



HOWARD UNIVERSITY

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2900 Van Ness Street, N.W. Washington, DC 20008

(202) 806-8086 • Fax (202) 806-8148 • TDD (202) 244-7628 • e-mail [swalker@howard.edu](mailto:swalker@howard.edu)

**DIVERSITY MATTERS:  
Infusing Issues of People with Disabilities from Underserved  
Communities into a Trans-disciplinary Research Agenda in  
the Behavioral and Social Sciences**

*Bridging Gaps:  
Refining the Disability Research Agenda for Rehabilitation and the Social Sciences  
Hyatt Regency Hotel on Capitol Hill  
Washington, DC  
May 29-31, 2002*

**Theda Zawaiza  
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The Howard University Research and Training Center  
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**Copies of this report may be obtained by writing to:**

Dr. Sylvia Walker, Director  
Howard University Research and Training Center for Access to  
Rehabilitation & Empowerment Opportunities  
Howard University  
2900 Van Ness Street, N.W.  
Holy Cross Hall, Suite 100  
Washington, D.C. 20008

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**DIVERSITY MATTERS:  
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Trans-disciplinary Research Agenda**

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## I. Introduction and Purpose of Report

"It is not an exaggeration to believe that we can save this nation billions of dollars over the coming decade if we apply ourselves well, do good research and if we apply that research to public policy."

■ *Brian Baird*  
*U.S. House of Representatives, Co-chair of the Congressional Health and Behavior Caucus, at the launching of the Decade of Behavior, March 25, 2000.*

In the 21<sup>st</sup> century there continue to be millions of Americans with disabilities challenged by barriers to their independence and meaningful participation in the mainstream of society. Instead of being endowed with the unalienable rights of life, liberty and the pursuit of happiness, these individuals are relegated to the bottom rungs of society, often marginalized and demoralized by service delivery systems that cannot relate to them; stymied by paternalism and denied opportunities to reach their full potential.

Society has historically imposed barriers—attitudinal barriers (such as fear, ignorance, prejudice, stereotypes), physical barriers (such as architecture, communication, and institutional barriers (such as policies and procedures) on people with disabilities. Likewise, society has historically imposed some of these same barriers and others on individuals from racial and ethnic minority groups. The literature shows that there is an enduring need to equalize opportunities for minority persons with disabilities and implicates barriers to access and disparities in the quantity and quality of services.

In a recent report, The National Council on Disability identified a host of barriers to full participation by minority individuals with disabilities: Among them were the lack of culturally appropriate outreach, language and communication barriers, attitudinal barriers, and the shortage of minority individuals in the disability service professions. Some of the attitudinal barriers include: a lack of trust on the part of minority consumers; services that do not typically demonstrate respect for different cultural values and beliefs; fear regarding intentions of professionals requesting information; and patronizing approaches when serving minority persons.<sup>1</sup>

These are barriers that, with behavioral changes, could have been prevented or mitigated. Social and behavioral science research addresses a number of society's most intractable yet preventable problems. In March 2002, the American Psychological Association officially launched the *Decade of Behavior*, an interdisciplinary effort to promote the importance of behavioral and social science research.<sup>2</sup> The initiative's five themes

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<sup>1</sup> National Council on Disability (2000). *Carrying on the good fight: Summary paper from Think Tank 2000: Advancing the civil and human rights of people with disabilities from diverse cultures.*

<sup>2</sup> APA's Board of Scientific Affairs and science directorate began developing the idea for a *Decade of Behavior* in 1997 and were joined quickly by the Federation of Behavioral, Psychological and Cognitive

include health, education, safety, prosperity and democracy. The *Decade of Behavior* is designed to raise the visibility of insights gleaned from the behavioral and social sciences and highlight how research on behavior can be used to tackle some of society's most troubling problems.

In order to maximize the reliability and validity of behavioral research, underserved communities and sub-populations must be integral to, and infused throughout, that research. In this context, underserved communities refer to people who are racial and ethnic minorities, often from rural and/or remote areas and are poor, linguistically diverse and/or migrant. These communities historically have been overlooked in research, poorly served in policy and practice and consequently, underachieve on all measures of success and well being. The purpose of this report is to identify gaps in the behavioral and social science research agenda as they pertain to people with disabilities from underserved communities. This information, gathered from experts across the country, will be used to help develop a trans-disciplinary social and behavioral science research agenda.

Racial and ethnic diversity is not an agenda, rather it is a fact of our world. The United States has always been a culturally pluralistic society but is only now beginning to acknowledge and value diversity as a national strength, honoring the contributions of all peoples. Immigration has played a major role in increasing the diversity of the population especially in the rapid growth of the Asian and Hispanic populations. However, a report released in September, 1999, by the Center for Immigration Studies says that the number of impoverished people in the nation's immigrant-headed households nearly tripled from 2.7 million in 1979 to 7.7 million in 1997. This disturbing trend has been referred to as the "foreignization of poverty" and is one of the critical variables in a discussion of disability and race.

According to the Survey of Income and Program Participation (SIPP), the overall rate of disability in the U.S. population is 20.6 percent. Native American Indians have the highest rate of disability of any racial/ethnic group (23.9 percent), followed closely by blacks (21.6 percent) and whites (21.4 percent), while those of Hispanic origin have a significantly lower rate (16.2 percent). For Asians and Pacific Islanders, the disability rate is 12. percent. Blacks have the highest rate of severe disability.<sup>3</sup>

A cautionary note is warranted here. While statistics are useful tools for policy analysis and other activities, they do not describe any one individual. Researchers are quick to point out that "When a professional is working with a specific individual, statistics can be misleading or worse, they can be grossly misused to reinforce stereotypes and justify exclusion."<sup>4</sup> The use of statistics is confounded further when you consider that the main

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Sciences and the Consortium of Social Science Associations. More than 50 scientific organizations have joined the initiative (see Appendix C) as have over a dozen federal agencies [www.decadeofbehavior.org](http://www.decadeofbehavior.org).

<sup>3</sup> Census 2000, U.S. Department of Labor

<sup>4</sup> Kirchner, C. and Schmeidler, E. (1999). Life chances and ways of life: Statistics on race, ethnicity, and visual impairment. *Journal of Visual Impairment and Blindness*, 93(5), 319-324.

categories identified in civil rights laws such as “Hispanic” or “Asian” are extremely heterogeneous with many within group differences.

For example, Asian-Americans can include Chinese, Japanese, and Korean descendants as well as Filipinos, Pacific Islanders, and Southeast Asians, i.e., Cambodians and Vietnamese. Hispanic populations can hail from, among other places, Mexico, Puerto Rico, Cuba, other Caribbean Islands, and Central and South America.

Another caveat is that while rates of disability within Asian and Hispanic populations are significantly lower than the general population, some researchers believe these estimates do not accurately reflect the reality of the prevalence of disability. Variables such as immigration status and the perception of disability within a particular culture have an impact on the self-reported rate of disability within some sub-populations.<sup>5</sup>

With regard to the impact of race, the NCD report goes on to say, “One of the major hindrances to equity in American society is the attitude of the majority towards members of minority racial and ethnic groups. The world of disability policy and programs is not immune to this societal problem. Attitudes shape expectations, services provided, resources employed, and outcomes. The unfinished business of race relations in America has a devastating impact on people with disabilities from minority groups.”

Due to the efforts of grassroots consumers, advocates and those committed to advancing civil and human rights, federal disability policies now have in common the notion that disability is a natural part of the human experience and in no way diminishes the right of individuals to live independently; enjoy self-determination; make choices; contribute to society; pursue meaningful careers and enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream of American society. Newly introduced legislation aims to further ensure community integration and self-determination.<sup>6</sup> However, the promise of these policies has not been realized by a majority of people with disabilities especially those from underserved communities.

Federal disability policies promote two critical overarching principles: Universal design and Individual choice. Universal design refers to the way in which something is structured. Universal design is one where most people, including people with disabilities, have easy access. This concept applies to policies as well as programs, products, and procedures; from architectural design to designs for outreach to parents. Individual choice strikes at the heart of what it means to be an American—the right to decide how one will live one’s life. The authority to make decisions about questions as essential as “Where will I live?” “Where will I go to school?” and “How will I make a living?” historically had been removed from the person with a disability and given to the provider.

Federal disability policies are designed to move federal and state programs forward—in this instance, away from medical models that consumers found paternalistic and toward

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<sup>5</sup> Special Edition on Race and Ethnicity (1999) *Journal of Visual Impairment and Blindness*, 93(5), 319-324.

<sup>6</sup> MiCASSA, S. 1298, Medicaid Community-based Attendant Services and Supports



models that are inclusive, supportive, empowering, and holistic. Most of these policies focus on systemic change, i.e., changing the systems that provide services to people with disabilities.<sup>7</sup> Over the past three decades there has been a progressive movement toward increasingly more integration of people with disabilities into the mainstream of society utilizing advances in assistive, information and electronic technologies and findings from social and behavioral science research regarding best practices and new models. What effect, if any, has the new perspective in policy had on research? What are the implications for research? and How can research help meet the challenge of these initiatives?

Behavioral and social science research can yield new knowledge and understanding using the current and widely-agreed upon conceptual paradigm that maintains disability is a product of interaction between characteristics of the individual and characteristics of the natural, built, cultural, and social environments. Such research, applied and coupled with federal disability policies, has the potential of ameliorating many of the problems plaguing people with disabilities generally and particularly those from underserved communities and/or social environments who have been overlooked.

National research in the behavioral and social sciences is not spawned from a monolithic agenda. Rather, there are a host of loosely-affiliated agendas, at best and at worst, a heterogeneous group of agendas written in isolation from and without coordination between each other. These agendas, from the Centers for Disease Control to the National Institutes of Health have at least one thing in common; the goal of generating new knowledge and understanding that can be applied to solve some of society's toughest problems.

Federal disability policy and social and behavioral research are instruments of change, tools to be applied to bring about new ways of addressing and solving old problems. Each informs the other and as partners in change can effectuate enormous progress. Individuals with disabilities from diverse cultures ought to be a priority component of federal policies and research agendas because the number of minorities with disabilities is increasing and probably will continue to increase; disability within this population is disproportionately high, and the existing body of research literature on this population is woefully sparse.

## **II. Background on Conference and Format**

***Bridging Gaps: Refining the Disability Research Agenda for Rehabilitation and the Social Sciences***, a conference on the needs and gaps in the behavioral and social sciences research agenda, will be held May 29-31, 2002, at the Hyatt Regency Washington on Capitol Hill in Washington, DC. The conference is co-sponsored by the National Institute on Disability and Rehabilitation Research (NIDRR), Office of Special Education and Rehabilitative Services, U.S. Department of Education and the American

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<sup>7</sup> Silverstein, R. (2002). Framework of Federal Disability Policy. Center for the Study and Advancement of Disability Policy. Washington, DC.

Psychological Association (APA), Division 22 (Rehabilitation Psychology). The Research and Training Center and Continuing Education Center at the University of Wisconsin-Stout and the Howard University Research and Training Center for Access to Rehabilitation and Empowerment Opportunities (HURTC) will host the two and one-half day event.

The purpose of the conference is to gather stakeholder input that can be used to refine and develop a transdisciplinary research agenda in the social and behavioral sciences that contributes to gainful, meaningful, and purposeful participation of people affected by disability in their communities. It is also intended that the findings will serve to guide rehabilitation sciences by defining common goals of stakeholders; encourage the inclusion of persons with disabilities in the entire rehabilitation process; and promote the development of practice, leadership, and research capacities among a diverse population of future generations of leaders in the field.<sup>8</sup>

One of the HURTC's roles is to ensure that the conference includes issues related to the needs of persons with disabilities from underserved communities. This task is particularly important given the current and widely-agreed upon conceptual paradigm that maintains disability is a product of interaction between characteristics of the individual and characteristics of the natural, built, cultural, and social environments. There are a number of variables (including changing demographics, the impact and severity of disability within culturally diverse racial/ethnic groups, low income and underserved communities) which make it critical to include issues of diversity and low income status in the forthcoming conference.

The HURTC sponsored eleven regional focus groups via teleconference to garner this input. In preparation for the conference call, each participant was asked to review background material (including the organizing themes and areas of application that will be used during the May conference) and to provide at least three research priorities in the areas of behavioral and social sciences and their ranking.

### **Organizing Themes and Areas of Application**

Four organizing themes and three areas of application were identified to guide paper development and input from the field. Four panels will be convened at the conference, each covering one theme. Papers will be prepared and presented on applied areas of practice, policy, and public interest for each of the four themes. Input will be sought from stakeholders specific to each theme and area of application.

### **Organizing Themes**

According to the conference steering committee, these themes were selected because they cross over public and private sector investments in social, medical, technological, economic, policy, and institutional research, both nationally and internationally. These four themes are primary areas of peoples' lives that are affected by disability. The

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<sup>8</sup> University of Wisconsin-Stout, 2002

Committee suggests that these areas are thought to be social environments that are positively and negatively affected by disability and may be manipulated to alter positively and negatively the consequences of disability.

1. **Employment**, including status, changes, measures, conditions, models, impacts, benefits, and alternatives for productive activity.
2. **Well-being**, including physical, psychological, social, and medical dimensions and considers measurement; interaction and integration of behavioral and bio-medical systems; public and private practices and systems; advocacy issues; public and resource constraints.
3. **Community participation**, including independence and independent living; indicators of status; roles played by relationships, peer mentoring, choice and control, culture, individual and disability appropriateness; and models, measures, and alternative perspectives on quality participation.
4. **Resources**, including information, access, choice, subsidies, costs, funding, and other insurance; methods for delivery as systems, programs, services, and practices; technology (medical, rehabilitation); transportation (availability, funding, alternatives); housing (location, cost, choice).

### **Areas of Application**

**Practice** papers would focus on issues for research related to how, with what, when, why, and to what ends people can be better engaged within their communities and community opportunities. Focus in these analyses will be upon status of and gaps in knowledge or theory building respective to clinical, community, institutional, service, treatments, and other activities that influence the lives of persons affected by disability.

**Policy** papers would attend to gaps in knowledge respective to the impacts, influences, and interaction of public laws, policies, regulation expected to have direct (e.g., ADA, President's Task Force, the Rehabilitation Act) and indirect (e.g., Workforce Development, Supreme Court decisions, Transportation Act) effects on how people engage and are productively involved within their communities.

**Public interest** papers would focus on gaps and needs respective to applicability, utility, and appropriateness to various constituencies and intended beneficiaries of rehabilitation and social science research. They extend beyond current professional, individual, and advocacy concerns to issues of relevance of research for diversity, specific disabilities, and the experience and status of growth populations today.

The remainder of this report is organized as follows: A review of the literature on people with disabilities from diverse cultures is followed by a summary of the study methodology. A brief description of federal policies related to the particular topical theme precedes the research questions and recommendations which are presented in bullet format.

### **III. Disability Research and People with Disabilities from Diverse cultures**

Clearly there is a need to redefine the disability research agenda for the rehabilitation and the social sciences to meet the challenges of a growing population of people with disabilities from diverse cultures. Leung (1993) addresses the changing demography of the United States and how that change will affect state-federal vocational rehabilitation. During the last two decades, the population of the United States has changed significantly with regard to its ethnic, racial, and cultural background. Because of this shift, vocational rehabilitation and other service delivery programs must respond to these demographic changes in order to be effective.

Data show that there is a decline in Americans identifying themselves as White (80.3%). There was also an increase in immigration in the 1990s. These changes in demography indicate that various service delivery systems (including vocational rehabilitation and health care) must be able to accommodate diversity. Demographic changes present the challenge of shifting from a citizenship with similar values and views to a more diverse and different population of perspectives and world views (Chavez, 1997).

Consistent with the research cited above (Leung, 1993), the authorizing statute of Section 21 of the 1992 Amendments to the Rehabilitation Act documents the fact that the rate of population increase for minority Americans is substantially higher than it is for White Americans. The 2000 census revealed that there are 281,000,000 people residing in the United States. One of every three Americans is either of Hispanic, African, Asian, Hawaiian Native, or American Indian descent.

#### **• Rate of Disability**

Section 21 of the 1992 Amendments to the Rehabilitation Act documents the fact that the rate of disability for persons from minority groups is substantially higher than for the general population. The overall disability rate for African Americans is 21.6 percent. Approximately 24.2 percent of the working age population with a severe disability is African Americans. African Americans with a severe disability account for a higher percentage (71.8 percent of all African Americans with a disability). White Americans, by contrast, were 63 percent of persons with disabilities (Bowe, 1991; The President's Committee on Employment of Persons With Disabilities, 1997). Of the estimated 13,420,000 working age Americans with disabilities, approximately 1,012,000 or 7.5 percent are of Hispanic origin. This represents about 8.2 percent of all Hispanic Americans in this age group. Hispanic Americans with a severe disability account for an overwhelming 67.8 percent of all Hispanic Americans with disabilities.

Although American Indians comprise less than one percent of the total population, they have the highest overall disability rate (23.9 percent) compared to all racial/ethnic groups in the country. Among those who have severe disabilities, American Indians rank the second highest with a 9.8 percent prevalence rate, as compared to African Americans

who have a 12.2 percent prevalence of severe disabilities (McNeil, 1993; The President's Committee on Employment of Persons with Disabilities, 1997).

While specific rates of disability for Asian Americans are virtually non-existent, the information which is available on their health status is less than encouraging. For example, according to Gall and Gall (1993), five percent to 15 percent of Asian Americans are chronically infected with Hepatitis B in comparison to only 1% for the general population. Infected individuals are 300 times more likely than non-infected persons to develop liver cancer, and are at higher risk to develop cirrhosis and hepatica. Asian Americans and Pacific Islanders have 11.81 cases of malaria per 1,000 people in contrast to 0.15 for White Americans, 0.68 for African Americans, and 0.33 Hispanic American cases per 1,000 persons. In addition, tuberculosis is growing among Asian Americans and Pacific Islanders at a rate of five times that of the population in general.

Ethnic and racial minorities tend to have disabling conditions at a disproportionately high rate. The rate of work-related disability for American Indians is about one and one-half times that of the general population. African Americans are also one and one-half times more likely to have a disability than White Americans and twice as likely to have a significant disability. The National Institute on Disability and Rehabilitation Research (NIDRR) and the Rehabilitation Services Administration (RSA) have taken clear steps to remedy a number of the challenges cited above (including changing demographics, and prevalence of disability among minority groups) through the implementation of research, training and technical assistance activities relative to Section 21.

- **The Contrast in Service Delivery Effectiveness Between White American and Non-White American Communities**

The fact that minority persons with disabilities receive substantially fewer services than their White American counterparts was a strong argument for the inclusion of Section 21 in the 1992 Amendments to the Rehabilitation Act. Patterns of inequitable treatment of minority persons have been documented in all major junctures of the vocational rehabilitation process. As compared to White Americans, a larger percentage of African American applicants to the vocational rehabilitation system are denied acceptance. Of applicants accepted for services, a larger percentage of African American cases are closed without the persons being rehabilitated. Persons from diverse cultural groups are provided less training than their White American counterparts. Consistently, less money is spent on minority persons than their White American counterparts.

The vocational rehabilitation system, as well as other service systems such as health care, is challenged by problems created by a lack of cross-cultural understanding and ineffective communication between professionals and consumers with disabilities from culturally diverse backgrounds (Bricker, 1996). As a result, minority persons with disabilities are underserved. Vocational rehabilitation and other professionals have a critical role to play in assisting minority individuals with disabilities (many of whom may not be familiar with the social service delivery system or American culture) to locate and retain employment and services at a level supportive of their preferred lifestyle.

The effectiveness of vocational rehabilitation and other professionals in assuming this role and any related responsibilities will be enhanced by (1) the extent to which they are trained to embrace and respond to cultural diversity in the delivery of services; and (2) the extent to which they are capable of assisting these individuals to become empowered (Ponterotto, 1997). Studies indicate that while the need for rehabilitation and related services, including health care among minority persons, has been established, substantial differences may be noted in the status or levels of participation in the rehabilitation process between persons from minority and White American communities (Atkins, 1980, 1988; Atkins & Wright, 1980; Walker, 1986; Walker, 2000). Research conducted by Atkins (1980) and Atkins & Wright (1980) compared African American clients and White American clients using closure data from all of the states and territories participating in the public rehabilitation program.

Findings revealed unequal treatment of African American people in all major dimensions of the public vocational rehabilitation process. These inequalities were found to exist throughout all regions of the country. For example, a larger percentage of African American applicants were not accepted for services. Of the applicants accepted for services, African American clients were less likely to be rehabilitated; they were screened out without receiving much needed services; and they have received less vocational rehabilitation educational services, training, and financial aid for colleges, universities, business schools, and vocational schools (Walker, Asbury, Rodrigues, & Saravanabhavan, 1995).

According to Ross and Biggi (1986), whose research focused on clients entering and exiting the New York State Rehabilitation System, placement rates for White Americans increased two percent while they decreased 18 percent for minority clients. Rehabilitation rates for White Americans increased by four percent and decreased by four and one-half percent for minority clients. At closure, White Americans were most often cited as "refused services," while minority persons were cited "failure to cooperate." In addition, White Americans were closed "rehabilitation at/above minimum wage," while minority persons were most often assigned the status "non-rehabilitated." Research conducted by Walker, et al. (1995) also confirmed that minority clients were: (a) less likely to attain successful case closure than White Americans, (b) under-employed related to their educational level, (c) took longer to be evaluated and accepted for services; and (d) were perceived as not cooperating more frequently. Data obtained from eight urban settings revealed the fact that the percentage of persons of color receiving services is one third to one half of White Americans. In addition, the proportion of minority clients enrolled in the wide array of available services is lower than would be expected by chance based on statistical analysis (Walker, Akpati, Roberts, Palmer, Newsome, 1986; Walker, et al., 1995).

Similar trends were noted in research regarding rehabilitation services available to minority persons from a variety of groups. Cooney (1986) stated that counseling needs of Hispanic American clients were not being adequately met. The importance of developing culturally relevant delivery systems for Hispanic and other Americans has not been adequately addressed by rehabilitation policy makers (Leal, 1990; Walker, 2000; Walker,

et al., 1995). Specific problems that Hispanic Americans have with the rehabilitation system include: (a) they tend to be identified as ineligible for services more frequently; (b) they remain in the referral and application status and/or in guidance and counseling status longer; and (c) their time in training is substantially less than non-Hispanic Americans (Leal, 1990; Walker, 2000). Given the anticipated increase in the Hispanic American population, it is anticipated that there will be a greater gap between the need for services and the availability of services.

Chin, Lam, Wong, Leung, and Fang (1988) estimated that as many as 73,834 Chinese Americans have disabilities and could potentially benefit from rehabilitation services; however, services are underutilized. Asian Americans often have difficulty communicating with rehabilitation counselors and other service providers due to cultural differences and lack of acceptance of Western approaches to the provision of services (Woo, 1991). Research indicates that as many as 50% of the cases for Asian Americans are terminated prematurely (Leung & Sakata, 1988; Marshall, Wilson, & Leung, 1983; Chin et al., 1988; Walker, 2000). Asian Americans, just as Hispanic Americans and African Americans, are often closed with the status "failure to cooperate," "unable to locate," or "handicap too severe" (Leung & Sakata, 1988; Marshall, Wilson, & Leung, 1983). It is suggested that the reasons minority persons are not rehabilitated at closure are closely linked to linguistic and cultural barriers.

Similar problems have been identified relative to American Indians with disabilities. Morgan, Guy, Lee and Cellini (1986) report that vocational rehabilitation programs are largely unsuccessful with American Indians, particularly those with significant disabilities on rural reservations. Although American Indians are eligible for services, vocational rehabilitation programs rarely meet their needs. Unemployment among American Indians with disabilities may be as high as 50%-80% in communities where they must compete with persons without disabilities for jobs (Joe, 1991; Morgan, et al., 1986). A study conducted at Howard University which focused on the cost of purchased rehabilitation services, further documents the variations in service delivery for White Americans and persons with disabilities from minority groups in the United States (Walker et. al., 1995).

- **Persons with Disability from Minority Groups: "Double Jeopardy"**

While it is true that individuals with disabilities who are members of diverse racial and ethnic groups encounter the same challenges as other individuals with disabilities, these persons face special and unique problems because of socioeconomic, health, cultural, environmental, and other factors. In addition, prejudice, discrimination, and economic barriers continue to exclude a great number of minority persons from full participation in all aspects of society. However, relatively little research has focused on the unique needs of persons with disabilities from ethnic/cultural communities.

Research conducted by Bowe (1991a), Thornhill, HoSang, Hart, and Rivera (1991), Walker et. al. (1995) and Walker (2000) has documented the fact that disability is significantly higher among African Americans and other minority groups. The poverty rate for African Americans (31.37%) and Hispanic Americans (29%) is almost three



times as high as it is among White Americans (11%). Data concerning poverty rates are consistent across all age groups. The correlation between low socioeconomic status and disability is well documented. Thus low socioeconomic status families are at greater risk for disabilities throughout the life cycle (including the pre- and post-natal periods). During the last two decades the number of poor minority children and other dependent populations increased substantially.

The problems of non-white Americans with disabilities are indeed complex. Not only do they face excessive economic burdens, but adequate education is frequently not available. In many instances, access to health care facilities, community agencies, stores, schools, and transportation can only be acquired through the use of extreme measures. In addition, language, cultural, and attitudinal barriers impede access to needed resources. As a result of these circumstances, the minority person with a disability frequently finds him/herself excluded from the mainstream of everyday life. The unique status of non-White persons with disabilities tends to compound their disability problems.

Research conducted by Bowe (1991a+b), O'Connell (1987), Walker (1991) and Walker (2000) reveals that a substantial number of minority persons with disabilities are clustered in specific geographic locations. For example, at least 50 percent of all African Americans live in the South, 40 percent of Hispanic Americans reside in the West and Southwestern regions of the United States, whereas, approximately 46 percent of the American Indian population live on reservations (Asbury, Walker, Maholmes, Rackley, and White, 1991). A substantial number of Asians reside in the Northeast, Mid-Atlantic, and Western regions of the United States. A large number of Pacific Islanders and Hawaiian Natives live in the Pacific Basin, including Hawaii, Samoa, and Guam. Geographic distribution and available resources have significant implications relative to the provision of health care, special education, rehabilitation, and related services.

- **Research Needs**

A needs assessment survey, which was conducted by the Howard University Research and Training Center (HURTC), identified a number of research areas relative to the needs of persons with disabilities from diverse cultural groups and low income communities (Walker, 2000). The Participatory Action Research (PAR) Model was applied. The data collection process of the needs assessment survey was conducted by means of a variety of data collection methods: (1) the mailing of questionnaires to consumers with disabilities and their family members, advocates, service providers, and representatives from institutions of higher education; (2) the conduct of telephone interviews and discussions with directors of state rehabilitation agencies, Regional Rehabilitation Continuing Education programs (RRCEPs) in each of the ten federal regions, and personnel from the Center for Disease Control and Prevention and the Office of Minority Health; and (3) the use of numerous teleconferences to discuss and explore the outcomes of the needs assessment survey with representatives from the HURTC Research Team, directors of a number of Research and Training Centers and other National Institute on Disability and Rehabilitation Research (NIDRR) sponsored projects.



The needs assessment survey results identified the following areas relative to research needs: employment, technology, leadership development, and environmental, societal, and personal factors for individuals with disabilities from minority backgrounds.

In keeping with Section 21 of the 1992 Amendments to the Rehabilitation Act of 1973, as amended, there are a number of variables (including changing demographics, the impact and severity of disability within culturally diverse racial/ethnic groups, low income and underserved communities) which make it imperative to include issues of diversity and low income status in the forthcoming conference.

#### **IV. Study Methodology**

##### **Participants**

HURTC convened a series of nine conference calls with participants across ten RSA federal regions to address research needs and issues of disability, disparities in service in culturally diverse and low income communities. Sixty-two participants that included researchers, self-advocates, community activists, service providers, and family members participated in the nine focus groups (see of Appendix A for a complete list of participants). During each of the focus groups, participants were asked to address what is not working or not addressed in current research from their own unique perspectives. The issues identified for attention were not limited to consideration for implementation by NIDRR, but rather, the information (which was received through the nine regional conference calls and a follow up survey) was designed to help set a broad agenda that any public or private entity might review and find a place for itself in the implementation of this agenda.<sup>9</sup> Appendix B contains a copy of the follow up survey questionnaire.

This report outlines the recommendations of the 50 participants from across the United States on how the behavioral and social sciences research agenda can effectively address issues related to barriers to successful outcomes for culturally and linguistically diverse people with disabilities and persons living in underserved communities.

Their recommendations identified a broad range of possible research questions and issues that public and private entities may undertake to add to the current knowledge base and ultimately improve services and outcomes for culturally and linguistically diverse people with disabilities and their families who are traditionally unserved or underserved.

These recommendations are presented against the backdrop of federal disability laws in each of the theme areas (employment, wellbeing, community participation, and resources). All of the areas of research application, i.e., practice, policy and public interest, are referred to throughout the report. The intent of this study is to identify the

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<sup>9</sup>The calls were facilitated by Theda Zawaiza, Ph.D., a consultant on education issues and disability policy. The following scenario was presented and call participants were asked to respond: "If you were asked to testify before a Congressional Committee on the Behavioral and Social Sciences research agenda, what would be your top three priorities and why".

driving forces behind programs, resources and, in some instances, barriers for people with disabilities and underserved communities.

## **V. Findings and Recommendations**

Our democracy, our economy and social life generally, face no greater challenges than those of racial and ethnic justice. Race is either quite explicit or a critical subtext in virtually every significant social and economic debate facing communities around the nation, and the demographic trends in race and poverty will make this even more so.

--Harvard Civil Rights Project <sup>10</sup>

This section, which focuses on the findings and recommendations from the nine conference calls and the follow up survey, is divided into 5 major subheadings as follows: cultural competence, employment, well being, community participation, and resources. Each subheading contains a) relevant literature and b) findings and recommendations.

### **Cultural Competence**

#### **Background**

Cultural competence refers to the ability to relate and communicate effectively when the individuals involved in the interaction do not share the same culture, ethnicity, language, or other salient variables. When applied to organizations rather than individuals, cultural competence refers to the organization's ability to be responsive to the unique cultural, ethnic, or linguistic characteristics of its constituency or clientele. <sup>11</sup>

The research literature provides many reasons for increasing cultural competence and creating culturally competent systems of care, but three reasons are cited most frequently. The rapidly-changing U.S. demographics (Zawaiza, 1996; Chavez, 1997), the shift to more consumer-centered services (Harry, 1992) and the importance of validation for people with disabilities from racially, culturally, and linguistically diverse heritages (Barrera & Kramer, 1997). Here validation refers to opportunities for underserved individuals to see people of the same racial, ethnic, cultural, or linguistic background participate in valued roles of authority and decision-making within society.

In 1986, the American Psychological Association accreditation standards required graduate programs to provide multicultural preparation however this requirement, while laudable, yielded some unintended consequences, for example, the illusion of adequate preparation, i.e., taking one course results in culturally competent service professionals. As a beginning step to providing assurances of quality and cultural appropriateness, the Department of Health and Human Services (HHS) has developed the National Standards

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<sup>10</sup> Harvard Civil Rights Project (2002) aims to inject a racial and social justice dimension into public policy debates, and arm local and national civil rights organizations with research to bolster their efforts.

<sup>11</sup>Hains, A.H., Lynch, E.W., and Winton, P.J. (2000). Moving Towards Cross-Cultural Competence in Lifelong Personnel Development: A Review of the Literature. Technical report #3, Washington, DC.

for Culturally and Linguistically Appropriate Services to address cultural appropriateness in health services delivery.<sup>12</sup>

### **Cultural Competence: Recommendations and Research Questions:**

The single most frequently offered recommendation was in the area of cultural competence. During each of the focus groups, at least one researcher referred to the need for cultural competence in service delivery systems, professional preparation and in-service personnel training. Further, they recommended evaluative/summative research of federal, state and local programs to determine how culturally appropriate their current practices, policies and products are and to study the relationship between cultural competence and successful outcomes for minority persons with disabilities.

- Study the degree of awareness in the field of disability of cultural factors that impact treatment, families, consumers, and the community.
- Research the correlation between program capacity, increased cultural competence, and outcomes for minorities with disabilities.
- Examine various training models for personnel preparation to identify salient features and promising practices.
- Apply what is known in the area of “racial identity development” from the counseling literature to the development of courses and curricula in cultural competence.
- Implement research which answers the following questions:
  1. Does the effectiveness of programs improve for minorities as professionals of color move into professional systems?
  2. What role might underutilized venues and leaders e.g., community churches and ministers, play in improving outcomes for minorities with disabilities?
  3. What does Universal Design mean in the context of redesigning service delivery systems and systemic change? Is it equivalent to cultural competence? What are the elements of a system that is useable and accessible by the population at large including people who are of diverse ethnic, racial, cultural, and socio-economic backgrounds?

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<sup>12</sup>In December 2000, HHS' Office of Minority Health published final recommendations on national standards for culturally and linguistically appropriate services (CLAS) in health care. The 14 standards serve as a framework for organizations, health facilities and policy makers nationwide to implement culturally competent policies and procedures. Organized into three themes, the standards support culturally competent care, language access services and organizational supports for cultural competence. To view the standards, go to <http://www.omhrc.gov/CLAS>

# Employment

## Background

The most-recently enacted employment legislation pertaining to people with disabilities is the *Ticket to Work and Work Incentives Improvement Act of 1999*, enacted on Dec. 17, 1999. This legislation increases beneficiary choice in obtaining rehabilitation and vocational services; removes barriers that require people with disabilities to choose between health care coverage and work; and assures that more Americans with disabilities have the opportunity to participate in the workforce and lessen their dependence on public benefits.

Most Social Security and Supplemental Security Income (SSI) disability beneficiaries will receive a "ticket" which they may use to obtain vocational rehabilitation, employment or other support services from an approved provider of their choice. The Ticket to Work Program is voluntary and will be phased in nationally over a three-year period.<sup>13</sup> There is considerable concern among consumers, their families and advocates about the adequacy of incentives to serve people with more significant disabilities that may cost more and take longer to serve. People with disabilities from diverse cultures may be disproportionately represented in the group of "involuntary non-participants", i.e., people that want to receive vocational training and get a job but no employment network will serve them. Research might examine who is being denied services and why.

Another federal law that supports employment of people with disabilities is the Vocational Rehabilitation Act of 1973, as amended. It was reauthorized on August 7, 1998 as Title IV of the Workforce Investment Act of 1998 and is due for reauthorization in 2003. The stated purpose of the Act is to:

Empower individuals with disabilities to maximize employment, economic self-sufficiency, independence and inclusion and integration into society, through statewide workforce investment systems that include comprehensive and coordinated state of the art programs of vocational rehabilitation; independent living centers and services; research; training; demonstration projects; and the guarantee of equal opportunity; and to ensure that the federal government plays a leadership role in promoting the employment of individuals with disabilities, especially individuals with significant disabilities, and in assisting states and providers of services in fulfilling the aspirations of those individuals for meaningful and gainful employment and independent living.<sup>14</sup>

Here again, one finds the expressed themes of empowerment, community integration, and independence. Data will be needed to substantiate maintaining or adding provisions

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<sup>13</sup> SSA, Office of Employment Support Programs, 2002.

<sup>14</sup> Purpose section, Vocational Rehabilitation Act of 1973, as amended.

related to people from diverse cultures and underserved communities when this law is reviewed and extended next year.

**Employment: Research Questions and Recommendation**

- Survey employer awareness of the ADA and attitudes about people with disabilities in traditionally underserved communities. Follow-up on findings to determine why these employers would not hire: cost, misperceptions about chronic illness, fear of litigation, etc.
- Research is needed to determine effective models, services, and resources related to the vocational rehabilitation of people with disabilities from diverse cultures.
- The Bureau of Labor Statistics employment data collected on workers should include workers with disabilities from communities of color. Data should be disaggregated based on race and disability.
- Conduct research which answers the following questions
  1. How can the universe of employers of people with disabilities from underserved communities be expanded?
  2. How can employment opportunities in underserved communities be enhanced?
  3. To what extent are small business, entrepreneurship, and self-employment being promoted for people with disabilities from underserved communities?
  4. Why has the existing body of research not made a difference in the employment and self-sufficiency of people with disabilities from diverse cultures?
  5. How can capitalist strategies empower people with disabilities from underserved communities, e.g., leveraging Empowerment and Enterprise Zones?
  6. Are people with disabilities from underserved communities over-represented in the category of “involuntary non-participants” in the Ticket program?
  7. How do the outcomes for people with disabilities from underserved communities compare to other people with disabilities at One-Stop Job Centers?

8. What strategies promote and sustain employment of people with disabilities from diverse cultures?
9. To what extent do health, poor health care, and subsequent development of secondary conditions play a role in the inability of people with disabilities to secure and maintain employment?

## **Well-being**

### **Background**

There is a growing concern, particularly in the public health arena, regarding the utility of race and ethnicity measures since many believe these measures serve to reinforce stereotypes and stigmatization. The focus group experts concluded that the national research agenda should continue to use race and ethnicity data with the proviso that it is collected and analyzed in relation to other interacting variables, e.g., socioeconomic status.

In November 2000, health disparities research was elevated when Public Law 106-525, the Minority Health and Health Disparities Research and Education Act of 2000 was signed, establishing at NIH the National Center on Minority Health and Health Disparities (NCMHD). The Center conducts and supports basic, clinical and behavioral research, emerging programs, training and information dissemination aimed at reducing the disproportionately high incidence and prevalence of disease, burden of illness, and mortality experienced by racial and ethnic minorities and other groups, such as the urban and rural poor.<sup>15</sup>

### **Well-being: Research Questions and Recommendations**

- Research the effects of including disability as an emerging health issue, since poor health and unhealthy lifestyles can lead to disability.
- The meaning of “best practices” should be investigated as it applies to diverse populations when addressing health disparities.
- Accelerate research related to prevention, treatment, and awareness of disabling conditions prevalent in underserved communities.

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<sup>15</sup> [www.healthdisparities.nih.gov](http://www.healthdisparities.nih.gov)

- Need better measures and information on disability nationally, disaggregated by disability and diversity.
- Need an inventory of various datasets to support behavioral and social sciences.
- Conduct Research which answers the following questions:
  1. How do Medicaid policies impact outpatient recovery and prevention of secondary disabilities of African American and Latino youth who are coping with recently acquired spinal cord injury?
  2. How does one deal with the lingering emotional effects of catastrophic physical disability?
  3. What is the impact of trauma and physical disability on well-being?
  4. What are the effects of service provider perceptions of consumers with disabilities from underserved communities on health outcomes?
  5. Do randomized control group studies equate to best practices?

## **Community Participation**

### **Background**

In February 2001, President Bush issued Executive Order 13217, "Community-Based Alternatives for Individuals with Disabilities," June 18, 2001. The order calls upon the federal government to assist states and localities to swiftly implement the decision of the United States Supreme Court in *Olmstead v. L.C.* In that case, the court found that, under certain circumstances, the Americans with Disabilities Act (ADA) requires states to provide community-based services for persons with disabilities and holds that unjustified institutionalization of a person with a disability is discrimination under the ADA.

Executive Order 13217 directs six federal agencies, including the departments of Justice (DOJ), Health and Human Services (HHS), Education (ED), Labor (DOL) and Housing and Urban Development (HUD) and the Social Security Administration (SSA) to evaluate their policies, programs, statutes and regulations to determine whether any should be revised or modified to improve the availability of community-based services for qualified individuals with disabilities and to report back to the President with their findings. The Departments of Transportation (DOT) and Veterans Affairs (VA) and the Office of Personnel Management (OPM), though not named in the Executive Order, also joined in the implementation effort. This is a very comprehensive effort that has critical implications for 13 applied policy research areas. Secretary of Health and Human Services (HHS), Tommy Thompson recently reported on the federal agencies' activities

to date.<sup>16</sup> In addition, the New Freedom Initiative covers sweeping changes in the areas of housing, education, transportation, etc. that have implications for community participation.<sup>17</sup>

### **Community Participation: Research Questions and Recommendations**

- Evaluate accessibility in the private and public sector to determine how effective support services have been.
- Research the issue of the juvenile justice systems' provision of educational services to minority youth with disabilities.
- Since there is little or no practical information available concerning sexuality and persons with disabilities, therefore research should be conducted in this area.
- Conduct research on transition of minority youth with disabilities which targets the lack of information given to families, weak interagency collaboration, and limited options for supports beyond school.
- Conduct research which answers the following questions:
  1. What are the effects of the lack of education in traditionally underserved families and communities (including Hispanic Americans, African Americans, Hawaiian Natives, Asian Americans, American Indians and Alaskan Natives) on the services provided to individuals with disabilities?
  2. What can be done to make diverse communities more physically accessible?
  3. How can we work with schools, businesses, and organizations in order to provide technical assistance (TA) to help make diverse communities more accessible? What works and why?
  4. How do community resources and infrastructure impact employment, independent living, and transportation?
  5. Violence and people with disabilities—is this population more vulnerable to violence in the community, in families, and among service providers?
  6. How effective is special education in preparing African American, Latino, and other traditionally underserved groups to lead productive lives?

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<sup>16</sup> See Appendix A for complete list of Agencies

<sup>17</sup> [www.whitehouse.gov](http://www.whitehouse.gov).



7. How do poor early outcomes impact the ability of adult systems to achieve better outcomes?
8. Are second language learners becoming disabled by systems that inaccurately labeled them minimally or borderline language skills and biased assessments?
9. What models exist for teaching sexuality to people with disabilities from diverse cultures?
10. Do minority students with disabilities who receive transition planning have more successful outcomes than those who do not?
11. To what extent is transition planning for minority students with disabilities occurring? What works with this population and why?
12. What roles can the church or religious community and families play in improving outcomes, outreach, and follow through?
13. What is working currently in our communities?
14. How can the elements of successful programs be identified, analyzed, replicated, and/or integrated into existing systems?
15. Have sanctions been applied when inaccessibility is found?

## Resources

Besides appropriations and other funding mechanisms, the expert participants expressed interest in seeing research agendas examine other resources such as data—its collection and how it is reported; effective models of collaboration (e.g., consortia); new conventions regarding work (e.g., telework) and methods of capacity-building in professional development, service delivery, and community-based advocacy.

### **Resources: Research Questions and Recommendations**

- Research the effectiveness of skills development models of research and PAR strategies that provide research participants tangible benefit from the research.
- Conduct research which answers the following questions:
  1. Does the lack of representation of students of color across federal databases or, as markers in the data systems impact funding initiatives that might focus on special populations?

2. What capacity building approaches to service delivery can be used or developed?
3. Native American Indians represent only 1% of the population with 520 tribes but are often considered statistically insignificant and discounted. How tribal people collaboration on common issues of concern might across racial, ethnic, language and cultural lines and what is the effect of inter-tribal collaborations on Native American Indian outcomes?
4. Are there alternative approaches to building opportunities in the community for working on or researching issues related to disabilities? These approaches might also be used to build sensitivity and awareness of laws and of other resources.
5. Might community-based research methods--more holistic approaches--provide insight or a new and different perspective on what makes for better skill development, transfer, and maintenance and overall better outcomes for underserved groups?
6. To what extent can collaboration across systems improve the availability of appropriate services to serve the whole person, particularly in rural communities?
7. What makes for successful outreach in a human services initiative-- What are the components?
8. Research to practice knowledge transfer is an area for research. Are there partnerships models that can be developed to facilitate this transfer of knowledge? To whom?
9. What are promising models for information dissemination in underserved communities?
10. Commerce statistics indicate that people with internet access seem to have a better general knowledge base as professionals- people in communities of color have less access to this technology, and people with disabilities have even less.
11. What can be done to close the digital divide and ensure culturally and linguistically diverse people with disabilities have the same access to electronic and information technology as the general population?
12. How are people of color with disabilities benefiting from telework and other unconventional opportunities to work?
13. What is the role of technology as it relates to employment and education? Is there differential access to assistive technology?

14. How does technology empower people to live as independently as possible?  
For those who have it, how is it enriching or empowering their lives?

15. What is the differential impact on outcomes of cutbacks in funding of those  
serving diverse populations?

The purpose of the follow up survey to the nine regional focus groups was to provide information which may be used to inform presenters and attendees at the May 29-31, 2002 conference. Both the focus groups and the follow up survey allowed the participants the opportunity to provide valuable input relevant to the May 29-31, 2002 conference. Participants were asked to rank eight challenges that face persons with disabilities which included employment, resources, community participation, well being, housing, transportation, access to information, and technology. Participants were also given the opportunity to identify and rank up to four additional challenges. The survey also enabled respondents to list up to three research topics that could be carried out in the behavioral and social sciences as they relate to the needs of persons with disabilities from underserved communities.

Eighty-three individuals participated in the conference calls. Sixteen surveys were returned. The challenges from the survey are listed in order of priority- **Employment** was ranked as the number one challenge facing individuals with disabilities; **Transportation** and **Housing** received equal attention and were ranked as number two for challenges facing individuals with disabilities; **Access to Information** and **Resources** were ranked at number three; **Well Being** was ranked as four; **Community Participation** was ranked as number five; and **Technology** was ranked sixth.

Information garnered through the survey concerning relevant research topics can be placed in several different categories. The research topics included housing, community integration, family concerns, education, cultural competence, inclusion in research, technology accessibility and service delivery, and sexuality.

Table 1 contains a compilation of the research topics.

V. Compilation of Research Topics	
Housing	<ul style="list-style-type: none"><li>• Ways to increase availability of accessible housing for people with activity limitations</li><li>• Natural Supports related to housing and transportation</li></ul>
Community Integration	<ul style="list-style-type: none"><li>• Ways to increase numbers of people with physical impairments in the Rehabilitation field (2)</li><li>• How persons with disabilities in underserved communities "survive" and even "prosper".</li><li>• Improving the transition from school to work.</li></ul>
Family Concerns	<ul style="list-style-type: none"><li>• Role of the family in the self-esteem of persons with disabilities.</li><li>• Family issues (support systems)</li></ul>

Education	<ul style="list-style-type: none"> <li>• Global economy model infused in the curriculum: a barrier to be overcome by persons with disabilities.</li> <li>• Inclusion of people in national educational assessments in compliance ESEA and IDEA Mandates</li> <li>• Comprehensive system of Personnel Development (professional development, skills enhancement, certification/licensure and competency of tribal VR personnel)</li> </ul>
Employment	<ul style="list-style-type: none"> <li>• Employment related research (2)</li> <li>• What are the main deterrents to employment</li> <li>• Effective interventions for eliminating social and cultural barriers to independence and employment</li> </ul>
Cultural Competence	<ul style="list-style-type: none"> <li>• Issues related to social/racial identity development</li> <li>• Cultural competency of the counselor</li> <li>• Multicultural competency of rehabilitation counselors and other service providers.</li> <li>• Role of language and communication style</li> </ul>
Inclusion in Research	<ul style="list-style-type: none"> <li>• Use of whole community based research strategies in designing and implementing government-funded evaluations</li> <li>• Reliance on persons with disabilities from underserved communities as active participants in research endeavors-whether publicly or privately funded</li> <li>• Community Inclusion Research</li> <li>• How can society's attitudes towards disabled people become more realistic</li> <li>• Policy and how persons with disabilities from underserved communities can be better impacted</li> </ul>
Technology	<ul style="list-style-type: none"> <li>• Role of technology for people of color with disabilities.</li> <li>• Applications of attainable and functional assistive technologies</li> <li>• Assistive technology and its impact on: access, information, usage, universal design, employment and quality of life.</li> </ul>
Accessibility And Service Delivery	<ul style="list-style-type: none"> <li>• Service accessibility by minority populations.</li> <li>• Effectiveness of current service delivery.</li> <li>• Economic impact/opportunities from service accessibility.</li> <li>• Perceptions of diverse populations about current services</li> <li>• Needs of minority rural populations</li> </ul>
Sexuality	<ul style="list-style-type: none"> <li>• Sexuality and disability</li> </ul>
Health Issues	<ul style="list-style-type: none"> <li>• Emerging health issues: obesity, diabetes and hypertension.</li> <li>• The role of health as a factor in independence and employment</li> </ul>

### Summary Statement

The findings and recommendations from the current study are consistent with the recommendations resulting from a National conference on minority persons with disabilities which was sponsored by the National Council on Disability in 1992. The summary of proceedings from this public meeting sponsored a decade ago by the NCD delineated eleven recommendations. They are just as relevant today as they were then.<sup>18</sup> In spite of the fact that ten years has passed since the NCD conference, these recommendations are still relevant. If anything the recommendations from the conference held a decade ago are even more relevant today in light of the increasing gaps between

<sup>18</sup> National Council on Disability (1992). *Meeting the unique needs of minorities with disabilities: A report to the President and the Congress*. Summary of proceedings, Washington, DC.

the “haves” and “have nots” which have occurred during the last decade. Clearly, the findings from the current study and the 1992 NCD conference point to the urgent need for a concerted research effort on behalf of minority people with disabilities.

Listed below are eleven recommendations that are consistent and support the recommendations that are the result of the nine regional conference calls and the follow up survey:

1. Issues involving minority persons with disabilities are complex and require the coordinated attention of many public and private programs as well as the competencies of professionals from a wide array of different disciplines.
2. As a group, minority persons with disabilities are more at risk, have fewer personal and family resources, have less knowledge and understanding of externally available resources, and fare less well socioeconomically than do minority persons without disabilities.
3. There has been limited research on issues related to minority persons with disabilities. Consequently there are insufficient data on these populations to offer substantial guidance for policy or service development.
4. Service delivery systems staff members (including the state/federal vocational rehabilitation programs) are not sufficiently trained to work with multicultural populations.
5. There have been insufficient outreach efforts to ensure the participation of minority persons with disabilities in the mainstream of their communities.
6. There have been insufficient efforts to address issues concerning prevention of disability that often affect minority persons, including the effects of racism, violence, substance abuse, and poor general health.
7. There is a need to develop and implement a data set sufficiently descriptive to assess incidence and prevalence of disabilities and the impact of interventions among all minority populations regardless of population size.
8. Education continues to be a key factor for minority persons with disabilities in achieving success; therefore, it must be designed to be more positive and effective, focusing on the abilities of children with disabilities rather than on their limitations.
9. Minority children with disabilities require adequate academic accommodations and support through the attention of sensitive educational personnel and mentors.
10. The ADA holds great promise for minority persons with disabilities, but the promise will be realized only if specific efforts are made for outreach, education, and removal of barriers in minority communities.

11. There is a need to develop grassroot networks and to establish a funded pool of resources to help minority persons with disabilities become part of the mainstream of their communities.

### **Conclusion**

Research in the behavioral and social sciences provided answers to some of the most intractable problems of the 20<sup>th</sup> century. With a refocused research agenda that is inclusive and prioritized according to the greatest need, people with disabilities from diverse cultures may reap the benefits of research and ultimately claim their share of the American dream in the 21<sup>st</sup> century.

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**Appendix A**  
**PARTICIPANTS LIST**

**RESEARCH COORDINATING TEAM**

Dr. Sylvia Walker, Director  
Howard University Research  
and Training Center (HURTC)  
2900 Van Ness Street, N.W.  
Suite 100, Holy Cross Hall  
Washington D.C. 20008  
(202) 806-8086  
(202) 806-8148 (FAX)  
swalker@howard.edu

Dr. Theda Zawaiza, Moderator  
Legislative Expert/  
P.O. Box 305  
Ashton, MD 20861  
(301) 260-2116  
(202) 358-6421 (FAX)

Ms. Charlotte Spinkston, Recorder  
Disability Expert  
1472 Tremont Street  
Roxbury Crossing, MA 02120  
(617) 445-3191  
(617) 445-8309 (FAX)

Dr. Willie T. Howard, Associate Director  
HURTC  
2900 Van Ness Street, N.W.  
Suite 100, Holy Cross Hall  
Washington D.C. 20008  
(202) 806-8086  
(202) 806-8148 (FAX)

Ms. Delores Watkins, Project Officer  
National Institute of Disability and Rehabilitation Research  
Mary E. Switzer Building, Room 3426  
330 C Street, S.W.  
Washington, DC 20202  
(202) 205-9195  
(301) 372-6592 (H)  
(202) 205-9515 (FAX)  
delores.watkins@ed.gov

### **HURTC RECORDERS**

Ms. Shirley R. Ball, Project Coordinator  
Rehabilitation Capacity Building Project  
Rball1913@msn.com

Mrs. Maima Fahnbulleh McQueen, Research Assistant  
mmcqueen@howard.edu

Ms. Danielle Anderson, Research Assistant

**REGION I PARTICIPANTS****DATE: March 12, 2002****LOCATION: The Massachusetts Commission on Rehabilitation, Boston, MA**

Ms. Margaret Amaranti, Area Office Director  
River Area of Massachusetts Rehabilitation Commission  
170 Pleasant Street  
3<sup>rd</sup> Floor, Room 300  
Fall River, Massachusetts 02721-3015  
(508) 678-9041  
(508) 676-2734 (FAX)

Mr. Ron E. Armstead, Executive Director  
Congressional Black Caucus  
Veterans Braintrust  
12 Homestead Street  
Boston, MA 02121  
(617) 994-8351

Ms. Cheryl Cumings  
Massachusetts Commission for the Blind  
88 Kingston Street  
Boston, MA.02111  
(617) 626-7495  
(617) 626-7685

Mr. Orlando Espinal, Vocational Rehabilitation Counselor  
Massachusetts Rehabilitation Commission  
Area Office Brockton Massachusetts  
55 City Hall Plaza  
Brockton, Massachusetts 0231  
(508) 583-1530  
(508) 427-5788 (FAX)

Dr. Marianne Farkas, Director  
Training & International Division  
RRTC in Rehabilitation Of  
Persons with Long-term Mental Illness  
Center for Psychiatric Rehabilitation  
Boston University  
940 Commonwealth Avenue, West  
Boston, MA. 02215  
(617) 353-3549  
(617) 353-7700 (FAX)

Dr. Shiela Fesko  
Institute For Community Inclusion  
300 Longwood Avenue  
Boston, MA 02115  
(617) 355-6271  
(617) 355-7940 (FAX)  
sheila.fesko@umb.edu

Ms. April Holley, Consumer  
Administrative Office  
Massachusetts Rehabilitation Commission  
27-43 Wormwood Street  
Boston, MA 02210  
(617) 204-3638  
(617) 727-1354 (FAX)

Dr. Alan M. Jette  
Sargent College  
Rehabilitation Research and Training Center  
Boston University  
635 Commonwealth Avenue  
Boston, MA. 02215  
(617) 353-2704  
(617) 353-8619 (FAX)  
ajette@bu.edu

Mr. Albert Jones, Jr., Civil Rights Officer  
Massachusetts Commission on Affirmative Action  
Administrative Office  
Massachusetts Rehabilitation Commission  
27-43 Wormwood Street  
Boston, MA 02210  
(617) 204-3762  
(617) 727-1354 (FAX)

Ms. Joan Mainichie, Vocational Rehabilitation Counselor  
Area Office Brockton Massachusetts  
55 City Hall Plaza  
Brockton, MA 02310  
(508) 583-1530  
(508) 427-5788

Mr. Donald McManuf, Vocational Rehabilitation Counselor  
Massachusetts Rehabilitation Commission

Roxbury Area Office  
40 Dimock Street, 3<sup>rd</sup> Floor  
Roxbury, MA 02119-1210  
(617) 442-5510  
(617) 442-5724 (FAX)

Mr. Jorge Messmer, Area Office Director - Springfield  
16<sup>th</sup> Fort Street  
Springfield, MA 01103-1284  
(413) 736-7296  
(413) 737-5693 (FAX)

Mr. George Mitchell, Vocational Rehabilitation Counselor  
Massachusetts Rehabilitation Commission  
Roxbury Area Office  
40 Dimock Street, 3<sup>rd</sup> Floor  
Roxbury, MA 02119-1210  
(617) 442-5510  
(617) 442-5724 (FAX)

Mr. Emeka Nwokeji, Director of Consumer Affairs  
Administrative Office  
Massachusetts Rehabilitation Commission  
27 Wormwood Street, 5<sup>th</sup> Floor  
Boston, MA 02210  
(617) 204-3624  
(617) 727-1354 (FAX)  
[emeka.nwokeji@mrc.state.ma.us](mailto:emeka.nwokeji@mrc.state.ma.us)

Ms. Matlyn Starks, Executive Director  
Vienne S. Thomson Independent Living Center  
555 Amory Street  
Jamaica Plain, MA 02130  
(617) 522-9840

## **REGION II PARTICIPANTS**

**DATE:** February 28, 2002

**LOCATION:** Department of Rehabilitation Medicine, Harlem Hospital,  
New York, NY

Ms. Pamela Childs Bates, President  
504 North Star  
3315 Manhattanville Station  
New York, NY  
(212) 222-6439  
(212) 222-0035 (FAX)  
pamdring@netzero.net  
www.northstar504.org

Ms. Maureen Blagrove, Nurse Coordinator II  
Dept. of Rehabilitation Medicine  
Harlem Hospital Center  
506 Lenox Avenue  
New York, NY 10037-1802  
(212) 939-4414

Ms. Beatrice Davis, Dietitian  
Dept. of Food Services  
Harlem Hospital Center  
506 Lenox Avenue  
New York, NY 10037-1802  
(212) 939-1932

Ms. Yonette Douglas, Associate Director  
Harlem Independent Living Center  
5-15 West 125<sup>th</sup> Street  
New York, NY  
(212) 396-9283

Mrs. Ellen Duran, Rehabilitation Counselor  
172-12 133<sup>rd</sup> Avenue  
Jamaica, NY 11434  
(718) 341-1509

Dr. Peter B. Flemister, Assistant Director  
Department of Rehabilitation Medicine  
Harlem Hospital Center  
506 Lenox Avenue  
New York, NY 10037-1802  
(212) 939-4419



Ms. Faith Fogelman, Director  
Student Support Services  
New York City Technical College  
The City University of New York  
300 Jay Street, A - 237  
Brooklyn, NY 11201-2983  
(718) 260-5143  
(718) 254-8539 (FAX)  
ffogelmannyc@CUNY.edu

Mr. Herman Frogberg, Disability Advocate  
801 Tilden Street  
Bronx, NY 10467  
(718) 324-1819  
frogberg2@aol.com

Ms. Sonja Hamlin, Speech Language Pathologist  
Department of Rehabilitation Medicine  
Harlem Hospital Center  
506 Lenox Avenue  
New York, NY 10037-1802  
(212) 939-4410

Mr. Isaac W. Hopkins, President  
World Youth Workshop, Inc.  
P.O. Box 9007  
Newark, NJ 07104-9007  
(908) 561-2396  
(973) 483-0886 (H)  
(973) 483-2675 (FAX)

Ms. Fawn McClamb, CSW, Social Worker  
Department of Social Work  
Harlem Hospital Center  
506 Lenox Avenue  
New York, NY 10037-1802  
(212) 939-1903

Dr. Gerlene Ross, Bureau Chief  
Office of Vocational & Educational  
Services for Individuals with Disabilities  
New York State Education Department  
One Commerce Plaza Room 1607  
Albany, NY 12203  
(518) 474-2587  
(518) 486- 5154 (FAX)  
gross2@mail.nysed.gov

Dr. Ernst Saint-Leger, Chief  
Inpatient Unit  
Department of Rehabilitation Medicine  
Harlem Hospital Center  
506 Lenox Avenue  
New York, NY 10037-1802  
(212) 939-4455

Ms. Vendetta Stewart, Acting Chief  
Inpatient Unit  
Department of Rehabilitation Medicine  
Harlem Hospital Center  
506 Lenox Avenue  
New York, NY 10037-1802  
(212) 939-4890

Dr. Herbert L. Thornhill, Director  
Department of Rehabilitation Medicine  
Harlem Hospital Center  
506 Lenox Avenue  
New York, NY 10037-1802  
(212) 939-4401  
hlhl@columbia.edu

Ms. Gloria Tull, Coordinating Manager  
Department of Rehabilitation Medicine  
Harlem Hospital Center  
506 Lenox Avenue  
New York, NY 10037-1802  
(212) 939-4409

Ms. Pat Wohl, Chairman of 504 North Star  
332E 29<sup>th</sup> Street  
Manhattan, NY 10016  
(212) 684-1544  
offtothewalls@aol.com

Ms. Vanessa Young, Chief  
Physical Therapy  
Department of Rehabilitation Medicine  
Harlem Hospital Center  
506 Lenox Avenue  
New York, NY 10037-1802  
(212) 939-4444

### **REGION III PARTICIPANTS**

**DATE:** March 5, 2002

**LOCATION:** Rehabilitation Services Administration, Philadelphia, PA

Dr. Lewellyn Cornelius, Associate Professor  
Assistant Dean for INFORMATICS  
School of Social Work  
University of MD at Baltimore  
525 West Redwood Street  
Baltimore, MD 21201-1777  
(410) 706-7610  
(410) 706-6046  
lcorneli@ssw.umaryland.edu

Dr. Donald N. Dew, Director (RCEP) Region III and Professor  
George Washington University  
2011 Eye Street NW, Suite 300  
Washington DC 20052  
(202) 973-1550  
dondew@gwu.edu

Dr. Martin Gould, Senior Research Specialist  
National Council on Disability  
1331 F. Street, NW, Suite 850  
Washington DC 20004  
(202) 272- 2004  
(202) 227-2222 (FAX)

Dr. Michael Marge, Research Professor  
PM & R, SUNY Upstate Medical University  
750 E. Adams Street, 310 Jacobsen Hall  
Syracuse, NY 13210  
(410) 965-0149  
(410) 966-4071  
Michael.marge@ssa.gov

Mr. James Royal, Jr., Vice President Development  
The Delta Organization, Inc.  
72 E. Swederford Road, Suite 214  
Malvern PA 19355-1488  
(610) 640-9700 Ext. 23  
(610) 640-9775  
jeroy2/@deltaorg.com

Dr. Nguyen Dinh Thang, Executive Director  
Boat People S.O.S, Inc.  
6400 Arlington Boulevard, Apt. #640  
Falls Church, VA 22042  
Phone: 703-538-2191  
Fax: 703-538-2191  
[bpsos@bpsos.org](mailto:bpsos@bpsos.org)

**REGION IV PARTICIPANTS****DATE: March 15, 2002****LOCATION: Georgia Department of Rehabilitation, Atlanta, GA**

Mr. Judge L Anderson, III, Disability Advocate  
3916 Harley Farm Drive  
Marietta, GA 30066  
(770) 591-2296  
ajudge@bellsouth.net

Ms. Lucy Curtis  
100 Atteiram Drive  
Rome, GA 30161- 5706  
(706) 291-4666

Mr. Norris Curtis, Rehabilitation Counselor  
Georgia Department of Labor, Rehabilitation Services  
450 Riverside Parkway, Suite 200  
Rome, GA 30161-2942  
(706) 295-6400  
(706) 802-5188 (FAX)  
1-800-546-6401

Ms. Carol Ford, Host House Manager  
Independent Waiver Program  
1024 Falls Brooke Dr.  
Conyers, GA 30094  
(770) 602-2633

Ms. Kate Gainer, Disability Advocate  
Multicultural Coalition on Disability & Diversity  
55 Maple Street, N.W. Suite 708  
Atlanta, GA 30314  
(404) 581-0626  
ngainer@msn.com

Dr. Frank L. Giles, Coordinator  
Rehabilitation Counseling  
Jackson State University  
Jackson, MS  
(601) 898-7755

Ms. Carol A. Miller  
Georgia Division of Vocational Rehabilitation  
Department of Labor  
1700 Century Circle, Suite 300  
Atlanta, GA 30345  
(404) 463-0084  
(404) 463-6424

Mr. Brown Pollard  
P.O. Box 1571  
Cedartown, GA 30125-1571  
(770) 748-1323

Mrs. Elaine Pollard  
P.O. Box 1571  
Cedartown, GA 30125-1571  
(770) 748-1323

Dr. Carolyn Rollins, Assistant Professor  
Rehabilitation Counseling, College of Education  
Florida State University  
215 Stone Building  
Tallahassee, FL 32306  
(850) 644-1286  
(850) 644-4335  
crollins@coe.fsu.edu

Ms. Valencia Thomas, Outreach Coordinator  
Georgia Department of Labor  
Vocational Rehabilitation Program  
1700 Century Circle, Suite 300  
Atlanta, GA 30345  
(404) 638-0383  
vathomas@dhDHR.state.ga.us

Ms. Mary Wells  
DHR District 1, Unit 1  
72 Massell Dr., Apt. 250  
Cartersville, GA 30121  
(770) 387-0832

**REGION V PARTICIPANTS**

**DATE:** March 19, 2002

**LOCATION:** Department of Rehabilitation Chicago, IL

Dr. Fabricio Balcavar  
Advocacy and Employment Program for Minorities  
Department of Disabilities & Human Development  
University of Illinois at Chicago  
(312) 413-1646

Ms. Ethel Briggs  
National Council on Disability  
10114 Bruck Drive  
Silver Spring, MD 20903  
(301) 439-4917 (H)  
(202) 272-2004

Ms. Audrey McCrimon  
Member National Council on Disability  
Chicago, IL

Dr. Renee A Middleton, Associate Professor and director  
Rehabilitation Counseling, College of Education  
Auburn University  
3084 Haley Center  
Auburn, Alabama 35107-14051  
(334) 844-4446  
middlre@auburn.edu



**REGION VI PARTICIPANTS**

**DATE:** March 21, 2002

**LOCATION:** Center for Minority Training and Capacity Building for Disability  
Research, Texas Southern University, Houston, TX

Dr. Madan M. Kundu, Coordinator and Professor  
Rehabilitation Counseling  
Southern University  
229 Blanks Hall  
Baton Rouge, LA 70813  
(225) 771-2819/2990  
(225) 771-2293 (FAX)  
[kundusubr@aol.com](mailto:kundusubr@aol.com)

Mr. Darrell Simmons, Project Coordinator  
Center for Minority Training and Capacity  
Building for Disability Research  
3100 Clebume Ave., Farchild Bldg. #114  
Houston, TX 77004  
(713) 313-7953  
(281) 261-1331 (FAX)  
[dksimmons@pdg.net](mailto:dksimmons@pdg.net)

Dr. Leon Thornton, Consultant  
Former Director, Region VI RCEP  
Route 3, Box 68  
Bismarck, AR 71929  
(501) 865-3307  
(501) 865-1237 (FAX)  
[clthorn2@capc.net](mailto:clthorn2@capc.net)

## **REGIONS VII & VIII PARTICIPANTS**

**DATE:** March 26, 2002

**LOCATION:** Rocky Mountain Technical Assistance and Consulting Center,  
Denver, CO

Dr. Morris C. Hansen, Director Region VIII RCEP  
University of Northern Colorado  
Rehabilitation Continuing Education Program  
Greeley, Co 80639  
(970) 351-6956  
(970) 351-1317 (FAX)  
mhansen@rrcep.unco.edu

Mr. Daniel Hopkins, Executive Director  
Dan Hopkins & Associates  
1563 Kingston Ave.  
Aurora, CO 80012  
(303) 337-2210  
(303) 337-2261 (FAX)  
danhopkins1@home.com

Dr. Marilyn Johnson, Director  
Laguna Acoma Vocational Rehabilitation Project  
P. O. Box 389  
Pueblo of Acoma, NM 87034  
(505) 552-0620  
(505) 552-6146 (H)  
(505) 552-0623

Dr. C. David Roberts, Director Region VII RCEP and Research Associate Professor  
Department of Educational and Counseling Psychology  
University of Missouri  
98 Corporate Lake Dr.  
Columbia, MO 65211  
(573) 882-3807  
(573) 884-1727 (FAX)  
robertsc@missouri.edu

## **REGIONS IX & X PARTICIPANTS**

**DATE:** March 28, 2002

**LOCATION:** American Indian Rehabilitation Research and Training Center,  
Northern Arizona University, Flagstaff, AZ

Dr. Daniel D. Anderson, Director  
Pacific Basin Rehabilitation  
Research and Training Center  
University of Hawaii  
1268 Young St., #204  
Honolulu, HI 96814  
(808) 947-5368  
(808) 947-5909  
dalton@lava.net

Dr. Mitchell La Plante, Director  
Disability Statistics Rehabilitation Research and Training Center  
University of California Institute for Health and Aging  
University of California-San Francisco  
3333 California Street, Room 340  
San Francisco, CA 94118  
(415) 502-5214  
(415) 502-5208  
laplant@itsa.ucsf.edu

Dr. Fred McFarlane, Director Region IX RCEP  
Interwork Institute  
San Diego State University  
5850 Hardy Ave., Suite 112  
San Diego, CA 92182-5313  
(619) 594-4228  
(619) 594-4208 (FAX)  
fmcfarla@maul.sdsu.edu

Ms. Priscilla Sanderson, Director  
American Indian Rehabilitation Research and Training Center  
Northern Arizona University  
Institute for Human Development  
PO Box 5630  
Flagstaff, AZ 86011-5630  
(928) 523-8130  
(928) 523-9127 (FAX)  
(928) 23-16985 (TTY)  
Priscilla.sanderson@nau.edu

## Appendix B

### REDIFINING THE DISABILITY RESEARCH AGENDA FOR REHABILITATION AND THE SOCIAL SCIENCES

#### Follow Up Survey Form

Thank you for participating in one of the nine regional calls. The input that you provided was valuable. As you know, a two and a half day consensus conference titled "Redefining The Disability Research Agenda For Rehabilitation And The Social Sciences" is scheduled for May 29-31, 2002. This survey is being carried out in order to obtain additional input that can be used to refine and develop a trans-disciplinary research agenda in the social and behavioral sciences. Since the report must be finished by April 17<sup>th</sup> I am asking you to mail or fax the completed form immediately.

#### SECTION A: BACKGROUND INFORMATION

Please supply as much information as possible (**PLEASE TYPE or PRINT**)

1. Name (optional): \_\_\_\_\_  
Title \_\_\_\_\_  
Organization/Agency \_\_\_\_\_  
Address: \_\_\_\_\_  
\_\_\_\_\_  
State: \_\_\_\_\_ City \_\_\_\_\_ Zip \_\_\_\_\_
2. Phone: ( ) \_\_\_\_\_
3. E-mail Address \_\_\_\_\_
4. Gender: Male \_\_\_\_\_ Female \_\_\_\_\_
5. Do you have a disability Yes (If yes please specify) \_\_\_\_\_ No \_\_\_\_\_
6. Special Needs: Wheel Chair User Yes \_\_\_\_\_ No \_\_\_\_\_  
Large Print Yes \_\_\_\_\_ No \_\_\_\_\_ Braille Yes \_\_\_\_\_

Audio Tape

Yes\_\_\_\_\_

No\_\_\_\_\_

Other (please specify)

---

## SECTION B: SURVEY

A number of challenges confront persons with disabilities and their families from under served communities. Listed below are several items which may be considered challenges for persons with disabilities and their families. Please complete this section by ranking the items listed below in order of their importance (with 1 being most important). While eight items are listed, space is provided for you to identify up to four additional items.

Challenge	Rank
A. Employment	_____
B. Resources	_____
C. Community Integration	_____
D. Well Being	_____
E. Housing	_____
F. Transportation	_____
G. Access to information	_____
H. Technology	_____
I. _____	_____
J. _____	_____
K. _____	_____
L. _____	_____

## SECTION C: OTHER COMMENTS

Please add any additional comments relative to the research agenda and under served communities.

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Thank you for your cooperation. Please fax or mail the completed form to the following address:

Dr. Sylvia Walker  
Howard University  
Research and Training Center  
(202) 806-8148 (fax)  
(202) 806-8086 (office)  
2900 VanNess St North West  
Holy Cross Hall  
Suite 100  
Washington, DC 20008

## **Appendix C**

### **The Decade of Behavior**

The following organizations have endorsed the Decade of Behavior:

- Academy of Behavioral Medicine Research
- American Anthropological Association
- American Association for Public Opinion Research
- American Association of Colleges of Nursing
- American Association of Spinal Cord Injury Psychologists and Social Workers
- American Educational Research Association
- American Institute of Stress
- American Organization of Nurse Executives
- American Political Science Association
- American Psychiatric Nurses Association
- American Psychological Association
- American Psychological Society
- American Public Health Association
- American Society of Criminology
- American Sociological Association
- Association for Behavior Analysis
- Association for the Advancement of Behavior Therapy
- Association of Schools of Public Health
- Association of Teachers of Preventive Medicine
- Behavior Genetics Association (president and past presidents)
- College on Problems of Drug Dependence
- Consortium of Social Science Associations (13 member societies)
- Council of Applied Masters Programs in Psychology
- Council of Graduate Departments of Psychology (more than 350 member departments)
- Federation of Behavioral, Psychological and Cognitive Sciences (18 member societies)
- German Neuropsychological Society
- Gerontological Society of America
- Human Factors and Ergonomics Society

- International Social Science Council
- International Society for Developmental Psychobiology
- International Study Group Investigating Drugs as Reinforcers
- International Union of Psychological Science
- Linguistic Society of America
- National Academy of Neuropsychology
- National Communication Association
- National League for Nursing
- Neurobehavioral Teratology Society
- Psychonomic Society
- Public Health Institute
- Research Society on Alcoholism
- Society for Computers in Psychology
- Society for Judgment and Decision Making
- Society for Personality and Social Psychology
- Society for Public Health Education
- Society for Research in Child Development
- Society for Research on Adolescence
- Society for Research on Nicotine and Tobacco
- Society for Stimulus Properties of Drugs
- Society of Behavioral Medicine
- U.S. National Committee of the International Union of Psychological Science
- U.S. National Committee for the International Union of Anthropological and Ethnological Science
- Virginia Psychological Association



## Appendix D

### Federal Agency Activities under Executive Order 13217

**1. Health Care Structure and Financing:** When the Medicaid program was created nearly 40 years ago, few community-based alternatives were available for people with disabilities who required health care services. Despite the expanded possibility of community alternatives available today, approximately 73 percent of Medicaid long-term care funding pays for institutional care while only 27 percent is directed toward home- and community-based services.

- HHS will establish a Medicaid Community Services Reform Task Force with representatives from within the disability community and national, state and local organizations to advise the department on actions within the Medicaid program that may be advisable to remove barriers and promote community living for people with disabilities.
- HHS will develop a strategy to address quality of care issues in home- and community-based settings, including: establishing defined expectations for home- and community-based services; assisting states in how to best use the results of HHS quality reviews of community placements; providing technical assistance to states in effective systems design or quality improvement strategies; and implementing new quality assurance and improvement systems for services in the home.
- HHS is providing states with substantial resources to improve community-based services through Systems Change grants (\$125 million in fiscal years 2001 and 2002), Medicaid Infrastructure grants to promote the employment of people with disabilities (\$25 million in fiscal year 2002) and through the National Caregiver Support Program (\$142 million in fiscal year 2002).

**2. Housing:** The lack of accessible, affordable housing continues to be a major barrier to the participation of people with disabilities in their communities and in the economic life of the nation. As more people with disabilities leave institutions for community life, this housing shortage will become more acute unless actions are taken.

- HUD will provide technical assistance to local public housing authorities to improve information on the need and use of vouchers for people with disabilities. HUD will strongly encourage local authorities to consult with local disability organizations on how best to maximize the use of vouchers in their areas.
- HUD will coordinate efforts with DOJ to devote substantial resources toward investigations and enforcement actions against developers, architects and site engineers who design or build multi-family housing that does not comply with the accessibility provisions of the Fair Housing Act.
- HHS will provide technical assistance and clarification as to methods through which Medicaid is able to assist individuals in transitioning from institutional to community residence.

**3. Personal Assistance, Direct Care Services and Community Workers:** There is already a critical need for personal care assistants and other direct care staff to provide services to people with disabilities living in the community. The administration will work to increase the number of these workers through recruitment, training, and work-related benefits.

- DOL's Office of Disability Employment Policy will work with other federal partners to identify and propose options for increasing the availability of personal assistants for people with disabilities and providing paths of career progression for personal assistants and other direct care staff.
- HHS will work with a limited number of volunteer states to initiate a national demonstration to address workforce shortages of community service and direct care workers. The demonstration will test the extent to which workforce shortages might be addressed through better coordination with the Temporary Assistance for Needy Families program and the availability of vouchers to workers for health insurance or for tuition or day care credits.

**4. Caregiver and Family Support:** The vast majority of direct care for people with disabilities is provided by families, friends and neighbors. However, despite the enormous contribution of family and informal caregivers to the community integration of people with disabilities, these caregivers receive little direct assistance and often face great financial and emotional pressures.

- HHS will seek authorization and funding from Congress for a demonstration to allow states to include respite care for adults. Unrelieved caregiver burden is a major contributing factor to institutionalization of individuals with disabilities; respite care is the service most often requested by families in order to keep a family member with a disability at home.
- HHS will also seek authorization and funding from Congress to implement a 10-year demonstration to provide respite services to caregivers of children who have a substantial disability.

**5. Transportation:** Accessible transportation is necessary for people with disabilities to go to work, get an education, receive medical care and to have an active, inclusive role in society. Barriers to transportation include a lack of available transportation options such as public transportation and a lack of access to existing transportation services.

- DOJ will look for opportunities to participate in private lawsuits as *amicus curiae* on issues involving paratransit services and accessible public transportation and will continue its efforts to expand the available modes of accessible transportation nationwide.

**6. Employment:** The dignity, responsibility and economic independence resulting from gainful employment is one of the most effective ways of enhancing self-reliance, changing attitudes, reducing dependency on public benefits and promoting community acceptance of people with disabilities.

- DOL will undertake an *Olmstead Community Empowerment Initiative*, developing and implementing a coordinated strategy to ensure that all DOL policies and activities fully address the employment and training needs of people with disabilities who are at risk of institutionalization or who are transitioning from an institution to the workplace and community living.
- DOL will award *Olmstead Community Employment Planning and Implementation Grants* to states that develop an employment focus for persons with disabilities in their *Olmstead* state implementation plans and incorporate activities coordinating employment and related supports at the state and local level.
- ED will coordinate with state vocational rehabilitation agencies and state education agencies to evaluate and improve transition services provided to youth with disabilities who are making the transition from school to work or to postsecondary education.

**7. Education:** Young people with disabilities face particular barriers to succeeding in school and going to college. Low educational attainment and confusing government programs and benefits have resulted in many young people with disabilities not making successful transitions from school to post-secondary education, employment and independent living.

- ED's Office for Civil Rights will prepare a resource document for nationwide distribution targeted to parents and students that clarifies the rights of students and the obligations of schools as students with disabilities transition from high school to postsecondary education and will carry out training and technical assistance initiatives in this area.
- ED's Office of Special Education Programs will engage in activities to ensure compliance with requirements of federal special education laws for transition planning and transition services so that students and families may be better prepared for the challenges and complexities of the adult world.

**8. Access to Technology:** Assistive technological devices enable people with disabilities to live independently or reduce their need for other assistance services. Technology also provides a gateway to a wealth of information about employment opportunities, community events and educational forums and has fundamentally changed the skills and knowledge needed to fully participate in the 21st century workplace.

- DOL will work with ED, HHS, the Department of Agriculture and other agencies to coordinate and implement a plan that improves the availability, affordability and accessibility of technology in the school, home and workplace for youth and adults with significant disabilities.

**9. Accountability and Legal Compliance:** There is a need for an array of activities to promote states' compliance with the *Olmstead* decision, including: greater federal oversight of programs that serve people with disabilities; stronger enforcement of laws that protect the rights of people with disabilities; guidance to states on effective planning

to provide services in the most integrated setting; and greater and more effective outreach to assist individuals with disabilities and their family members in understanding the ADA and *Olmstead's* requirements.

- DOJ will use its Fair Housing Testing program to identify patterns or practices of discrimination against individuals with disabilities by those who sell or rent housing.
- DOJ will expand the use of its mediation program for *Olmstead*-related claims, including: providing additional training to mediators regarding the decision; investigating ways to train lay advocates; and working toward implementing a formal arrangement under which HHS' Office for Civil Rights would refer appropriate unresolved complaints to DOJ for mediation.

**10. Public Awareness, Outreach and Partnerships:** Many people with disabilities and their families are not aware of the full range of community services that are available to them. Outreach to provide information and incorporate the views of people with disabilities and other stakeholders into federal policy will help fill this knowledge gap.

- DOL will launch a comprehensive public awareness campaign to decrease stigma, eliminate attitudinal barriers, and increase employment opportunities for adults and youth with significant disabilities. The campaign will target business and industry, lenders and families among others.
- DOJ will develop technical assistance documents to educate people with disabilities living in institutions or at-risk of living in institutions about their rights and to assist states in implementing their community-integration responsibilities under the *Olmstead* decision.

**11. Income Supports:** Cash and medical benefits can be critical to an individual's ability to live in the community. Cash benefits, often in conjunction with food stamps and housing subsidies, can provide for basic needs such as food, clothing and shelter. Medical benefits can enable someone to obtain treatment that may be critical to his or her ability to function in a community setting. Of course, work also contributes significantly to an individual's ability to thrive in a community setting.

- SSA is providing special training to agency staff who serve the public directly, emphasizing the importance of key policies and procedures to assist people with disabilities and promote the community-integration goals of the *Olmstead* decision.

**12. Gathering, Assessment and Use of Data:** The successful integration of people with disabilities into community settings requires consistent data collection to measure the progress of existing programs and initiatives and to determine the specific needs of people with disabilities.

- HHS' Centers for Medicare & Medicaid Services will work with states, universities, foundations and others to ensure that there is an adequate base of

knowledge to inform public policy-making regarding: the impact of the Medicaid and Medicare actions under the President's Executive Order; state initiatives to improve community living services; methods for designing long-term care systems so that they promote the ADA and can address the population growth expected due to demographic changes; and methods for designing quality assurance and improvement systems uniquely suited for services in one's own home.

- HUD will conduct a "Housing Choice Voucher Tenant Accessibility Study" to assess the feasibility of conducting a nationwide mail survey of voucher program enrollees who have disabilities regarding their experiences in searching for accessible housing.

**13. Cross-Agency Collaboration and Coordination:** In order to effectively meet the needs of individuals with disabilities and to efficiently utilize federal resources, the various federal agencies that develop disability policy and provide, fund and support community-based services will communicate about and collaborate on their objectives.

- HHS proposes that the President formalize and permanently establish the ICCL, which Secretary Thompson convened to accomplish the tasks set out in Executive Order 13217. The council would articulate a strategic interagency plan to expand and promote home- and community-based services as well as issues related to housing, employment, the long-term care workforce, assistive technology and education.
- DOL's Office of Disability Employment Policy will work to develop a memorandum of understanding (MOU) with other federal agencies to work together to improve resources and employment opportunities for people with disabilities. The MOU will serve as a model for state-level coordination to ensure that employment becomes part of the planning process for people transitioning from institutional care into the community.

## ***Diversity***

*Diversity...generally understood and embraced, is not liberal tolerance of anything and everything not yourself. It is not polite accommodation. Instead, diversity is, in action, the sometimes painful awareness that other people, other races, other voices, other habits of mind, have as much integrity of being, as much claim upon the world, as you do. No one has an obligation greater than your own to change, or yield, or to assimilate into the mass.*

*The irreconcilable is as much a part of a social life as the congenial. Being strong in life is being strong amid differences while accepting the fact that your own self can be a considerable imposition upon everyone you meet. I urge you to consider your own oddity before you are troubled or offended by that of the others. And I urge you, amid all the differences present to the eye and mind, to reach out and create the bonds that will sustain the commonwealth that will protect us all. We are meant to be here together.*<sup>19</sup>

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<sup>19</sup> Chace, William M. (1989). The Language of Action, *Wesleyan* LXII, #2, Fall 1989, p. 36.

