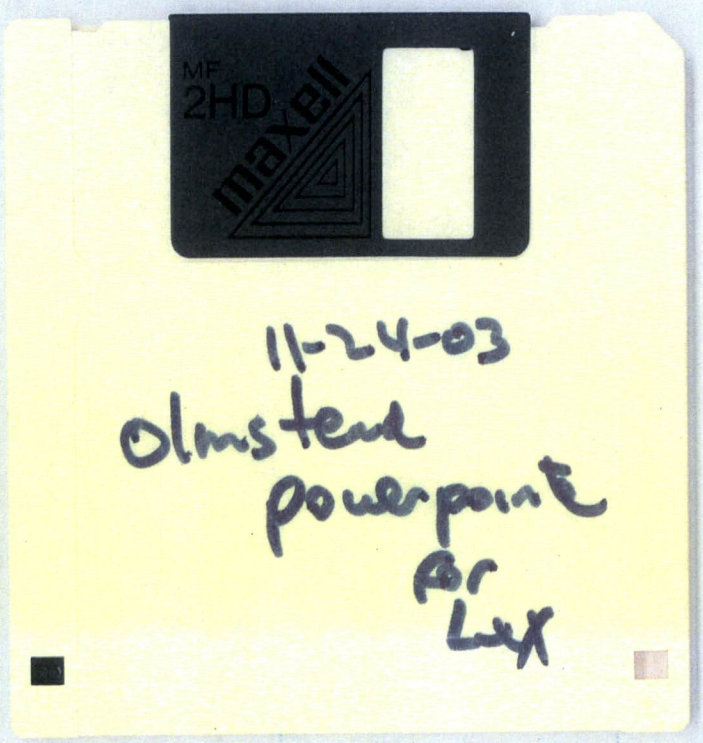

Encourage collaboration between people with disabilities and businesses
*
Identify resources within your organizations that can support this effort
*
Propose ways in which businesses and people with disabilities can continue the work begun today to make the promise of the ADA a reality
*
Specifically today's topic addresses issues of providing access to a large and growing segment of our population - people with disabilities - and working with this audience to develop effective marketing techniques for them.
*
The market is made up of 54 million people with disabilities in the U.S. with an aggregate income of $1 trillion. This figure includes $220 billion dollars of discretionary spending. If we add the discretionary spending of Canadians with disabilities, we're talking about $245 billion dollars of spending power.
*
This $245 billion figure equals approximately 3 times the spending power of North American teenagers.
*
The market of 54 million people does not include older adults who benefit from accessible design and the families and friends of both groups. Adding in these individuals swells the market's size enormously.
*
By the year 2020, 75 million Baby Boomers will be over the age of 55 and demanding products that work for them but don't look medical or different. Well-designed, accessible products fill that bill.
*
General Motors discovered that some of its best resources for product design, environmental access, and marketing to people with disabilities came from its own workforce.
*
GM worked with its employees with disabilities to establish employee resource groups, forums, and product execution teams that collaborated with the corporation to improve both employee and customer accessibility. These collaborations have resulted in vehicles that are more universally usable, improved accessible emergency evacuation from company office space, and a program to develop a skilled workforce of young adults with disabilities.
*
McDonald's Corporation gained a loyal, dependable workforce when it began hiring people with disabilities. An unexpected benefit of this practice became clear when the corporation also discovered that people who appreciated and approved of their hiring practices became loyal customers.
*
In these days of shrinking global economies, businesses can look to accessibility concerns as inspiration for potential new design directions and to

Transform *disincentive* into *incentive....*
Employment for Persons with Physical Disabilities

This letter represents an unsolicited proposal to the Social Security Administration to increase employment among persons with physical disabilities. The loose of social security income and benefits has long been viewed as a *disincentive* for employment. The heart of this proposal is to transform this employment disincentive into an *incentive* to encourage persons with physical disabilities to seek employment without having to risk losing their social security income and benefits.

Summary

For many years now, considerable research has been focused on reducing the number of people with disabilities who receive Social Security Disability Income (SSDI) income and benefits. And for years the approach has been to force people with disabilities to choose between their SSDI income and benefits, and employment. Previous attempts to increase employment rates among people with physical disabilities have failed, which suggest that it's time to try another approach.

This study launches a new paradigm by encouraging people with physical disabilities to seek employment without having to lose their SSDI income and benefits. This project represents a *transformation of what was once a disincentive into an incentive for employment.* When people with physical disabilities become employed they will generate income tax revenues. They will have access to employer benefit plans that could reduce their social security benefits. Also, research has shown an overall improvement in health status for people with disabilities who are employed. (reference?)

This research will lay the foundation for a pilot study that will encourage employment of people with physical disabilities by adding the *incentive* to keep their social security income and benefits when they become employed. The purpose of this project is to define the characteristics of persons with disability who would return to work if they did not have to relinquish their social security disability income and benefits. The target population of this study is largely persons with physical disabilities who were once employed, but currently are unemployed. The survey and focus groups will be based on the principles of Independent Living, review of the literature, and existing statistical data. Our ultimate goal is to lay the foundation for an SSA pilot study to increase employment among people with physical disabilities who can work without having to give up their social security income and benefits. The number of people with physical disabilities who would seek employment if they could keep their SSDI income and benefits will be quantified as a result of the focus groups and existing statistical data. The focus groups will provide an in depth qualitative analysis of the employment characteristics of people with physical disabilities.

Introduction

Describe ILRU. Describe grant history, and ILRU personnel.

ILRU shares the Social Security Administration goal to increase employment among persons with physical disabilities.

Statement of the Problem

Historically, efforts have been introduced to promote return to work among SSDI beneficiaries, such as encouraging participation in vocational rehabilitation and introducing program features designed to protect income and health insurance benefits for a time following a return to work. However, return-to-work efforts have had very limited success, with only about one half of one percent of all DI beneficiaries having left the rolls for employment (GAO, 1997). In fact, there has been no increase in the employment rate among people with disabilities from 1988 to 2000, and labor force participation has declined among people with disabilities based on NHIS and CPS data (Improved Employment Opportunities for People with Disabilities, Steve Kaye, October 2001).

In one report based on the Disability Supplement to 1994 to 1995 National Health Interview Survey, researchers found a relatively small but important subset of claimants and beneficiaries of working age adults. These working age adults are not working now, but appear to be capable of entering or re-entering the workforce (222,000 recipients and 301,000 applicants fell in this category). Among the perceived barriers to seeking employment of nonworking SSDI beneficiaries were: (1) lose of health insurance or Medicaid coverage (19% of those who currently receive SSDI), (2) lose of disability income (21% of those who currently receive SSDI). (A Profile of SSDI Applicants and Beneficiaries, Age 18-64: Estimates from the 1994 and 1995 National Health Interview Surveys on Disability (Kennedy, Olney, Richer. 2001))

This project would help the SSA achieve two objectives listed in the FY 2003 Annual Performance Plan. One objective is to "promote policy changes, based on research, evaluation and analysis, that shape the SSDI program in a manner that protects vulnerable populations, anticipates the evolving needs of SSDI populations, and integrates SSDI benefits with other benefit programs to provide a safety net for aged, blind, and disables individuals". The basic premise of this project is about providing a safety net for vulnerable populations by encouraging persons with physical disabilities to seek employment by allowing them to maintain their SSDI income and benefits. This research project also addresses the integration of SSDI benefits with private benefit plans offered through employment.

Another objective is to "promote policy changes, based on research, evaluation and analysis, that shape the disability program in a manner that increases self-sufficiency and takes account of changing needs, based on medical, technological, demographic, job market, and societal trends". This research project promotes the idea of self-sufficiency found through employment, taking into account the changing demography of people with physical disabilities and societal trends that affect the job market.

Research Objectives

This research project will answer the following questions:

- How likely are persons with physical disabilities to return to work if they are allowed to keep their SSDI and benefits?
- What behaviors and/or attitudes exist among persons with physical disabilities regarding employment status (i.e., low self-esteem, reduced productivity, perceived benefits of working versus not working, etc.)
- What are the socio-demographic characteristics (age when disabled, ethnicity, cultural issues, gender, age, education, rural versus suburban) of persons with physical disability who currently receive SSDI?
- What is the work history of persons with physical disability who currently receive SSDI (i.e., blue collar vs. white collar, how many years since employment, job skills, etc.)
- What type of work are persons with physical disabilities likely to seek upon reentry in the work force? Self-employment?
- What can be done to insure longevity of employment (support, job coach, job progression, etc.)?
- What other employment obstacles (i.e., employment skills and retraining, transportation, physical access, work place accommodations, personal assistance services) might affect the employment status of persons with physical disabilities?
- How can the principles of Independent Living help persons with physical disabilities become employed?
- How could the Stages of Change (Transtheoretical Model of Change) help persons with physical disabilities move from unemployment to employment?

Methodology and Data Analysis

This research proposes to use written survey and focus group methodology to determine the characteristics of persons with physical disabilities who would return to work if they did not have to relinquish their social security disability income and benefits.

A survey will be developed based on review of the literature using a 6-point Likert scale. The survey will be distributed to 500 persons with physical disabilities across the United States through Centers for Independent Living. Focus groups will be conducted with 30 persons with physical disabilities to better understand the attitudes of persons with physical disabilities toward employment. Focus group techniques will allow participants to record rankings among a selection of items to quantify certain employment issues. Thus, focus groups will yield both qualitative and quantitative data.

Focus group analysis will include both qualitative and quantitative data.

- Text analysis software can be used to perform detailed content analysis of focus group transcripts, revealing the frequency and circumstances surrounding specific words and phrases. Focus group transcripts can be coded using words, word meaning, sentences, paragraphs, or overarching themes.
- Conjoint Analysis allows the researcher to determine which aspects or attributes of an issue are important or unimportant to an individual. Using this technique, the researcher can determine the relative importance of an attribute compared to other attributes, and which level of attribute is preferable. For instance, using this technique, a researcher may be able to determine whether preference levels for certain attributes are affected by demographic differences (gender, age, education, etc.)
- Perceptual Mapping/Metric Sealing Techniques are often described as a form of quantifying qualitative data. These techniques provide a way of visually representing the relationships among the variables of interest in a focus group study. Optimal scaling techniques are appropriate for examining single and multiple sets of variables across a variety of measurement levels.

Future funding

An unsolicited proposal will be sent in the near future to describe design and implementation of two interventions based on the results of the above research project to encourage employment among persons with physical disabilities. Both interventions will include being able to return to work without having to risk loosing social security disability income and benefits. The interventions will be based on the Transtheoretical Model of Behavior Change (Prochaska & DiClemente, 1983) and the Independent Living philosophy. Two evaluation approaches will be used: (1) theory-based evaluation to examine the intervention process (key employment components and expected program outcomes);(2) participatory evaluation that involves close collaboration between researchers and persons with physical disabilities in developing, implementing, and interpreting the evaluation.

Project Time Table

Year 1
Month 3 – Conduct literature review
Month 5 – Develop written survey and focus group questionnaire
Month 7 – 9 Recruit for focus groups (principles of Independent Living and questions from NHIS survey)
Month 10 –11 Distribute survey

Year 2
Month 3 – Conduct focus groups
Month 5 – 7 - Analyze survey data (quantitative)
Month 8 – 10 Analyze focus group data (qualitative and quantitative)
Month 11 – Write Reports/Papers

Budget

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The Implications of Emerging Demographics

A Commentary on the Meaning of Race and Income Inequity to Disability Policy

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The intersection of disability and minority status has been a fixture in U.S. disablement paradigms. In the following commentary I argue that the character of the discussion has become formulaic, focused on vague allusions to discrimination and bias in the delivery of services and supports. Although the disability community has moved from relative apathy to consistent concern over the past two decades, our field has attempted to address symptoms rather than the more fundamental question of the manner in which race and ethnicity matter.

In the following pages I paint a demographic portrait of Americans with a disability (see Note). A very broad brush will be used. Although many different demographic features, methodological concerns, and disability issues are explored, each coalesces on a core question—are race and ethnicity significant to those of us in the disability community? I say "address" the question rather than "answer" for the very practical reason that I have no answers.

This was the question of President William Clinton's Initiative on Race (Executive Order No. 13050). I doubt anyone believed the response would be anything but "yes." However, the ways in which race affect us remain very much a matter of debate. The lesson of the presidential initiative was that although we all understand in very general terms the profound influence of race, we truly do not understand its "genesis and consequences" (Advisory Board to the President's Initiative on Race, 1998, p. 3). Until we do understand its consequences and look deeply into its history and dynamics, problems will remain ill-defined and solutions elusive. As always, the devil is in the details.

In the recent flurry of public debate over affirmative action, and in all the rhetoric generated by the presidential "race initiative," I am somewhat surprised that we have not directly addressed this question of race in greater depth within the disability community. If we were to poll people in the field, I am certain the consensus—implicit in words if not deeds—would be a resounding "yes." Race is a standard item in our list of disability concerns. We have our centers, initiatives, demonstration projects, coalitions, caucuses, and special interest groups. To its collective credit, over the past two decades the disability community has moved from relative apathy to consistent concern regarding the issue of race. But do we, as members of that community, agree on how it matters?

Perspectives on Policy Analysis

My focus on matters of race and ethnicity is stimulated not by a specific interest in minority affairs or demographics, but rather by my perspective on the connection of research to the development and implementation of public policy. I have long believed one of the most useful roles filled by social scholarship is the very basic act of describing our societies. Raw information has the power to inform policy decisions and galvanize advocacy (e.g., Fujiura, 1994). In this paper I approach the disability policy implications of race indirectly—by looking at U.S. demographics and, in particular, the demographics of disability. This demographic work in turn has led me to two familiar themes in disability policy—the role of race and the role of poverty. Although the thought is not new to the policy dialogue, I am arguing for a reaffirmation of the relevance of race and poverty to disability concerns and national domestic policy in general.

I am not trained in the disciplines of public policy—a significant deficit because my work is often characterized as policy related. I still struggle with operational definitions of

policy research and analysis. *Policy analysis* strikes me as one of those terms we all intuitively understand but, when pressed, cannot exactly define—much like the word *disability.* So I tread carefully here. As I will note later in this paper, my perspective very much parallels evolving views on disability—that disability is a process rather than a definable entity. There are four features I consider central to disability policy analysis research:

1. provision of information relevant to agenda setting, decision making, and advocacy;
2. a focus on choices in the public domain where alternatives typically represent competition for limited economic (and public) resources;
3. incorporation of values; and
4. a pragmatic, nonparadigmatic approach to research ("methodological multiculturalism," to paraphrase Datta, 1982).

The emphasis I give here to disability statistics reflects my belief in the value of basic factual information, but I recognize these facts for what they are—merely the "outer shell" of inquiry. Very few relevant questions are directly answerable via statistical summaries of populations. This is for me a starting point, and I defer to other methodological "cultures" to round out the portrait in order to inform disability policy.

Perspective on Demographic Inquiry

There are many incarnations of demographic inquiry, although probably none of these have appeal to the casual observer. These lines of inquiry range from the basic expository head counts of the national censuses to multiequation mathematical models of population movement or labor markets. Whatever the choice, the discipline hews to its core meaning from the Greek translation: "description of the people." The mechanics of case definition, sampling, estimation, and description do not inspire great passion. But as the heroine of the *Undoing of Lamia Gurdleneck* noted, "It's not the figures themselves, it's what you do with them that matters" (Kendall & Stuart, 1967).

Indeed, the roots of demography lie in what was termed the "political arithmetic" of migration, poverty, and literacy in England in the 1600s (Clark, 1972, p. 16). Of significance to the present discussion, the focus of these political arithmeticians (and their statistics) was reform in the health care arena (Wright, 1988). Oberschall (1972) noted that the demand for extensive and detailed information by "social reformers, civic groups, philanthropists" was the foundation of much statistical work in the 19th century in order to provide a baseline for future solutions (p. 6). Although a veneer of "science" now encompasses demography and population statistics, the connection to reform as a fundamental purpose remains close to the surface. For example, a recent debate has emerged within the public health field regarding the proper role of statistical surveillance and epidemiology—whether research that directs attention to social inequality is an act of an objective science or of policy advocacy (Krieger, 1999; Savitz, Poole, & Miller, 1999). I will not venture into this debate here, but I want to make it clear that this paper is not about demographics but rather about the policy implications of demographic data. Demography has deep roots in the analysis of societies. It is not the numbers themselves, it is what you do with them that truly counts.

Perspectives on Labels and Definition

The matter of language must be addressed prior to dealing with the actual numbers. There are few universal conventions regarding how human variance is defined and labeled.

Race and Ethnicity

A cursory review of materials related to disability and ethnic and racial minorities (which I will refer to hereafter as simply "minorities") reveals layers of labels, often with variable meanings: *cultural diversity, cultural pluralism, culture and diversity, cultural competence, cultural sensitivity, multicultural, transcultural,* and so forth. Although *multicultural* has achieved a certain degree of common usage in the field, the sheer breadth of the concept serves to obscure direct discussions on race. Culture is pervasive. Culture and its corollary, competence, defines an enormous agenda for the field because it reflects not just a constituency of people but also skills, attitudes, policies, statutes, and practice (Roberts et al., 1990). I cannot deal with this in a brief paper on demography. Instead, I will work from an older referent point—*minority status*—a term widely criticized now as an anachronism because the minority label is frequently applied to the numerical majority in many urban regions. The projection by the U.S. Census Bureau that Americans of European descent will be a scant majority in approximately 30 years is one of the most oft-quoted statistics in the literature related to minorities and disability (middle projections, U.S. Bureau of the Census, 1996).

But the minority concept has potent meaning beyond the literal definition—it is synonymous with differences in political power and wealth (Cross et al., 1989; Harry, 1994). The term *minority* as it is traditionally used is still meaningfully linked to racial politics and our principles of civil rights and equity. As *Chicago Tribune* columnist Clarence Page (1999) noted recently, "Black is not just a race. It is an interest group waiting to be reassured." The minority concept is also directly related to emerging concepts of self-identify within the disability community (Hahn, 1993), a key ingredient in any discussion of race and disability. The central point in the matter of word choice is consistency with what I perceive to be the most fundamental issue of race relations—political power and economic inequity.

Disability

Much of the balance of this paper is an extended recitation of disability statistics. Let me state at the outset that a universally accepted accounting of persons with a disability does not exist: There are different estimates under varying survey schemes and sampling frames. The fundamental source of variability is the matter of definition; indeed, some analysts cannot agree that disability is in fact a "countable" entity (Zola, 1993). The "approaches" to obtaining data about disabilities are best viewed as crude approximations at a point in time, with considerable but not total communality. Discrepancies between estimates underscore the fluidity of the disability construct and the vagaries of identification. In the end, the act of disability identification is a judgment on the human condition. This is my caveat in interpreting the data that follow—*disability* is a contested concept, and the reader of any data must not presume there is one true or better number representing all Americans with a disability (Fujiura & Rutkowski, in press).

Statistical summaries of disability typically employ definitions based on (a) the presence of a physical or health impairment or (b) an assessment of "loss of function." Either concept is common to everyday experience. In practice, however, layers of nuance are revealed. Impairments may not functionally affect an individual's life. Function is not so readily operationalized—Which skills or functions are most important? What is the threshold of loss? Are thresholds absolute or relative? To what extent are external accommodations—assistive devices or environmental modifications—incorporated into the definition?

These questions in part reflect a third perspective best represented by the (still-evolving) notion of "restricted participation" in life situations as stated in the International Classification of Functioning and Disability (ICIDH-2). The defining element is the interchange of person-level characteristics with the social context or environmental setting. The challenge of translating these concepts into easily administered "head counts" is enormous. In fact, under what might be termed *situational disablement paradigms,* the principle measurement unit is not the person but the specific interaction. In other words, the logical manifestation of a surveillance system based on a new paradigm of a disability would be a statistical summary of interactions within a society, not a tally of persons. The simple dichotomy of labeling Americans as having or not having a disability is not particularly relevant from this perspective. To date, no large-scale statistical surveillance efforts have incorporated these conceptual schemes (Fujiura, & Rutkowski, in press).

Policy Implications

In the balance of this presentation I begin each section with the policy implication and then outline my rationale, supporting it with what I consider to be the relevant demographic trends. Again, the unifying theme is the meaning of race to the field of disability.

Professionals in the disability/rehabilitation field must avoid defining the minority agenda in this field only in terms of skin color, which represents the most superficial form of redress. It should be about those persons who are un-served or under-served. (The reader should not misinterpret the shift in emphasis—there are significant and well-documented differences in vulnerability to chronic health conditions and disability prevalence across racial and ethnic groups [Adama & Marano, 1995; Fujiura & Yamaki, 1997; LaPlante & Carlson, 1996; McNeil, 1993; Seelman & Sweeny, 1995].) Previous research (e.g., Fujiura, Yamaki, & Czechowicz, 1998) underscored the profound interaction of these prevalence differences across age cohort, an issue of considerable significance to the disability and diversity agenda and one to which I will return.

A fundamental underlying dynamic in these prevalence differences among racial and ethnic groups are the conditions of poverty and the risks associated with poverty (Fujiura et al., 1998). Some context is necessary before I elaborate on this point. In the midst of our historic economic expansion, the fact that poverty remains an issue of considerable importance needs to be underscored.

Despite significant and widely publicized declines in the proportion of Americans living in poverty, the absolute numbers are large (35 million in 1998), with substantial disparities across groups. In 1998, poverty rates for Black and Hispanic Americans were triple those of White Americans (U.S. Bureau of the Census, 1999). A second feature of the economic dynamics of the latter part of the century—and one of great potential concern to the demographics of disability—are trends in the distribution of wealth and poverty in the nation. Shown in Figure 1 are 50 years of the Gini Index, a statistical summary of the distribution of income in the United States (U.S. Bureau of the Census, 1999). The higher the value, the greater the concentration of wealth among a smaller number of households.

Of great concern is the steadily increasing disparity in economic wealth during what has been an unprecedented economic expansion (U.S. Bureau of the Census, 1999). Many economic dynamics are represented in this paradox of increased disparity in an expanding economy. An important factor has been the two-tier growth in employment, with many low-income service positions and relatively small gains in highly compensated positions. Underscored in the Gini Index is the fragmentation of the U.S. middle class into an increasingly bimodal distribution—the "winners" and "losers" of the expansion and, equally important, the persistent existence of an underclass largely unaffected by domestic prosperity. All boats have not risen equally in the rising tide of affluence.

If U.S. minorities are more likely to be poor, and if poverty is linked to disability, then it stands to reason that if poverty were extracted from the equation, differences between racial and ethnic groups should be greatly attenuated. Indeed,

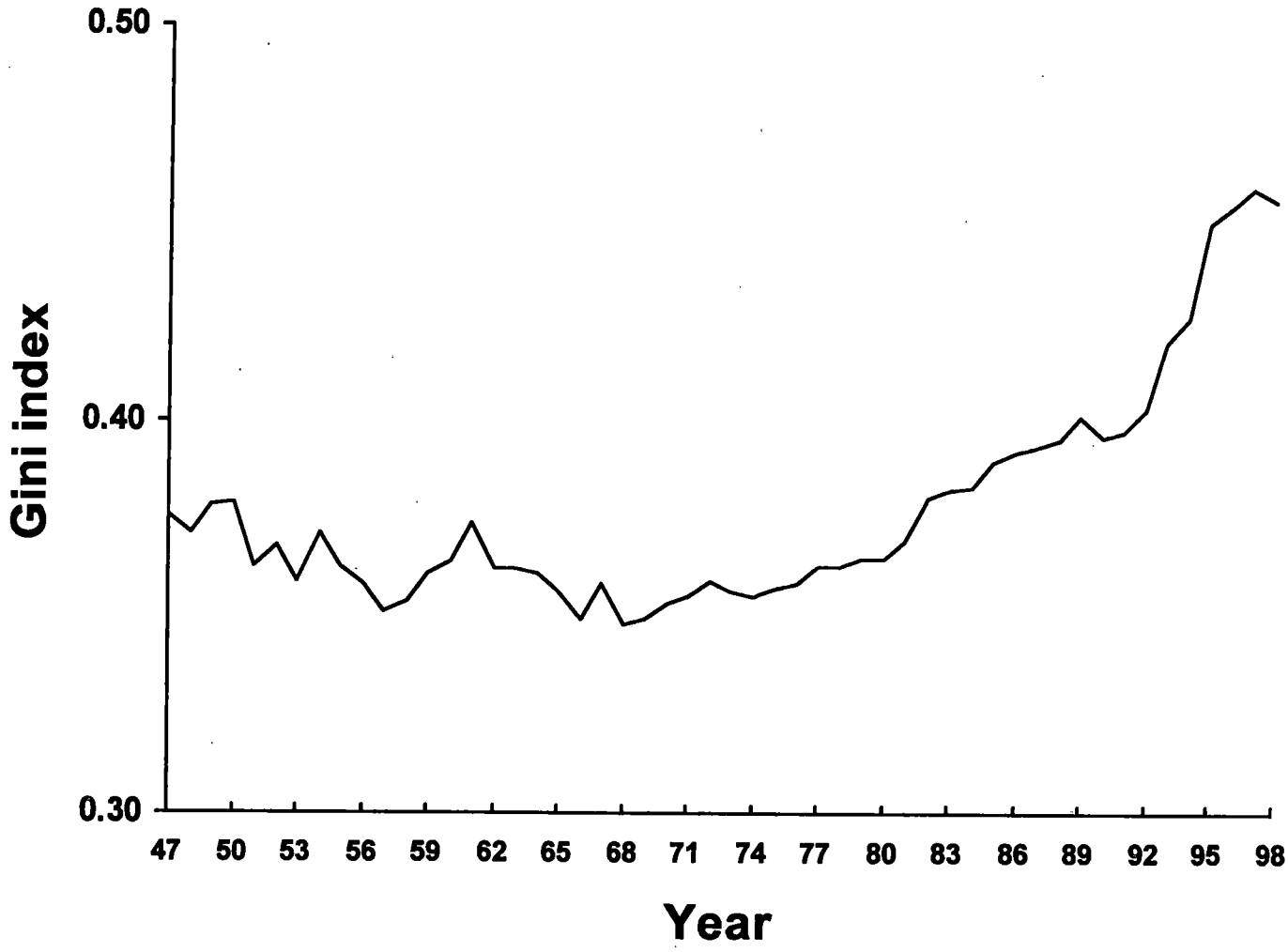

FIGURE 1. Gini Index of income inequity in the United States: 1947–1998 (data from the U.S. Bureau of the Census, 1999).

that is what I found. Using data from the *Survey of Income and Program Participation* (SIPP) put out by the U.S. Bureau of the Census, Fujiura et al. (1998) found modest but largely nonsignificant differences between groups within income level. For the most part, group differences occurred between those above and below the poverty threshold. The importance of incorporating poverty into any discussion of race and disability was stressed in their analysis.

The lack of differences across groups should not be interpreted as an indicator of the irrelevance of minority status. The population base is shifting due to differential birth rates, immigration, and exposure to risk. Fujiura et al. (1998) reported substantially greater growth in total numbers of persons with a disability from ethnic and racial minorities in the United States (50.4% growth in total population versus 11.3% for White non-Hispanics). Furthermore, significantly greater growth in absolute population size was seen across all age cohorts, with the greatest growth occurring among children.

Nonetheless, skin color is not the most relevant distinction. A policy agenda based only on race serves to exclude natural coalitions based broadly on need and inequity—a more stable common ground for our diverse groups. I will return to this point.

The Family

Why do we in the disability field partition deliberations regarding the family? In recent years, the more sophisticated concepts of disability have been anchored in the individual's experience and his or her interactions with environment and culture. Because the majority of people in this country do not live alone, it would seem that the context and character of household setting and those with whom it is shared should be a factor of considerable immediacy and importance.

The pie chart in Figure 2 graphically illustrates the importance of family context for adults with a disability (data adapted from Fujiura et al., 1998). Households were classified according to the status and age of the family member with the disability in the following order of precedence: household

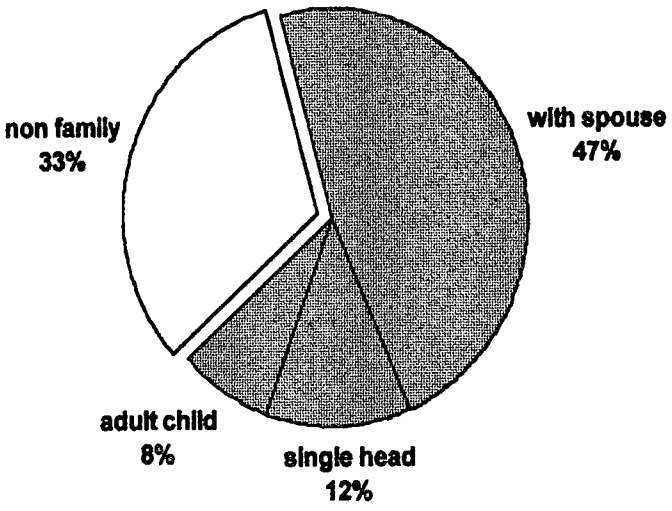

FIGURE 2. Household status of adults with a disability: 1993 *Survey of Income and Program Participation.*

head with a disability, spouse with a disability, adult child or other relative with a disability. (There were approximately 100,000 households with both an adult and a child under the age of 18 years identified as having a disability. These data were incorporated into summaries of both adult and child households.) The critical point in this figure that I want to emphasize is the fact that the vast majority (67.5%) of Americans with a disability live with spouses, are parents of children, or live as an adult in a parent or relative's home. Only a few live alone or with an unrelated roommate, but the family perspective is rarely the focus of disability policy. Family concerns, much like minority concerns, are often relegated to the category of "special interest."

In recent years, research on poverty has increasingly emphasized family and family structure (Lerman, 1996). Our disability demographics affirm the importance of the interrelationship of poverty status and family type (e.g., Fujiura, 1998). Poverty affects some families more than others. In the comparison shown in Figure 3, I have categorized poverty rates into "non-disability households" and "disability households" (households that include at least one child with a disability). It should be noted that single-head households are far more likely to live in poverty, which is to be expected. The effect is most pronounced among minority children. What is no-

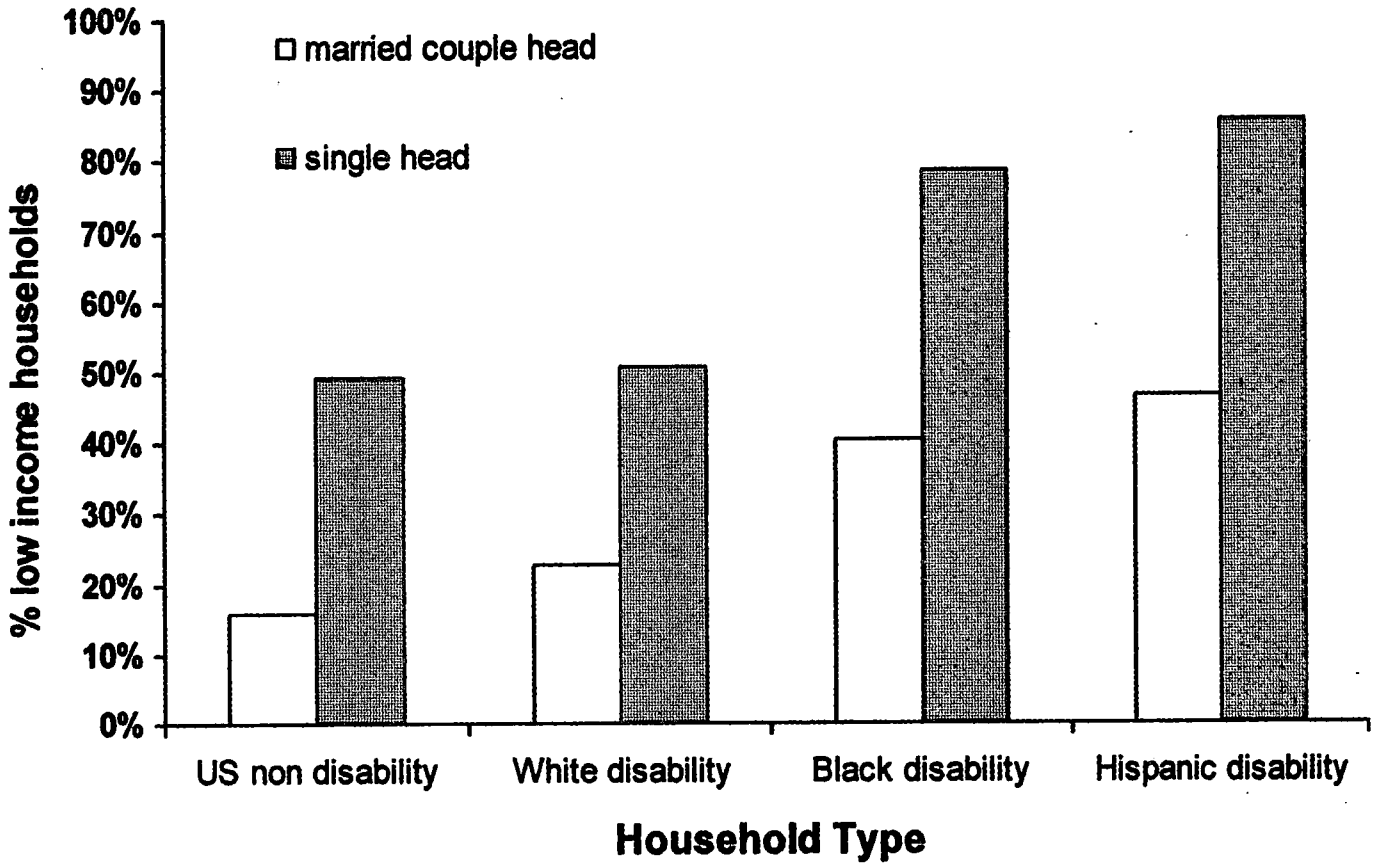

FIGURE 3. Proportion of low-income households with a child by family type: 1993 *Survey of Income and Program Participation.*

table in the statistics is the sheer magnitude of poverty among single-parent (primarily female-headed) households. The data for adults were not dissimilar, although less dramatic. If in this country you have a disability and you are from a minority group, odds are that you and your family live in poverty and that you will be poorer than others of your class and race.

The interpretation of these numbers is indeterminate at this time. To what extent do households fall into poverty because of the disability and loss of household income? To what extent is the disability an outcome? While compelling questions, they are less critical than the fact and extraordinary size of the constituencies.

In a recent study of childhood disability trends, we employed a statistical comparison of predictors of disability status using national data from the NHIS in 1983 versus 1996 (Fujiura & Yamaki, 2000). The intent of the analysis was relatively simple—to examine the increment in risk associated with single-parent families, poverty, and racial and ethnic group. In other words, does being Black or Hispanic in and of itself add to your risk beyond living in poverty or in an unstable household? (Asian and Native American children were excluded from the analysis due to extremely small sample sizes within some groups.) For the single-parent household, the estimated odds of a child having a disability were 55% higher in 1983 and 88% higher in 1996. Poverty was associated with an 86% increment in risk of disability in 1996. No additional risk was associated with racial or ethnic minority status once poverty and family status were statistically controlled. The single most profound factor emerging from the analysis was family type. Disability policy must address the family.

Universalism and Disablement

Coalitions with nondisabled constituencies are critical. This is not a recommendation so much as a restatement of what all of us know. A great deal of effort has already been invested in coalition building, and I include this in my list only as a reaffirmation of its importance. Minority initiatives within the disability community represent important awareness-raising efforts, but there is a danger that the agenda will become formulaic in approach, fragmented into so many isolated demonstration projects, and largely disconnected from larger social forces surrounding the disability field.

In the Fujiura and Yamaki (2000) logit regression, poverty emerged as a potent predictor of disability status during the 14-year interval between 1983 and 1996. The implications of the alteration in the relationship between poverty and disability prevalence were manifested in relatively flat rates of disability over time among children at or above the poverty level, contrasted against a sharp rise in rates among children below the poverty level after the mid-1980s. Similar trends are observed when plotting data across groups that are disproportionately exposed to poverty—minority groups and the single-parent family. Prevalence rates track sharply upward as well for Black children and children from single-parent families even when there are no statistical adjustments for poverty level.

Rising disability prevalence rates only among the poor suggests an exacerbation of the link between poverty and the family and disability. The meaning of this change is unclear at this time. Causal ambiguity confounds interpretation of the poverty–disability association. Was there greater exposure to conditions of risk? Conversely, does onset of disablement simply exaggerate existing financial problems among economically marginal families? Is the increase an illusion, representing greater awareness of disability rather than greater numbers? Certainly, effects such as these and other unidentified determinants operate simultaneously at some level of effect. Whatever the portrayal of causality, the data underscore the growing importance of poverty in the disability dialogue—whether as real increases in prevalence or greater recognition of need within the communities of the poor in the United States.

The point here is the importance of finding common cause in poverty policy and advocacy generally. Our perspectives on the population of Americans with a disability tend to be predicated, explicitly or not, on the assumption of fixed populations. We are forever trying to determine the prevalence of some condition, and much of our advocacy work focuses on expanding a base system of services measured against a relatively static population. Although issues of income and economic well-being represent long-held concerns for the disability community, the trend data suggest more fundamental policy challenges than providing greater outreach or culturally sensitive service delivery and technical assistance.

Other data on trends across race and economic status underscore the intersection of broader domestic policy concerns with disability priorities. Figure 4 illustrates the link among the aging, poverty, and disablement agendas within the context of minority concerns. (Only low-income persons in this country are represented in the figure.)

Despite the widely publicized declines in rates of disablement among the older population in this country, the link between aging and acquired disability is one of profound importance. It is a major dynamic in disability demography. The data trends illustrate three central themes:

1. the vulnerability of older Americans to significant functional limitations,
2. the extraordinary exposure of low-income older Americans to disability—largely attributable to the onset of chronic diseases or occupational injury, and
3. the longstanding and still continuing health crisis in the Native American community.

Employment data represent a third and final example of the need for finding "common cause" with other social reform initiatives. Comparing disability employment statistics across racial and ethnic groups introduces complexities in interpre-

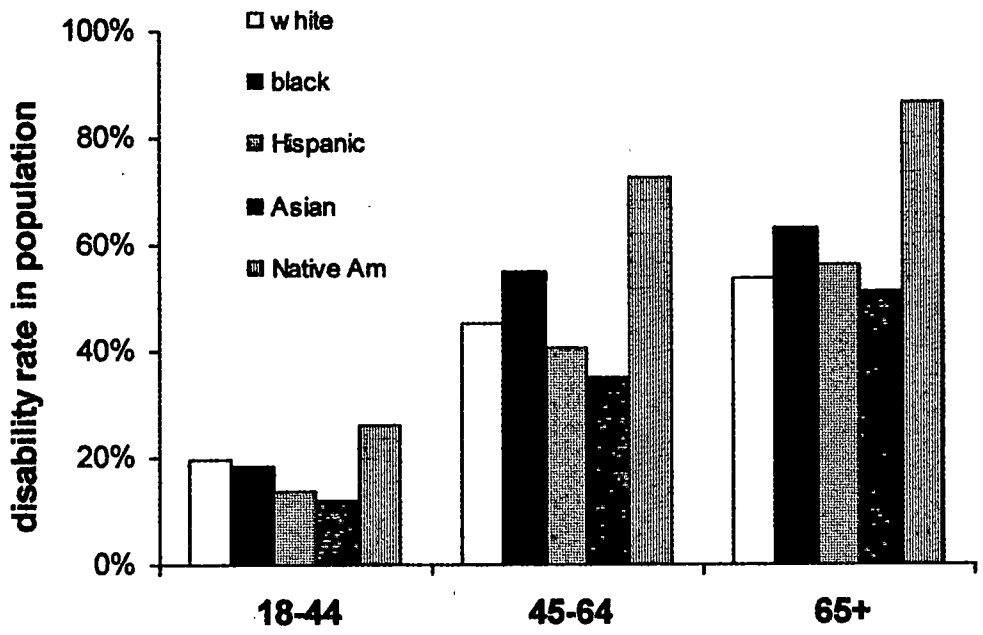

FIGURE 4. Adult disability prevalence among low-income Americans across age cohort: 1993 *Survey of Income and Program Participation.*

tation because of the early onset of chronic illness and greater exposure to occupational hazards among minorities. It is impossible to separate employment rate differences that are attributable to systematic biases such as lack of access or opportunity from a loss of capacity that affects minority workers to a greater extent (due to early onset of chronic illness, differential exposure to injury, etc.).

My focus in this area is on bias, and the data presented in Figure 5 are concerning a life-long condition, developmental disability. These data are based on national employment rates for Americans with a developmental disability (Yamaki & Fujiura, 1999). Shown on the left side of Figure 5 is the U.S. employment profile in 1990–1991. Approximately three quarters of all nondisabled Americans between the ages of 22 and 64 had worked during the month of the survey. On the right are summarized the employment statistics for White and Black Americans with a developmental disability. Estimates were excluded for Hispanic, Asian, and Native American groups due to high standard errors. Based on these data, it can be stated that if you have a significant disability, odds are your employment profile will be bleak. It is worse if you are a member of a minority group. The rate of employment overstates the actual employment picture. In the analysis of earnings using the SIPP, wage earnings are marginal at best (Yamaki & Fujiura, 1999).

Although it is true that the differences we see between Americans with and without a disability, and the differences we see between Americans who are White and those who are minorities, are compounded and exacerbated among minorities with a disability, the central point is that the core dynamics transcend the disability field itself. It is more than better methods of vocational training or placement services and outreach. Equity demands some hard analyses of the secondary employment market, issues of health-care access for the working poor, and our social welfare systems for the vulnerable so that a common cause can be found.

Cultural Competence

In 1968, the executive director of the Urban League, Whitney M. Young, made a presentation to a meeting of the International League of Societies for the Mentally Handicapped. He said, "The Negro has been studied, inspected, analyzed, and dissected ad infinitum. Thank you for so much attention" (1969, p. 26). Instead, he suggested, time would be better spent addressing bias, lack of access, the paucity of Black professionals, and the crushing poverty that puts Black children at risk.

I agree on the importance of the competence agenda, but individuals and organizations must not be deluded into the presumption that cultural competency is the sole form of redress for the core issues confronting minorities with a disability. It is a critical piece of the equity-and-access puzzle but not the only piece. Cultural competence, as commonly applied, plays out in our traditional professional–client contexts. We provide culturally competent services. We respect the cultural perspectives of those we serve (Jaskulski, 1993). However, a competency agenda that does not challenge organizations or individuals to directly address the source of inequity is only half a solution. In this case, one is merely better equipped to deal with the aftermath of those inequities.

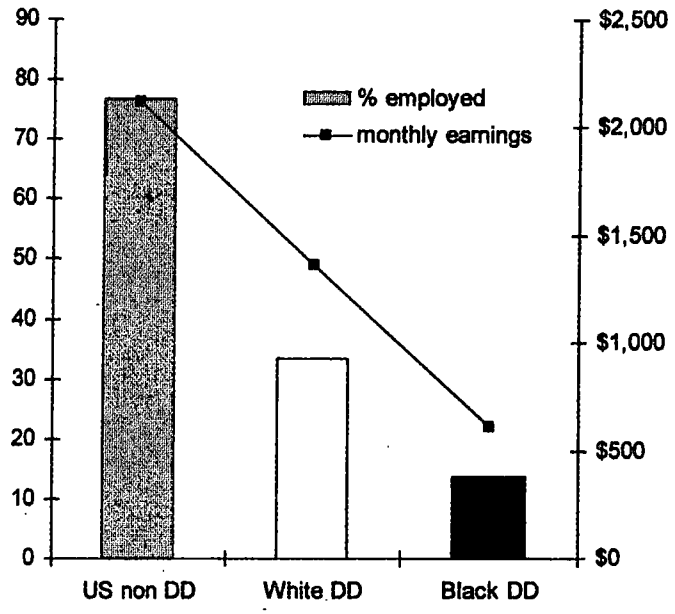

FIGURE 5. Employment and earning status for Americans with a developmental disability: 1990–1991 *Survey of Income and Program Participation.*

Policy Implementation

A report summarizing a national study of minority participation in the nation's disability system provided the following findings in its executive summary:

1. Poverty is one of the main impediments to participation and advocacy;
2. Minority persons do not have full knowledge of and do not fully utilize the services and programs of nearby agencies;
3. There has been a failure to bring minority clients and professionals into the mainstream of the movement;
4. Although minorities are proportionately represented among employees of disability service programs, they are rarely represented in the highest categories of employment as professionals or in administrative leadership;
5. Leadership is essential to remediate these problems; the field needs to expand outreach and technical assistance; providers need to be sensitive to ethnic needs and sensitivities; and consumers need to be directly involved on boards and advisory committees, and in research.

These findings and recommendations should strike the reader as both reasonable and familiar. Virtually all policy documents on minorities and disability incorporate some or all of these points (e.g., National Council on Disability, 1999; President's Committee on Employment of People with Disabilities, 1991). I should note also that these recommendations were taken from a report produced by the Bureau of Developmental Disabilities (the predecessor to the U.S. Administration on Developmental Disabilities) over two decades ago (Bureau of Developmental Disabilities, 1979)!

I am struck by the void in what we know about the implementation of the many minority and disability initiatives that were launched over the years. This is of more than academic interest. The long view can tell us about past mistakes or innovations that have been forgotten. What these events were and where they led should be important to those of us interested in informing the future. I would very much like us to invest some effort in understanding our past.

The constancy of the minority agenda over the years suggests that whatever good and innovative ideas were implemented for the previous generation, they either were inadequate in scope and magnitude or did not directly address core problems. I know that many projects have been funded, research conducted, and language inserted into our legislation, bylaws, and program standards. Most certainly these changes are having their cumulative, positive impact. But what has been the net effect of all the initiatives in the past two decades? How much greater is access now than before? To what extent have minority disability professionals assumed positions of leadership? How well do we understand how our own perspectives on race have affected our conduct and thinking in the field of disability? Not well, not yet.

Leadership

The notion of affirmative action is badly bruised today, but the premise—not of quotas, but of aggressive outreach, recruitment, and opportunity—must be held onto in the disability field. We should not let the backlash from affirmative action negatively affect the desperate need within our field to nurture a new and different generation of leadership. It will be a challenge. Minority recruitment initiatives, youth leadership programs, and the like have long been fixtures in the disability field. I cannot comment on their system-wide effectiveness. My impression is that there is a pool of professional talent increasing in both size and diversity. I would argue, however, for a reinvestment in the effort. I am increasingly concerned about two things—a "glass ceiling" for the few who have penetrated into management and a calcification into formulaic approaches: token representation on committees, councils, advisory panels, and similar roles ancillary to leadership in the field. It is extraordinarily difficult to find talented and capable professionals committed to working in the disability field.

U.S. Department of Education (1998) postsecondary statistics indicate that the number of minority graduate level students in disciplines related—directly or indirectly—to disability concerns is not compelling. In 1996 approximately 175,000 master's and doctoral degrees were awarded in the

social, psychological, health, education, and biological sciences. Of this total only 27,000 recipients were Black, Hispanic, Asian, or Native American. We have no national data on career-level decisions, but I suspect that the number of graduate students who commit to a disability-related field is far more discouraging.

The minority and disability agenda will not move forward without an active and passionately involved leadership. This requires a generation of professionals from minority constituencies with disabilities in positions of influence and power who find it in their own self-interest to change things. We need to recruit and mentor a very different generation of research, administrative, and professional leadership.

Concluding Comments

Does race matter? The intent of the charts and my analyses was not to dismiss color-based considerations within our field nor to support them but rather to suggest that "minority" issues are multilayered. Poverty, lack of access, and economic inequity confound and complicate discussions of race. My answer is equivocal—yes and no.

The dialogue we should engage in is multifaceted to those within the minority and disability movement. We must look beyond race. Skin color matters, but I do not think we have truly, deeply considered the *many ways* that it does and does not matter. Until we move beyond vague allusions to racism or discrimination and articulate the specifics of bias in the disability field, specific solutions will not be forthcoming. No, race does not matter, because a focus on color alone is—in the words of one political commentator—"reform on the cheap" (Page, 1999) and does not address underlying inequities of access across class lines in this nation.

To those who do not see themselves as directly invested in the minority and disability agenda, I state the obvious: One cannot avoid the significance of skin color in this country. Minority status in America serves as a proxy for inequity and for poverty and its attendant risks. A concern for "minority affairs" is a concern for issues infused into the very fabric of American life. In the realm of human service, one cannot *not* be concerned with minority affairs. The association of poverty status and other forms of social disadvantage to disability and minority status is a fixture in American disablement paradigms. Unfortunately, the topic has become something of a "white noise" in the field—acknowledged but largely relegated to the background of our deliberations. The demographic data and emerging trends highlighted here underscore the fundamental importance of inequity, across both color and class, for American disability policy.

ABOUT THE AUTHOR

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NOTE

When I use the word "Americans," I am referring to residents of the United States.

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The George Washington University
WASHINGTON DC

NATIONAL HEALTH POLICY FORUM

Expanding Community-Based Care: Is Olmstead Making a Difference?

Tuesday 25, 2003
The Washington Court Hotel
Ballroom

Speakers

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Senior Vice President
The Institute of Rehabilitation and Research
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Houston, TX 77030
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Frieden has worked in the independent living movement for severely disabled people since the early 1970s and has published several books and papers on independent living. From 1984 to 1988, he served as executive director of the National Council on Disability (then called the National Council on the Handicapped). In this capacity, he was instrumental in conceiving and drafting the Americans with Disabilities Act (ADA). Frieden has a bachelor's degree from Tulsa University and a master's degree from the University of Houston.

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Before joining CMS, Lutzky served as the chief of the Office on Disabilities and Aging within the District of Columbia's Medical Assistance Administration. He was also a senior manager with the Lewin Group and an analyst with the U.S. General Accounting Office. He has written and presented extensively on a variety of long-term care and disability issues. Lutzky received a Ph.D. in gerontology and public policy from the Andrus Center at the University of California and a master's degree from Cornell University.

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Rosenbaum is co-author of *Law and the American Health Care System*, a widely used health law textbook. From 1993 through 1994, she worked for the White House Domestic Policy Council, where she directed the drafting of the Health Security Act for President Clinton. Rosenbaum received her bachelor's degree from Wesleyan University and her law degree from Boston University Law School.

The George Washington University
WASHINGTON DC

NATIONAL HEALTH POLICY FORUM

EVALUATION FORM

SEMINAR TITLE: Expanding Community-Based Care: Is the *Olmstead* Decision Making a Difference?

SPEAKERS: Lex Frieden, Sara Rosenbaum, and Steven Lutzky

DATE: November 25, 2003

1) What is your overall rating of this meeting?

☐ Excellent ☐ Good ☐ Fair ☐ Poor

2) What is your rating of how well this meeting improved your understanding of this issue?

☐ Excellent ☐ Good ☐ Fair ☐ Poor

3) What did you particularly like about this program?

4) Was the background paper helpful? If so, how?

5) What did you dislike about this program?

6) What specific additional programs would you like to see on this issue?

7) What other topic areas would you like the Forum to address in its future programming?

8) Do you work for:

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☐ **Executive branch**
☐ **Foundation**
☐ **Trade association**
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National Health Policy Forum

Medicaid and the ADA in a *Post-Olmstead* World

Sara Rosenbaum
Hirsh Professor and Chair,
Department of Health Policy
The George Washington University Medical Center
School of Public Health and Health Services
November 25, 2003

Supported by a grant from the Center for Health Care Strategies.
Analyses available at www.chcs.org

Olmstead's Essential Framework for Subsequent Cases

- Institutionalization that is medically unjustifiable in the view of state officials constitutes legal discrimination under the ADA.
- Title II obligates reasonable modifications in public programs and services (including Medicaid where relevant). Fundamental alterations (changes in the essential nature of a program or service) lie beyond the power of courts to order and are a legislative matter.
- State officials can be ordered to make prospective, reasonable modifications despite 11th Amendment sovereign immunity in the case of claims for money damages or monetary relief
- Whether a requested change is a fundamental alteration or is happening at a reasonable pace is a question of fact
- A state defendant can meet the burden of showing compliance by showing an "effectively working" community integration plan moving at a "reasonable pace," broadly viewed.

The ADA's Judicial/Legislative Dichotomy Under ADA Title II

- Judicial
  - Empowered to inquiry into whether a requested change amounts to a "fundamental alteration" or a "reasonable modification" and whether the pace is "reasonable"
  - Empowered to order reasonable modifications on a prospective basis, even when the program is a legal entitlement subject to broad state design choices
  - Medicaid must meet the overarching requirements of the ADA and has related requirements of its own (e.g., non-discrimination in required services, promptness of medical assistance) that are subject to judicial enforceability
- Legislative
  - Considers fundamental alterations as part of the political process to promote the ADA's ultimate goal of community integration

In the Courts

- Powerful fact patterns are critical to both sides
- *Fundamental alteration v reasonable modification:* Courts appear to be less easily persuaded than previously thought that Medicaid changes should be classified as "fundamental."
  - Contrast *Rodriguez v City of New York* with *Townsend v Quasim, Henrietta v Bloomberg,* and *Fisher v Oklahoma Health Authority*
- *Reasonable pace:* Courts will pay close attention to the cumulative picture of a state's ongoing efforts to achieve change and will accord great discretion to a state's judgment regarding what is achievable (e.g., getting more money to grow a waiver program and community residence)
  - *Williams v Wasserman*

The Supreme Court Once Again Enters the Federalism Fray in Ways That Could Affect ADA Enforcement

- Tennessee Student Assistance Corp v Hood
  - Does Congress have the power under Article 1 to abrogate state sovereign immunity, even on a matter where it is specifically granted plenary national standard-setting powers (e.g. bankruptcy)?
  - Can a state be bound by national bankruptcy standards that permit a public debtor to discharge a state student loan?
- Frew v Hawkins
  - Do state officials waive their 11th amendment sovereign immunity when they voluntarily enter into a consent decree?
  - Does the 11th amendment bar enforcement of a decree unless plaintiffs can show that a federal right is violated by failure to comply? Does voluntary agreement to a consent decree create its own enforceable rights?

CMS' Efforts to Facilitate Individual Control and Community Integration for Individuals with Disabilities

Steven Lutzky, Ph.D.
Disabled and Elderly Health Programs Group
Center for Medicaid and State Operations
Centers & Medicare and Medicaid Services

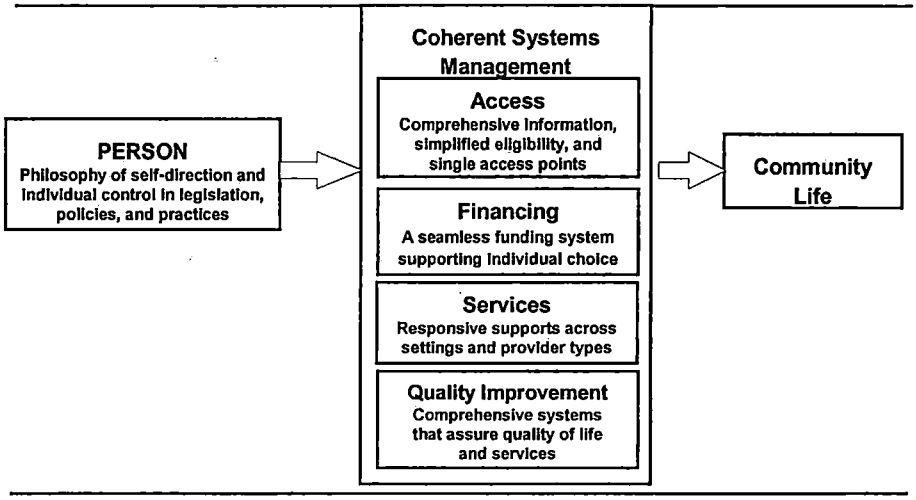
CMS Supports States in Redesigning their Medicaid Programs by:

- Providing leadership
- Technical assistance
- Grants
  - Real Choice Systems Change
  - Medicaid Infrastructure
  - Demonstration to Support Employment & Independence
  - Direct Service Community Worker
- Removing federal barriers

Providing Leadership – Applying a MFP Paradigm to Delivery Systems

- Currently, most support delivery systems are built around services
- Money Follows the Person (MFP) requires designing systems around the needs and preferences of the individual receiving the supports
- Two major tenets
  - Philosophy of Self-Direction and Individual Control
  - Community Integration
- Policy recently described in State Medicaid Director Letter

Key Building Blocks of a System in Which Money Can Follow the Person



CMS TA Approach Facilitates Cross-State Information Sharing

- Providing information from states with well developed programs or program components to other states
- Major mechanisms:
  - Real Choice TA Exchange – TA to grantees from participant states and other experts
  - MIG TA partners – TA to facilitate employment for individuals with disabilities
  - Annual Real Choice Systems Change conference
  - HCBS Clearinghouse – www.hcbs.org - contractor website
  - Promising Practices on the web at: www.cms.hhs.gov/promisingpractices

CMS Offers Several Categories of Grants to Assist Building Support Delivery Infrastructure

- Real Choice Systems Change
- Medicaid Infrastructure
- Demonstration to Support Employment & Independence
- Direct Service Community Worker

Removing Federal Barriers

- Streamlining waiver applications (Independence Plus)
- Providing expanded flexibility under current law
  - "Transitions" SMD letters
- Implementing new legislation
  - Medicaid "Buy-In"
- Proposing new legislation
  - President's FY 2004 NFI demonstrations

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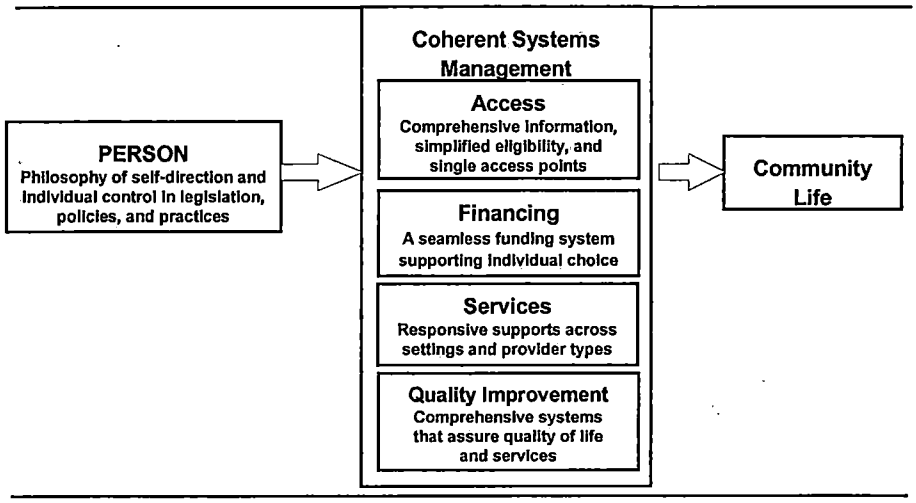

Philosophy of Self-direction and Individual-Control Incorporated into:

- Mission statement
- Policy guidelines
- Published rules or regulations
- Executive order
- Legislation

Coordinated Planning and Management of LTC Systems at the State level

- Combine separate agencies into one agency
- Create interagency agreements or other cooperative efforts between agencies
- Obtain key stakeholder involvement

Access to Long Term Supports

- Integrate access to multiple services, including the use of single point of entry systems
- Administratively streamline eligibility for Medicaid and/or HCBS
- Expand eligibility for Medicaid and/or HCBS
- Transition/divert individuals either currently in or at risk of entering institutions
- Assure informed consumer choices (e.g., through educational efforts, options counseling)

Finance – State Budgeting

- Consolidate funds for multiple long term care programs into one budget
- Shift funds from institutional care to home and community services

Finance - Reimbursement Rates and Methodologies

- Modify payment methodologies for individual services to meet individuals' needs and preferences
- Allow individual flexible HCBS budgets (e.g., Independence Plus, Cash & Counseling)
- Use of capitated budgets to cover home and community services as well as institutional and/or acute care costs.

Service Creation/Modification

- Add new services to existing programs
- Modify current services to meet individuals' needs and preferences
- LTC Workforce
  - Wage increases
  - Health insurance
  - Career path
  - Backup systems
  - Training/Education/Marketing
  - Worker organizations
  - Culture change

Quality Improvement

- Modify quality assurance systems to assure consistent with goal of self-direction
- Modify licensure/survey systems to assure consistent with goal of self-direction
- Build data-driven quality improvement systems

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CMS Offers Several Categories of Grants to Assist Building Support Delivery Infrastructure

- Real Choice Systems Change
- Medicaid Infrastructure
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Real Choice Systems Change Grants for Community Living

- Three round of grants
  - Currently have 101 grants for $165 million in 49 states
- States and others, in partnership with their aging and disability communities applied
- For use in building infrastructure to improve community long-term support systems
- Funds for "04 in President's Budget

Medicaid Infrastructure Grants (MIG)

- 11-year grant program to build infrastructure to support employment
- Grant award - $500,000 per year or 10 % of a state's Medicaid buy-in expenditures
- Total funds authorized at $150 million for 5 years (remaining year funds tied to inflation)
- States must cover personal assistance services (PAS). Continued funding is tied to expansion of PAS.
- Grant funds can be used to implement/expand Medicaid buy-in or other activities that will support employment
- Forty states and DC have been awarded grants to date

Demonstration to Improve the Direct Service Community Workforce (DSW)

- Addresses the DSW shortage and increasing demand
- Close to $6 million awarded to 5 organizations that provide direct care services to Medicaid recipients.
- The money can be used to implement a solution to the recruitment and retention problems faced by employers.
- Awards include three of proposals that provide of health insurance to workers.

DSW (cont.)

- Examples of projects that CMS received are:
  - transportation programs;
  - vacation incentive programs;
  - supervisory training;
  - career ladder wage increases;
  - tuition reimbursement; and
  - cultural competency training.
- Projects will last for three years and may be funded up to $750,000 or $1.5 million depending on whether provide health insurance

DSW (cont.)

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  - transportation programs;
  - vacation incentive programs;
  - supervisory training;
  - career ladder wage increases;
  - tuition reimbursement; and
  - cultural competency training.
- Projects will last for three years and may be funded up to $750,000 or $1.5 million depending on whether provide health insurance

Demonstration to Maintain Employment & Independence

- A 6-year $250 million program targets individuals who have a significant disabling condition - likely lead to disability
- This early intervention project provides Medicaid coverage to workers before they become unable to work
- Mississippi and the District of Columbia have implemented demos

Section 204 of TWWIIA Relating to Demonstration

- $250 million
- Must be spent by 2009
- Recommendation to Congress for continued funding by October 2004
- Population: those with potentially disabling conditions that are expected, without services and supports, to result in eligibility for Social Security Disability Program
- Applications from State Medicaid Agency.
- Independent evaluation

Demonstration – Current Thoughts on New Solicitation

- New solicitation is being prepared.
- Broadens population and services definitions
- Clarifies opportunities for 100% CMS funding vs. partial CMS funding
- Strengthens evaluation design criteria

Removing Federal Barriers

- Streamlining waiver applications (Independence Plus)
- Providing expanded flexibility under current law
  - "Transitions" SMD letters
- Implementing new legislation
  - Medicaid "Buy-In"
- Proposing new legislation
  - President's FY 2004 NFI demonstrations

President's 2004 Budget: New Freedom Initiative

- "Money Follows the Person" – Rebalancing Initiative
- Demonstration Programs
- Spousal Exemption
- Medicaid Presumptive Eligibility

"Money Follows the Individual" - Rebalancing Initiative (proposed 2004)

- "Level the playing field" between institutional and community-based services
- Create more cost-effective choices between institutional and community options
- $350 million per year for 5 years/total $1.75 billion
- One year of federal funding for individuals who transfer with state paying thereafter.
- Requirements/selection criteria for States to build infrastructure that supports:
  - Consumer control over services
  - Cost-effective delivery of HCBS (e.g., single point of access)

Other Proposals in 2004 Budget

- Alternatives to Residential Treatment Demonstration
- Two Respite Demonstrations (Adults/Children)
- Coverage of spouses of §1619(b)
- Presumptive eligibility for §1915(c) waivers
- Additional funding for Workforce Demonstrations
- $40 million in additional funds for Real Choice grants

Sources for Updates on *Olmstead* Implementation

National Council On Disability

www.ncd.org

George Washington University School of Public Health and Health Services

www.gwhealthpolicy.org/olmstead.html

Centers for Medicare and Medicaid Services

http://cms.hhs.gov/olmstead/default.asp

Human Services Research Institute
Gary Smith
gsmith@hsri.org

Status Report: Litigation Concerning Home and Community Services for People with Disabilities

www.hsri.org/index.asp?id=news

CMS' Efforts to Facilitate Individual Control and Community Integration for Individuals with Disabilities

Steven Lutzky, Ph.D.
Disabled and Elderly Health Programs Group
Center for Medicaid and State Operations
Centers & Medicare and Medicaid Services

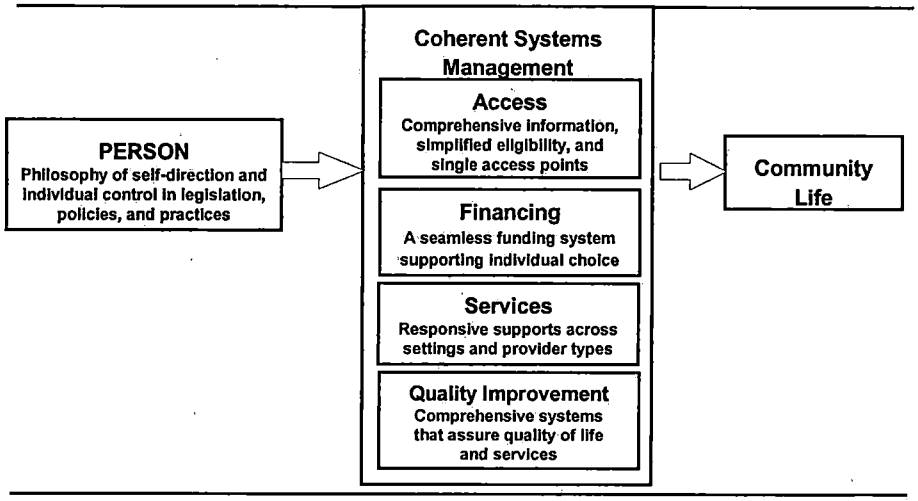
CMS Supports States in Redesigning their Medicaid Programs by:

- Providing leadership
- Technical assistance
- Grants
  - Real Choice Systems Change
  - Medicaid Infrastructure
  - Demonstration to Support Employment & Independence
  - Direct Service Community Worker
- Removing federal barriers

Providing Leadership – Applying a MFP Paradigm to Delivery Systems

- Currently, most support delivery systems are built around services
- Money Follows the Person (MFP) requires designing systems around the needs and preferences of the individual receiving the supports
- Two major tenets
  - Philosophy of Self-Direction and Individual Control
  - Community Integration
- Policy recently described in State Medicaid Director Letter

Key Building Blocks of a System in Which Money Can Follow the Person



CMS TA Approach Facilitates Cross-State Information Sharing

- Providing information from states with well developed programs or program components to other states
- Major mechanisms:
  - Real Choice TA Exchange – TA to grantees from participant states and other experts
  - MIG TA partners – TA to facilitate employment for individuals with disabilities
  - Annual Real Choice Systems Change conference
  - HCBS Clearinghouse – www.hcbs.org - contractor website
  - Promising Practices on the web at: www.cms.hhs.gov/promisingpractices

CMS Offers Several Categories of Grants to Assist Building Support Delivery Infrastructure

- Real Choice Systems Change
- Medicaid Infrastructure
- Demonstration to Support Employment & Independence
- Direct Service Community Worker

Removing Federal Barriers

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November 25, 2003

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America has the longest and richest history among nations in protecting the rights, and maximizing the opportunities, of people with disabilities. Organizations and individuals across this country have every reason to be proud of the efforts of citizen leaders, Republican and Democratic Presidents, Representatives, and Senators to secure the civil rights and legal protections that now exist.

People of all ages with disabilities want the same opportunities every American wants: not just to survive, but to thrive. They want to live in their own homes and make decisions about daily activities, so they can go to school, work, church, recreation, and can participate fully in their communities. Historically, people with disabilities have not always been allowed this birthright. Society has often focused on a person's disabilities rather than his or her abilities. But changes in philosophy and law have led to a new approach. People with disabilities are now recognized as wanting and being able to live in their own homes and other community settings and to lead satisfying and productive lives when provided the range of services and supports they need to do so.

And we have traveled a winding path on a number of roads to bring us to this point in American disability policy today.

The Independent Living Movement

During the 1960s and 1970s people with disabilities began to organize themselves to gain greater access to society and to challenge widely held stereotypic beliefs and attitudes about them. Influenced by the antiwar movement of the 1960s, the Black civil rights movement of the 1960s and the feminist movement of the 1970s, disability leaders began to articulate an agenda and engage in activities to promote their civil rights. Although there is no one defining event marking the birth of the independent living movement, the determination of a group of students with disabilities to attend the University of California at Berkeley in the 1960s is often considered the pivotal effort that began the disability rights movement. Those students were led by Ed Roberts, at the time a young man with significant disabilities who was determined to go to college.

The three cornerstones of the independent living philosophy are consumer sovereignty, self-reliance, and political and economic rights. The philosophy rejects the supremacy of professionals as decision makers and views disability as an interaction with the society and the environment rather than as a medical condition or physical or mental impairment.

Essential features of the independent living service model include consumer control, a cross-disability emphasis (inclusion of people with all types of disabilities--mental, physical, sensory), a community-based and community-responsive approach, peer role modeling, provision of a wide range of services, a community advocacy orientation and open and ongoing access to services.

Beginning in 1978, funding for independent living services was authorized through Title VII of the Rehabilitation Act. These funds were authorized to promote the development of service programs operated by and for people with disabilities. In 1979, 10 independent living center were funded throughout the country. Today there are hundreds of centers throughout the states, providing information and referral services, peer counseling, independent living skills training, and individual and systems advocacy.

The ADA

In 1990, the need for the ADA was compelling. In spite of heroic efforts by advocates, this country's existing laws and social benefit programs had proven inadequate. Vast numbers of individuals with disabilities lived in isolation and dependence. People with disabilities couldn't get a job, ride a city bus, or go to a restaurant or county library. We as a society had failed to eliminate attitudinal, architectural, and communications barriers.

Moreover, barriers in employment, transportation, public accommodations, public services, and telecommunications had imposed staggering economic and social costs on this country. We knew that each year federal, state, and local governments spent much more to support people with disabilities in their isolation than to promote their independence.

We were optimistic that the ADA would enable society to benefit from the skills and talents of individuals with disabilities. We knew that the ADA could allow us all to gain from the increased purchasing power of people with disabilities. We knew the ADA could lead to fuller, more productive lives for all Americans. It was our goal to bring millions of Americans with disabilities into the "mainstream" of American society.

Long-Term Services and Supports

The major source of public funding for long-term services and supports provided in home and community settings is the Medicaid program. Medicaid was first enacted in 1965 as a companion program to Medicare. It was designed as a joint Federal-state entitlement providing primarily medical care to low-income Americans. When first enacted, Federal Medicaid funding for meeting the long-term service needs of people with disabilities and chronic conditions was available mainly when the person was placed in an institutional setting (e.g., a nursing home), with few avenues for securing Medicaid dollars to support individuals in their homes and communities. State dollars (and, in some cases, Federal dollars) funded "home care" programs, but only on a limited basis.

In the 35 years since its enactment, Medicaid's "institutional bias" has been somewhat reduced through amendments to Federal laws and policy. These amendments have offered new options for states to fund comprehensive home and community long-term services. Beginning in the early 1980s, there has been an increase in the options available to states to secure Federal Medicaid dollars to underwrite long-term services and supports in home and other community settings. As a result, some states have expanded availability of these services for persons of all ages with physical and mental disabilities. Some states are leading the way in designing innovative and fiscally responsible ways to enable more persons with disabilities to receive necessary services in their communities instead of in institutions.

At one time, only a small portion of Medicaid long-term care spending was directed to home and community services. Today, 28 percent of long-term care spending is for such services, and these outlays are one of the fastest growing components of total Medicaid spending.

Some benefits may be offered through either the state's "regular" Medicaid program or through a home and community-based services (HCBS) waiver program. Moreover, a state may operate several HCBS waiver programs at once, each offering a distinct package of services and supports to a different group of individuals. These choices combine to give states considerable latitude in deciding which services and supports will be offered and in customizing benefit packages to meet the needs of particular groups. Medicaid home and community services are available to beneficiaries of all ages with many different types of physical and mental disabilities and chronic illnesses. Because of the way Medicaid was originally designed and has been amended over time, distinct programs were developed to provide services to certain categorical populations, most notably women with dependent children. In the long-term care context, covered categories include the "aged, blind, and disabled." These three populations account for the majority of Medicaid long-term care spending on home and community services, primarily through the personal care option, the HCBS waiver program, and the home health benefit. The "aged and disabled" categories taken together include people of all ages who have physical or mental disabilities, including serious mental illness, mental retardation, and other developmental disabilities.

Olmstead v. L.C.

Regardless of an individual's age or condition, all persons with disabilities and their families share common goals--to choose how to live their lives and to have some control over their daily activities in the most integrated settings. The recent Supreme Court decision in *Olmstead v. L.C.* affirmed the right of persons with disabilities to do just this.

The Court stated that institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life. Further, the Court noted that confinement in an institution severely diminishes the everyday life activities of individuals--including family relations, social contacts, work options, economic

independence, educational advancement, and cultural enrichment.[5] The Court also noted, however, that nothing in the Americans with Disabilities Act (ADA) condones termination of institutional settings for persons unable to handle or benefit from community settings, and that a state's responsibility, once it provides community-based treatment to qualified persons with disabilities, is not unlimited.

The Medicaid program can be an important resource to assist states in meeting the principles set out in the *Olmstead* decision. States may choose to utilize Medicaid funds to provide appropriate services in a range of settings from institutions to fully integrated community support.

As states work toward the goal of integrating persons with disabilities into the community, they may need to go through a process of fundamentally rethinking how programs serving people with disabilities should be structured and how long-term care resources should be allocated. The Medicaid program as currently structured provides many alternative ways to increase the availability of home and community services and still keep the costs of those services under control.

The Road to Be Traveled

America is being transformed. People with disabilities are beginning to assume their rightful roles as independent, self-supporting, involved citizens. But the type of fundamental change that we look for and need does not happen overnight.

Today, too many Americans fail to appreciate the essence of discrimination that people with disabilities still face in their daily lives. Many Americans still do not see the discriminatory barriers. Many Americans still remain trapped by society's stereotypes about disability. Many Americans still think the barriers faced by people with disabilities stem from their disabilities and not from what society has created.

The promises of the ADA, of *Olmstead*, of the Independent Living movement, of Long-term Services and Supports will be realized...and it will take hard work. So, how are we to ensure that America fulfills these promises?

thanks and acknowledgements

My role

provide historical background and philisophical underpinnings

medical advances – antibiotics – WW II

severely disabled – SCI, polio

civil rights movement

1968 – ABact

1972 – failed IL provisions

1973 – rehab act, 503, 504

1975 – EHA

1977 – Whitehouse Conference

1978 – 504 regs – Title 7 Rehab Act

1980 – government wide regulatory review – Bush

1984 – NCD review mandate

1986 – "Toward Independence"

1988 – NCD threshold

1990 – ADA

1995 – Olmstead filed

1999 – Olmstead decided

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People of all ages with disabilities want the same opportunities every American wants: not just to survive, but to thrive. They want to live in their own homes and make decisions about daily activities, so they can go to school, work, church, recreation, and can participate fully in their communities. Historically, people with disabilities have not always been allowed this birthright. Society has often focused on a person's disabilities rather than his or her abilities. But changes in philosophy and law have led to a new approach. People with disabilities are now recognized as wanting and being able to live in their own homes and other community settings and to lead satisfying and productive lives when provided the range of services and supports they need to do so.

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considered the pivotal effort that began the disability rights movement. Those students were led by Ed Roberts, at the time a young man with significant disabilities who was determined to go to college.

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Beginning in 1978, funding for independent living services was authorized through Title VII of the Rehabilitation Act. These funds were authorized to promote the development of service programs operated by and for people with disabilities. In 1979, 10 independent living centers were funded throughout the country. Today there are hundreds of centers throughout the states, providing information and referral services, peer counseling, independent living skills training, and individual and systems advocacy.

The ADA

The history of the United States has been marked by a constant evolution to open more doors, break down more barriers, and extend basic human rights to more and more people. It has been up to each generation in the United States to make good the promises of our founders, to extend constitutional rights to all Americans.

In 1990, the need for the Americans with Disabilities Act was compelling. In spite of heroic efforts by advocates, this country's existing laws and social benefit programs had proven inadequate. Vast numbers of individuals with disabilities lived in isolation and dependence. People with disabilities couldn't get a job, ride a city bus, or go to a restaurant or county library. We as a society had failed to eliminate attitudinal, architectural, and communications barriers.

Moreover, barriers in employment, transportation, public accommodations, public services, and telecommunications had imposed staggering economic and social costs on this country. We knew that each year federal, state, and local governments spent much more to support people with disabilities in their isolation than to promote their independence.

We who advocated for the ADA were optimistic that it would enable society to benefit from the skills and talents of individuals with disabilities. We knew that the ADA could allow us all to gain from the increased purchasing power of people with disabilities. We knew the ADA could lead to fuller, more productive lives for all Americans. It was our goal to bring millions of Americans with disabilities into the "mainstream" of American society.

In passing ADA (Public Law 101-336) in 1990, the Congress estimated that there were 43 million Americans with disabilities and found that these individuals had been isolated and segregated, faced restrictions and limitations, occupied an inferior status, and had been seriously disadvantaged. To remedy these problems, ADA established a clear and comprehensive prohibition of discrimination on the basis of disability. ADA defines disability as

(a) a physical or mental impairment that substantially limits one or more of the major life activities;

(b) a record of such an impairment; or

(c) being regarded as having such an impairment.

In trying to eliminate discrimination against all persons with disabilities, ADA's chief sponsor made it clear that the Act's definition of an individual with a disability was meant to be all-encompassing.

The spirit and intent of ADA are to strike a fair and proper balance between the rights of people with disabilities and the legitimate concerns of the public and private sector entities covered by the legislation. To strike that balance, the conceptual framework and language of ADA emphasize empowerment, independence, and inclusion of individuals with disabilities in all aspects of community life.

The Act prohibits discrimination in employment (Title I); public services including transportation (Title II); public accommodations (Title III); and telecommunications (Title IV). Title V covers miscellaneous areas such as

technical assistance. The ADA mandates that reasonable accommodations be provided to individuals with disabilities.

The phrase *reasonable accommodation* functionally means providing or modifying devices, services, or facilities, or changing practices or procedures in order to match a particular person with a program or activity. The underlying goal is to identify aspects of the disability that make it difficult or impossible for the person to perform certain aspects of the job, and then determine if there are any modifications or adjustments to the job environment or structure that will enable the person to perform the job. Title II applies, for example, to residential institutions, nursing homes, group homes, etc.

Undue hardship

Olmstead v. L.C.

Regardless of an individual's age or condition, all persons with disabilities and their families share common goals--to choose how to live their lives and to have some control over their daily activities in the most integrated settings. The recent Supreme Court decision in *Olmstead v. L.C.* affirmed the right of persons with disabilities to do just this.

L.C. and E.W. v. Olmstead case was brought in 1995 by the Atlanta Legal Aid Society on behalf of two women with mental retardation as well as psychiatric conditions who were patients in a state psychiatric hospital. The treating professionals in the hospital all agreed that they were appropriate for discharge into community programs, but slots were not made available. While the case worked its way through the courts, both women were placed in the community, where they have been doing very well. The case continued because the situation could arise again.

The state of Georgia asked the Supreme Court to decide "[w]hether the public services portion of the federal Americans with Disabilities Act compels the state to provide treatment and habilitation for mentally disabled persons in a community placement, when appropriate treatment and habilitation can also be provided to them in a State mental institution."

The case turned on the meaning of a regulation that the U.S. Department of Justice adopted to enforce Title II of the ADA, stating that:

"A public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities."

The Department of Justice had interpreted this regulation as requiring the community placement of institutional residents when the state's own treating professionals have recommended such placement.

In allowing the women's right to community placement, the 11th Circuit set a very high standard for a holding of "fundamental alteration" while also giving substantial deference to the Justice Department's analysis. It held that "by definition, where, as here, the State confines an individual with a disability in an institutional setting when a community placement is appropriate, the State has violated the core principle underlying the ADA's integration mandate."

In 1999, by a clear majority, the United States Supreme Court held in *Olmstead v. L.C.* that, under the Americans with Disabilities Act (ADA), undue institutionalization qualifies as discrimination by reason of disability and that a person with a mental disability is "qualified" for community living when the state's treatment professionals have determined that community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the individual, and the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others with mental disabilities.

Whereas the justices agreed that the state is not required to provide immediate relief in the form of community placement where such relief would represent a "fundamental alteration" of the state's programs, the majority did not agree on what constitutes a "fundamental alteration."

Only four justices agreed on the interpretation of the fundamental alteration defense set forth in Justice Ginsburg's opinion: that the defense should be construed to "allow the State to show that, in the allocation of available resources, immediate relief for the plaintiffs would be inequitable, given the responsibility the State has undertaken for the care and treatment of a large and diverse population of persons with mental disabilities."

Justice Ginsburg added that demonstrating that it has "a comprehensive, effectively working plan for placing qualified persons with mental

disabilities in less restrictive settings" is one method a state may use to show that it already has reasonably modified its programs and that no further alteration is necessary. This statement became the basis for the *Olmstead* planning initiatives.

In essence, the Court stated that institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life. Further, the Court noted that confinement in an institution severely diminishes the everyday life activities of individuals--including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment. The Court also noted, however, that nothing in the Americans with Disabilities Act (ADA) condones termination of institutional settings for persons unable to handle or benefit from community settings, and that a state's responsibility, once it provides community-based treatment to qualified persons with disabilities, is not unlimited.

As a result of the *Olmstead* ruling, the Clinton administration told states that it expected them to evaluate "all individuals with disabilities in institutional settings (such as state institutions, intermediate care facilities for the mentally retarded, nursing facilities, psychiatric hospitals and residential service facilities for children)," to see if their needs could be met in their communities.

Furthermore, through a June 2001 Executive Order the Bush administration declared that the Federal Government must assist States and localities to implement swiftly the Olmstead decision, so as to help ensure that all Americans have the opportunity to live close to their families and friends, to live more independently, to engage in productive employment, and to participate in community life.

Specifically, federal agencies are to work with States to help them assess their compliance with the Olmstead decision and the ADA in providing services to qualified individuals with disabilities in community-based settings, as long as such services are appropriate to the needs of those individuals.

These agencies are to provide technical guidance and work cooperatively with States to achieve the goals of Title II of the ADA, particularly where

States have chosen to develop comprehensive, effectively working plans to provide services to qualified individuals with disabilities in the most integrated settings. These agencies are to also ensure that existing Federal resources are used in the most effective manner to support the goals of the ADA. The Secretary of Health and Human Services has taken the lead in coordinating these efforts.

The Medicaid program can be an important resource to assist states in meeting the principles set out in the ADA and the *Olmstead* decision. States may choose to utilize Medicaid funds to provide appropriate services in a range of settings from institutions to fully integrated community support.

As states work toward the goal of integrating persons with disabilities into the community, they may need to go through a process of fundamentally rethinking how programs serving people with disabilities should be structured and how long-term care resources should be allocated. The Medicaid program as currently structured provides many alternative ways to: (a) increase the availability of home and community services and still keep the costs of those services under control, (b) decrease the numbers of unnecessary, costly, and overly restrictive institutional placements of individuals with disabilities. Institutional bias

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Expanding Community-Based Care:

Is the Olmstead Decision Making a Difference?

The Independent Living Movement

The 3 Cornerstones of IL

Consumer Sovereignty
Self-Reliance
Political & Economic Rights

--- 1978 ---

Title VII Added to Rehab Act

CIL: 4 Core Services

I & R
Peer Support
IL Skills Training
Systems & Personal Advocacy

The Americans with Disabilities Act

ADA
Definitions of Disability

--an impairment which limits major life activities

--a record of such impairment

--regarded as having such impairment

The Olmstead Decision

Pivotal DoJ Regulation re: Title II of ADA

Services administered in most integrated setting

Basis of Supreme Court Decision

Undue institutionalization equals discrimination

The road to be traveled

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Regardless of an individual's age or condition, all persons with disabilities and their families share common goals--to choose how to live their lives and to have some control over their daily activities in the most integrated settings. The recent Supreme Court decision in Olmstead v. L.C. affirmed the right of persons with disabilities to do just this.

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are incapable or unworthy of participating in community life. Further, the Court noted that confinement in an institution severely diminishes the everyday life activities of individuals--including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.[5] The Court also noted, however, that nothing in the Americans with Disabilities Act (ADA) condones termination of institutional settings for persons unable to handle or benefit from community settings, and that a state's responsibility, once it provides community-based treatment to qualified persons with disabilities, is not unlimited.

The Medicaid program can be an important resource to assist states in meeting the principles set out in the Olmstead decision. States may choose to utilize Medicaid funds to provide appropriate services in a range of settings from institutions to fully integrated community support.

As states work toward the goal of integrating persons with disabilities into the community, they may need to go through a process of fundamentally rethinking how programs serving people with disabilities should be structured and how long-term care resources should be allocated. The Medicaid program as currently structured provides many alternative ways to increase the availability of home and community services and still keep the costs of those services under control.

The Road to Be Traveled

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Today, too many Americans fail to appreciate the essence of discrimination that people with disabilities still face in their daily lives. Many Americans still do not see the discriminatory barriers. Many Americans still remain trapped by society's stereotypes about disability. Many Americans still think the barriers faced by people with disabilities stem from their disabilities and not from what society has created.

The promises of the ADA, of Olmstead, of the Independent Living movement, of Long-term Services and Supports will be realized...and it will take hard work. So, how are we to ensure that America fulfills these promises?

In Olmstead v. L.C., the U.S. Supreme Court, in interpreting the ADA and its implementing regulation 28 C.F.R. § 41.51(d), held that "[u]njustified isolation ... is properly regarded as discrimination based on disability." The logical consequence, the Court held, is that in appropriate circumstances, "proscription of discrimination

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services.

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Part III-B of Justice Ginsburg's opinion, joined by four Justices, rejected the court of appeals' formulation of the fundamental alteration test as the reasonableness of the marginal cost of a handful of additional community placements measured against the state's entire mental health budget. Obviously, the marginal cost will be such a small fraction that "it is unlikely that a state ... could ever prevail" under that test. Justice Ginsburg192 also rejected the cost-comparison test employed by the district court and expressed her concern that this would lead to overall increases in expenses without enabling the state "'to take advantage of the savings associated with the closure of institutions.'"193 Rather, she stated, "Sensibly construed, the fundamental-alteration defense would allow the State to show that, in the allocation of available resources, immediate relief for the plaintiffs would be inequitable, given the responsibility the State has undertaken for the care and treatment of a large and diverse population of persons with mental disabilities."

Justice Ginsburg then invoked the need to provide "a range of facilities," citing the need to provide a high level of support and supervision for those who need it to avoid improperly "dumping" persons with disabilities in homeless shelters and similar inappropriate settings. Justice Ginsburg suggested that states might need to maintain institutions for some persons. But she drew a remarkable conclusion from these assumptions:
To maintain a range of facilities and to administer services with an even hand, the State must have more leeway than the courts below understood the fundamental-alteration defense to allow. If, for example, the State were to demonstrate that it had a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated, the reasonable-modifications standard would be met.195

This conclusion is remarkable because it seems based on recognition of the relationship between the rights and needs of individuals and the configuration of the state's service system as a whole. Although Justice Ginsburg characterizes her standard as more generous to the state than the court of appeals' standard, in fact, the opposite is probably true under the facts of most deinstitutionalization cases. The "marginal cost" calculation invoked by the court of appeals would tilt in favor of the

state when the number of persons with disabilities seeking community placement is large. In contrast, Justice Ginsburg's standard would not require a "fundamental alteration" when large numbers of persons with disabilities are inappropriately placed in institutions. In a case in which the evidence shows that the entire population of a state institution could be relocated to the community where all institutional residents could receive better services at lower cost, it is difficult to see how the state could prove that community placement for all residents represented a "fundamental alteration."

Thus, while a clear majority of the Court held that unnecessary institutionalization of persons with disabilities represents discrimination and that unnecessarily institutionalized persons with disabilities have a right to community placement unless the state can show that community placement would represent an undue burden, only four members of the Court could agree on a single definition of "fundamental alteration." At least five members of the Court agreed, however, that states do not have discretion to keep persons with disabilities unnecessarily institutionalized for unreasonable lengths of time and that the state must at the very least maintain a waiting list that moves at a reasonable pace. The concluding statement of Justice Ginsburg's opinion seems to be a fair statement of the principles on which at least five Justices_agreed: States are required to provide community-based treatment for persons with mental disabilities when the State's treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated taking into account the resources available to the State and the needs of others with mental disabilities.

Expanding the Community-Based Care: Is the Olmstead Decision Making a Difference?

November 25, 2003

Remarks by Lex Frieden

America has the longest and richest history among nations in protecting the rights, and maximizing the opportunities, of people with disabilities. Organizations and individuals across this country have every reason to be proud of the efforts of citizen leaders, Republican and Democratic Presidents, Representatives, and Senators to secure the civil rights and legal protections that now exist.

People of all ages with disabilities want the same opportunities every American wants: not just to survive, but to thrive. They want to live in their own homes and make decisions about daily activities, so they can go to school, work, church, recreation, and can participate fully in their communities. Historically, people with disabilities have not always been allowed this birthright. Society has often focused on a person's disabilities rather than his or her abilities. But changes in philosophy and law have led to a new approach. People with disabilities are now recognized as wanting and being able to live in their own homes and other community settings and to lead satisfying and productive lives when provided the range of services and supports they need to do so.

And we have traveled a winding path on a number of roads to bring us to this point in American disability policy today.

The Independent Living Movement

During the 1960s and 1970s people with disabilities began to organize themselves to gain greater access to society and to challenge widely held stereotypic beliefs and attitudes about them. Influenced by the antiwar movement of the 1960s, the Black civil rights movement of the 1960s and the feminist movement of the 1970s, disability leaders began to articulate an agenda and engage in activities to promote their civil rights. Although there is no one defining event marking the birth of the independent living movement, the determination of a group of students with disabilities to attend the University of California at Berkeley in the 1960s is often considered the pivotal effort that began the disability rights movement. Those students were led by Ed Roberts, at the time a young man with significant disabilities who was determined to go to college.

The three cornerstones of the independent living philosophy are consumer sovereignty, self-reliance, and political and economic rights. The philosophy rejects the supremacy of professionals as decision makers and views disability as an interaction with the society and the environment rather than as a medical condition or physical or mental impairment. Essential features of the independent living service model include consumer control, a cross-disability emphasis (inclusion of people with all types of disabilities--mental, physical, sensory), a community-based and community-responsive approach, peer role modeling, provision of a wide range of services, a community advocacy orientation and open and ongoing access to services.

Beginning in 1978, funding for independent living services was authorized through Title VII of the Rehabilitation Act. These funds were authorized to promote the development of service programs operated by and for people with disabilities. In 1979, 10 independent living center were funded throughout the country. Today there are hundreds of centers throughout the states, providing information and referral services, peer counseling, independent living skills training, and individual and systems advocacy.

The ADA

In 1990, the need for the ADA was compelling. In spite of heroic efforts by advocates, this country's existing laws and social benefit programs had proven inadequate. Vast numbers of individuals with disabilities lived in isolation

and dependence. People with disabilities couldn't get a job, ride a city bus, or go to a restaurant or county library. We as a society had failed to eliminate attitudinal, architectural, and communications barriers.

Moreover, barriers in employment, transportation, public accommodations, public services, and telecommunications had imposed staggering economic and social costs on this country. We knew that each year federal, state, and local governments spent much more to support people with disabilities in their isolation than to promote their independence.

We were optimistic that the ADA would enable society to benefit from the skills and talents of individuals with disabilities. We knew that the ADA could allow us all to gain from the increased purchasing power of people with disabilities. We knew the ADA could lead to fuller, more productive lives for all Americans. It was our goal to bring millions of Americans with disabilities into the "mainstream" of American society.

Long-Term Services and Supports

The major source of public funding for long-term services and supports provided in home and community settings is the Medicaid program. Medicaid was first enacted in 1965 as a companion program to Medicare. It was designed as a joint Federal-state entitlement providing primarily medical care to low-income Americans. When first enacted, Federal Medicaid funding for meeting the long-term service needs of people with disabilities and chronic conditions was available mainly when the person was placed in an institutional setting (e.g., a nursing home), with few avenues for securing Medicaid dollars to support individuals in their homes and communities. State dollars (and, in some cases, Federal dollars) funded "home care" programs, but only on a limited basis.

In the 35 years since its enactment, Medicaid's "institutional bias" has been somewhat reduced through amendments to Federal laws and policy. These amendments have offered new options for states to fund comprehensive home and community long-term services. Beginning in the early 1980s, there has been an increase in the options available to states to secure Federal Medicaid dollars to underwrite long-term services and supports in home and other community settings. As a result, some states have expanded availability of these services for persons of all ages with physical and mental disabilities. Some states are leading the way in designing innovative and fiscally responsible ways to enable more persons with disabilities to receive necessary services in their communities instead of in institutions.

At one time, only a small portion of Medicaid long-term care spending was directed to home and community services. Today, 28 percent of long-term care spending is for such services, and these outlays are one of the fastest growing components of total Medicaid spending.

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