey, utilization rates had kept pace with the increase in the elderly population. Almost 90 percent of the nursing home residents were aged 65 or over. More than 30 percent were aged 85 and over.

The typical nursing home resident is a woman in her 80s displaying a mild form of memory loss and dementia. Although physically healthy for a woman her age, she needs help with approximately 4 of 5 activities of daily living (eating, transferring, toileting, dressing, bathing). The average resident will spend more than three years in a nursing facility due to her cognitive and physical disabilities. Her health insurance is limited to Medicare only with a modest Social Security check for income. (U.S. National Center for Health Statistics, 1997).

Financially incapable of meeting the costs of her care, the female resident must rely on Medicaid to pay for her 24-hour care and supervision. In order to qualify, she must impoverish herself to no more than \$2,000 in total assets (ACHA, 1997, The Looming Crisis: Nursing Facility Resident, p.1).

Recall that the typical nursing facility resident needs assistance with 4 of the 5 ADLs, where as the typical assisted living resident needs assistance with 1.3 ADLs. Only 14% of the disabled population moves from a nursing facility into an assisted living facility. While 59% move from home, due to increased dependency, into assisted living centers (AHCA, 1997, The Looming Crisis: Assisted Living Resident,).

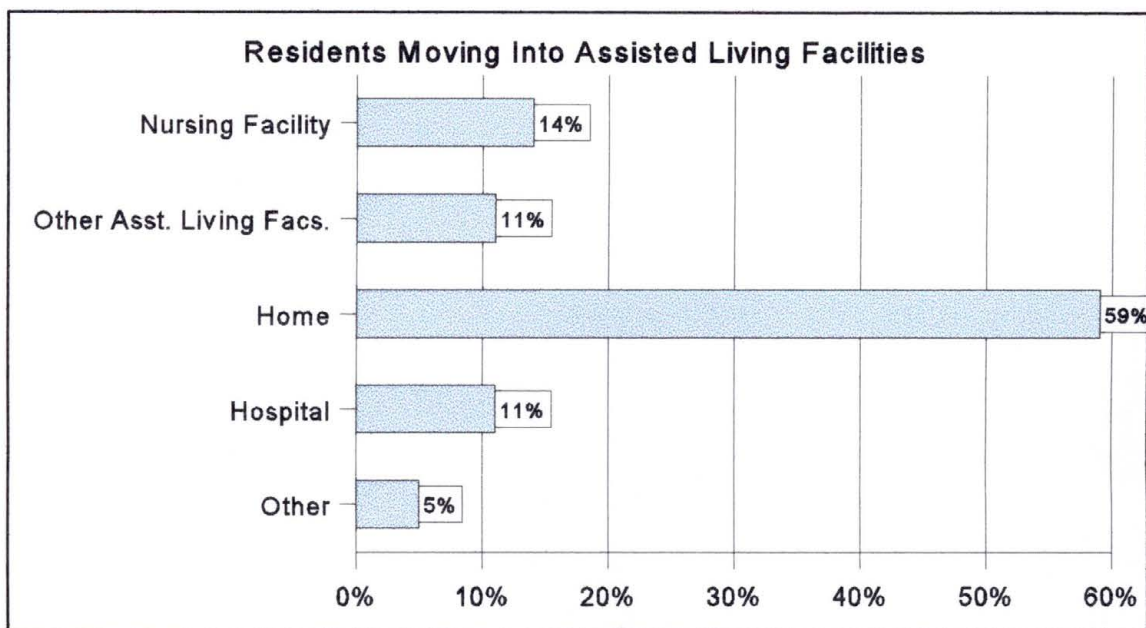


Fig. 20 Source: AHCA, Survey of Assisted Living Facilities, 1996.

More disabled individuals are utilizing assisted living facilities as dependency increases, however, few individuals are moving from nursing facilities to assisted living facilities.

In reaction to the trend towards community-based long-term care, there is a growing trend in the nursing facility industry toward long-term care specialization through Special Care Units (SCU). The National Nursing Home Survey, conducted in 1995, identified a national representative sample of nursing homes. Of the 17,000 responding nursing facilities, 35 percent report having at least one SCU and 16 percent report plans to develop one or more SCU. Of those facilities with SCUs in place, 22 percent are Alzheimer units, 12 percent are subacute units, 10 percent are rehabilitation units, with only 2 percent providing special programs for persons with HIV/AIDS. Nursing home specialization is projected to increase in the future (Leon, 1997).

Improving environments in nursing homes is another reaction to the challenge of community-based long-term care. Dr. William H. Thomas, author of *Life Worth Living: The Eden Alternative in Action*, has developed a nursing home concept which implements “home-like” qualities and environments in nursing home facilities. Dr. Thomas believes that for nursing home residents, “There’s more to living than just not dying. Being surrounded with life brings life back to the residents. It gives them something to look forward to and something to think about each day besides aches and pains” (Thomas, 1998, Website: Eden Alternative in Action.). He has incorporated cats, dogs, birds, and rabbits, that live and roam freely throughout the facility, with gardens, plants and children to lift moral and engage the residents in daily living. Dr. Thomas is promoting the Eden concept to established nursing facilities nationwide and provides training to facilities and state agencies on implementation. Dr. Thomas’ concept was featured on 48 Hours, entitled “Saving Mom and Dad,” on July, 31, 1998. The subject of the story was an elderly man, with limited mobility, who lived alone at home. Adamant that he wanted to stay in his own home, his daughters convinced him to “try” living at an Eden Alternative facility. A follow-up from 48 Hours several months later found the subject had greatly improved his mobility, was socially active and surprised that he was happy in his environment (CBS, 1998). Environmental changes in nursing facilities, similar to the Eden Alternative, can be expected to increase as the nursing home industry becomes more specialized and attempts to improve its public perception in order to compete with the rapidly growing home health care industry.

CHAPTER 6

CONCLUSION

Disabled Children

While this study focuses on the disabled adult population, it would be remiss not to briefly discuss the disabled children's population. With medical advances which promote survival, and in many cases unexpected survival, disabled children potentially represent the most costly to serve of all disabled populations.

Generally, disability data does not include children. Presently, there is no consensus on the questions that should be used to determine the disability status of young children or infants. The census disability survey asked whether children under the age of 6 had long-term conditions that limited their ability to run or a developmental condition which for the child has received therapy or diagnostic services. The proportion of children under the age of 3 with developmental conditions, is 2.6 percent, and the proportion of children 3 to 5 years of age with limitations in walking, running or using stairs is and/or a developmental condition is 5.2 percent. These figures are only used to depict disability prevalence by age and are not generally included in disability statistics. A wider range of questions to determine disability status is included in the survey for children and young adults 6 to 21 years of age.

Johns Hopkins University produced a study of 30,000 children who had ongoing serious health problems and were beneficiaries of the Washington State Medicaid Program. The study described the number and type of services received over a two-year period, actual costs of the services, and longitudinal patterns of services. This study focused on children with at least one of ten chronic conditions: asthma, chronic respiratory disease, cerebral palsy, epilepsy, cancer, diabetes, mental retardation, muscular dystrophy, spina bifida, and cystic fibrosis (Anderson, 1996, p.27).

The study determined:

The average cost per child who had at least one of these conditions is over six times greater than the average cost per child without one of the conditions, ranging from \$3000 to \$37,000. Asthma was the second lowest mean cost, but accounted for the highest total expenditures because of its significantly higher prevalence (46/1000 compared with 4.2/1000 for diabetes, for instance). Payments for home health care ranged from 4.4 to 116 times higher for chronically ill children than payments for the average child. These children represented 34 percent of total expenditures (Anderson, 1996, p.27).

The University of Chicago produced a study on all children in Illinois identified as having a disability in the state's multi-agency integrated database and Medicaid reimbursement files from 1989 to 1994 (Goerge, 1996, p.24). The study's major findings include:

- 1) Between FY 1990 and FY 1994 the number of children identified as disabled increased by 7 percent. In FY 1994, 8 percent of Illinois' children were identified as disabled.
- 2) The number of children receiving SSI increased from 12,184 in FY 1990 to 43,941 in FY 1994. The number of SSI children in special education decreased from 51% to 42% between FY 1990 and FY 1994.

- 3) The majority of children participating in Medicaid reimbursed services and either special education or SSI were being treated for mental disorders, with the majority in each year being mentally retarded (Goerge, 1996, p.24).

A study based on a telephone survey comparing 197 medically fragile children under 21 in Texas nursing facilities with 576 medically fragile children under 21 receiving services at home through the Medically Dependent Children Program (MDCP). The study “compared the cost, incentives, and outcomes for families, communities, and government for institutional care versus community care for children with disabilities” (Johnson, 1996, p.6). Findings for the study indicated:

- 1) Half of Medicaid recipients have a difficult time finding doctors to accept Medicaid payments.
- 2) Parents providing in-home care were significantly more likely to view the system as complex.
- 3) Families of uninsured children are more likely to delay care until high-cost emergency services are required.
- 4) Those with medically fragile children at home were significantly less likely to be ‘extremely’ satisfied with their child’s care.

This study above only included 197 of the approximately 450 chronically ill/medically fragile children who are in Texas nursing facilities. An interesting phenomenon was discovered during the course of this study regarding Johnson’s study. I determined, based on conversations regarding this study with twelve parents of children in Texas nursing facilities, that one of the reasons for the imbalance of the sample in this study, is that the parents of Texas children who require 24-hour skilled nursing care in an institutional setting are extremely distrustful of even discussions involving their children and community-based services and refuse to participate (or even to be identified for this

study). Many of these parents stated they were unable to secure adequate service in the community and that government agencies were non-responsive to their needs for services. Instead, several parents stated they were offered only foster care for their child, which meant having to give up parental rights. A great number of these parents are angry and distrustful of government agencies' ability to provide community services, even when those services are available. They expressed fears that they would remove the child from the institutional setting only to find the "promised" services inadequate, non-existent, or the funds will "disappear" and they will lose the services. They were concerned that if that were to happen, having lost their "slot" for nursing care, they could not adequately care for the child at home and his or her life could be placed in jeopardy. Parents of this population feel they made the appropriate, and only, decision available to them, to place their child in a nursing facility. Until the system is developed enough to assure appropriate, sufficient and consistent services for medically fragile/chronically ill children who require extensive skilled nursing care, many in this small subset population are not likely to willingly participate in HCBS.

...the view that 'home' is the best place for a child has dangerous ramifications. Government funds are cut for human services under the guise of anti-institutionalism. Well-meaning reformers who tell us how horrible the institutions are should be wary lest they become unwilling accomplices to politicians who only want to walk a tight fiscal line. It takes a lot of money to run residential facilities. No politician is going to say he's against caring for the handicapped, but he can talk in sanctimonious terms about efforts to preserve the family unit, about families remaining independent and self-sufficient. Translated, this means, 'You got your troubles, I got mine.' The hard truth is that the home is not the best place for every child. The harder truth is that even if it were, it might not be the best place for everyone else (Kupfer, 1997, p.20).

Update: Most Recent 105th Congressional Activity for Non-Defense Discretionary Program Budgets Affecting Disability Policies

The 105th Congress failed to adopt a Budget Resolution for fiscal year 1999, which passed in the House on June 5, 1998. This budget would have used \$101 billion in non- defense discretionary programs (which includes programs for the disabled) and SSI, SSDI, Medicaid and Medicare entitlements to offset a \$101 billion tax break for married couples (Bazelon Center for Mental Health Law, 1998).

Congress also failed to pass an appropriation bill for programs administered by the DHHS. A continuing resolution provided funding for several essential government programs, including mental health programs. The continuing resolution, Public Law 105-277, increased spending on mental health significantly. The state mental health block grant was increased by \$13.4 million, to total \$288.816 million for 1999. The increase ensures that no state will have block grant funds cut when a new formula takes effect in 1999 (Bazelon Center for Mental Health Law, 1998).

Mental health services and programs for children received an additional \$5 million, bringing to the current available funding for community-based interagency systems of care for children with serious emotional disturbance to \$78 million (Bazelon Center for Mental Health Law, 1998).

The House Ways and Means Human Resources Subcommittee's proposed efforts to tighten both the eligibility criteria and the eligibility determination process for SSI were never introduced to Congress during this session as a bill.

The House Budget Committee's proposals to make major cuts in Medicaid expired in committee because the Senate Committee, led by Senator Pete Domenici (R-NM), refused to accede to these reductions in conference. Although it appeared that some cuts in Medicaid administrative funds might be included in the continuing resolution, no cuts were made to Medicaid been reduced by \$13 billion in the Balanced Budget Agreement (Bazelon Center for Mental Health Law, 1998).

The FY 1999 VA-HUD Appropriations Act (P.L. 105-276) significantly increased funding for several programs benefitting people with disabilities. For the third year in a row, Congress increased funds for the HUD budget an additional \$40 million for tenant-based rental assistance for people with disabilities who have, or would, be adversely affected by designation of public and privately owned assisted housing as "elderly only." Fifty thousand additional "welfare to work" vouchers were provided through an increase of \$283 million in funding. "Welfare to work" vouchers are targeted to families eligible for welfare benefits but the vouchers may also be distributed to welfare applicants and SSI / SSDI beneficiaries in need of housing assistance in order to get or keep a job (Bazelon Center for Mental Health Law, 1998).

Funding for the HUD Section 811 program was frozen for the fourth consecutive year at \$194 million through the VA/HUD appropriations bill. The Clinton Administration recommended reducing section 811 funding by \$20 million. Both the House and Senate bills continued authorization for HUD to divert up to 25 percent of the 811 appropriations toward tenant-based rental assistance. This \$48 million "mainstream" voucher program is not connected to conversion of public and assisted housing for

"elderly only" (Bazelon Center for Mental Health Law, 1998).

On August 7, 1998, the President signed *PL. 105-220 (HR 1385, S 1579)*, Title IV-*Rehabilitation Act Amendments of 1998* into law. The information included in the discussion of *PL. 105-220* was obtained from UCPA (UCPA, 1998, *Rehabilitation Act of 1998*, p.1-9). This bill includes some of the provisions sought in *HR 3433* but Congress has still made no provisions for attendant services. Even with the passage of *PL. 105-220*, advocates are expected to continue efforts when Congress reconvenes to get personal care attendants through HCBS (*HR 2020*) and personal care attendants included in the work incentives bill (*HR 3433*) *PL 105-220* includes the following provisions:

- 1) Allows earmarking of private funds for service delivery in particular geographic areas of the state without a waiver of the state's statewideness obligations by the Commissioner of Health and Human Services is the state funds are unavailable for the federal match (p.1).
- 2) States will serve individuals with disabilities throughout the entire state workforce system, not only through the state vocational rehabilitation program (p.2).
- 3) Requires a comprehensive system of personnel development in order to ensure individuals with disabilities receive assistance from qualified vocational rehabilitation personnel (p.2).
- 4) Requires state Governor's oversight of inter-agency agreements with appropriate public entities, including the state's workforce investment system and public institutions of higher learning. The obligation of paying for vocational rehabilitation service to colleges and universities remains with the state vocational rehabilitation agencies (p.3).
- 5) Recipients of SSI and SSDI will be automatically presumed eligible for vocational rehabilitation services. To actually receive services, a person must have a disability and require vocational rehabilitation services to prepare for, severe, retain, or regain employment. The SSI and SSDI recipient must demonstrate a desire to work (p.4).

6) The bill enhances client control by requiring that clients have the opportunity to exercise informed choice in the development and implementation of their IEP by selecting employment goals, services, providers, and methods to procure services, as well as providing for extended services...Congress endorses increased independence for individuals with disabilities to informed choice (p.5).

7) The bill emphasizes expanded employment opportunities for individuals with disabilities (p.5).

8) Congress has appropriated funds for six years (FY 1999- FY 2004), effective July 1, 1999 (UCPA, 1998, *Title IV-Rehabilitation Act Amendments of 1998*, p. 1-9).

The Omnibus Budget Bill (HR 4328) includes a \$1.7 billion dollar measure to reform the Medicare home health interim payment system. The measure will be funded, in part, by increased taxation on gambling winnings. Under this bill, more than 65 percent of home health agencies will receive an increase in their Medicare payments. Congress, however, could predict how this agreement would impact access to home health care (UCPA, 1998, November 3, *Washington Watch*, p.4).

The Work Opportunity Tax Credit (WOTC), which had expired on June 30, 1998, has been extended. The tax credit is available to employers who hire individuals from one of eight targeted groups, including the disabled. The maximum credit per employee is \$2400, 40 percent of the first \$6,000 of qualified first year wages (UCPA, *Washington Watch*, 3 November 1998, p.1).

Numerous significant programs have emerged from the 105th Congress which benefit people with disabilities. Congress has authorized \$6 million dollars for the Commissioner of Social Security to use for federal-state partnerships. The partnerships will be developed to evaluate Medicare buy-in programs targeted to elderly and disabled individuals. SSA will allot \$1 million dollars for policy research to support the goals of the

Presidential Task Force on Employment of Adults with Disabilities. Vocational Rehabilitation State Agencies received \$2.3 billion dollars for direct services and \$39.6 million for personnel training for rehabilitation services to persons with disabilities. Last, Congress has authorized \$10.8 million dollars for Protection and Advocacy of Individual Rights (UCPA, 1998, November 3, Washington Watch, p.3).

Advocates for the disabled failed to get several disability policies and acts through the 105th Congress, including *HR 2020 and HR 3433*. As a whole, however, with the programs discussed above, the expansion of several program budgets, and the inclusion of several points in *HR 3433 in The Rehabilitation Act of 1998*, advocates for the disabled have been significantly successful in maintaining a forward momentum for disability policy and expansion of HCBS in this Congressional session.

Study Conclusions

The primary problem with current and proposed disability policies is that each is cost prohibitive to implement because the policies are all-inclusive, encompassing the entire disabled population regardless of the level of disability. Without cost controls, Congress cannot and will not implement these programs. Controlling program cost is not possible for policy that does not include controls for program participation. Disability advocates claim that the proposed personal attendant services are needed to stop forced institutionalization. If de-institutionalization is a common goal for both the disability advocates and Congress, as cost-saving initiatives and policies that promote independence, then new policies and existing policy expansion for personal attendant services should

target the institutionalized subset of the disabled population. As written, HR 2020s proposed personal attendant service is an all-inclusive policy that encompasses the entire disabled population without regard to current place of residency or level of disability. If applied as written, HR 2020's services will be extremely limited per individual. To be effective, the personal attendant care program must include limited program participation. Otherwise, services will be too limited due to program costs and, as a result, ineffective. Limiting eligibility for the program to those who are institutionalized, but desire to live in the community will aid in controlling costs, potentially reduce long-term care expenditures, and meet advocate's demands for de-institutionalization. The program should include limited emergency attendant services for those who already reside in the community. This provision will serve as a safety net to prevent institutionalization of those who temporarily need a personal attendant or need time to replace an attendant. Personal attendants provided by home health care organizations, however, must be certified and regulated in order to protect the disabled individual. Beneficiaries who wish to manage their personal attendants themselves should be required to sign a liability release by the program's administrating agency.

Some of the content in currently proposed disability policy, particularly the work incentive policy, is a Congressional reaction to fierce political pressure by disability special interest groups. For instance, Congress has been successful in reducing welfare program rolls by implementing mandatory job training, a capitation of lifetime benefits, and mandatory employment or loss of benefits. The changes in welfare policy have resulted in a decrease in program cost and a reduction in program participation. Congress made some

hard and firm decisions when they restructured the welfare program. Welfare policy now reflects the public sentiment that, as a nation, we will help those in need with welfare to get on their feet and find a job. It also, however, reflects the public's expectation that those who are able to work will find jobs. *HR 3433*, however, lacks any and all requirements or mandates for beneficiaries. All requirements and mandates in *HR 3433* apply only to the states. Those who are determined to be capable of working full or part time to are not required to participate in vocational training or to prove they are actively seeking employment. There is no capitation of benefits for those who are able to work but do not. As proposed, there is no requirement for those people with disabilities who can work, to work. The proposed work incentive policy is an all-inclusive policy which is applied equally to all disabled beneficiaries, regardless of the level of disability.

The primary reason that disability policy has become all-inclusive policy that applies to the entire disabled population is that there is no longer any distinction among the various subsets of the population. All persons with a disability are "disabled". Advocates for the disabled oppose the word "handicapped" due to its connotation of holding your cap out in your hands as a beggar. Advocates convinced Congress to change the language in the *ADA of 1990* from a "handicapped person", the term used in the *Rehabilitation Act of 1973*, to "persons with a disability" which they claimed better reflects society's perception of the disabled today and puts the emphasis on the person rather than the disability. This is a curious preference since *Webster's New Unabridged Dictionary* defines "disability" and "handicap" as:

- Disability :
- 1) lack of adequate power, strength or physical or mental ability; incapacity.
 - 2) a physical or mental handicap, especially one that prevents a person from living a full, normal life or holding a gainful job;
 - 5) legal incapacity; legal disqualification.
 - 6) synonyms- 1) disqualification, incompetence, incapability, impotence (Webster's, 1997, p.560).

- Handicap:
- 2) the disadvantage or advantage itself;
 - 3) any disadvantage that makes success more difficult;
 - 4) A physical or mental disability making participation in certain of the usual activities of daily living more difficult.
 - 5) to place at a disadvantage; disable or burden (Webster's, 1997, p.866).

Both the actual common meaning and connotation of the word “disability” are a condition or impairment that renders a person incapable and prevents them from living a “normal life and holding a gainful job”, whereas, the accepted common meaning and connotation of “handicapped” is an impairment of some nature that puts the person at a disadvantage or makes an activity more difficult.

Altering the legal reference for the entire population to “persons with a disability” is problematic in a number of ways. First, it distorts the reality and understanding of the characteristics of various segments of the population. Under this definition, there is no distinction for varying degrees or levels of impairment; all persons with disabilities are now equally disabled. There is no current label to distinguish the subset population of those who are “incapacitated” from those who live in the community but are considered “severely disabled” because they need assistance with one ADL. Most “persons with a handicap” are able to adapt to their impairments and live independently while other “persons with a handicap” need assistance with daily activities, but are still

capable of living in the community. In reality, the members of the able disabled population are not disabled, but “handicapped”. The phrase “living independently with assistance” is an oxymoron. The “truly disabled”, with or without personal assistance, cannot achieve independence. Those who are incapacitated are “disabled”. If disability policy is to be expected to address the needs of the various sectors of the disabled population, there must be a way to distinguish the various sectors of the population and their specific policy needs. Therefore, labels that accurately distinguish between “handicapped” and “disabled” are necessarily appropriate and effective labels for the development of disability policy.

Also problematic with the universal label of “disabled” for the entire population is that it not only removes any distinction between the various segments of the population and levels of severity within the population, but it also removes the distinction between disability advocates. Advocates for the “handicapped” purport to advocate for all persons with disabilities, yet do not acknowledge the different needs of various subsets of the population who have different levels of severity. As discussed in Chapter 2, advocates for the “handicapped” are highly organized with strong politicized coalitions at both the state and national levels, and are strongly influential with Congress. Advocates for the “handicapped” comprise virtually all of the disability policy lobby efforts at the national level. State and federal government agencies and Congress presume disability advocates for the “handicapped” do, in fact, advocate service and program demands for all segments of the population with all levels and types of impairments, when in reality, they do not. This analysis of the history of disability politics and the current political landscape demonstrates that modern disability policy has been developed without consideration of

the particular needs of the populations most severely disabled. The current trend and direction of disability policy toward deinstitutionalization and home and community-based services adversely affect and/or excludes the most severely disabled sector of the disabled population.

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