

LIFT
EVERY
VOICE

Modernizing Disability Policies and Programs
to Serve a Diverse Nation

Executive Summary

NATIONAL COUNCIL ON
DISABILITY
July 26, 1999

National Council on Disability
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LIFT EVERY VOICE AND SING
"The Black National Anthem"
James Weldon Johnson, 1900

Lift ev'ry voice and sing,
Till earth and heaven ring.
Ring with the harmonies of Liberty;
Let our rejoicing rise,
High as the list'ning skies,
Let it resound loud as the rolling sea.
Sing a song full of the faith that the dark past has taught us,
Sing a song full of the hope that the present has brought us;
Facing the rising sun of our new day begun,
Let us march on till victory is won.

Stony the road we trod,
Bitter the chast'ning rod,
Felt in the days when hope unborn had died;
Yet with a steady beat,
Have not our weary feet,
Come to the place for which our fathers sighed?
We have come over a way that with tears has been watered,
We have come, treading our path through the blood of the
slaughtered,
Out from the gloomy past,
Till now we stand at last
Where the white gleam of our bright star is cast.

God of our weary years,
God of our silent tears,
Thou who has brought us thus far on the way;
Thou who has by Thy might,
Led us into the light,
Keep us forever in the path, we pray.
Lest our feet stray from the places, our God, where we met Thee,
Lest our hearts, drunk with the wine of the world, we forget Thee,

Shadowed beneath thy hand,
May we forever stand,
True to our God,
True to our native land.

Executive Summary

On July 26, 1990, President George Bush signed into law the Americans with Disabilities Act (ADA), one of the most sweeping civil rights laws ever enacted. During the signing ceremony, President Bush emphasized the historic importance of the signing of the Act by comparing it to the fall of the Berlin Wall. "And now I sign legislation which takes a sledgehammer to another wall," he said, "one which has, for too many generations, separated Americans with disabilities from the freedom they could glimpse, but not grasp. Once again, we rejoice as this barrier falls, proclaiming together we will not accept, we will not excuse, we will not tolerate discrimination in America." Then, as he lifted his pen to sign the ADA, Bush concluded his remarks by declaring, "Let the shameful wall of exclusion finally come tumbling down."

Nine years later, ADA and the American disability rights movement have produced some tangible results for many Americans with disabilities. In towns and cities across the United States, ADA has produced evolutionary progress in removing barriers that keep Americans with disabilities and their families excluded. For a large segment of the population, however, particularly for those from diverse racial, cultural and ethnic communities, a shameful wall of exclusion continues to hinder their ability to participate fully in all aspects of American society. Whether the exclusion stems from one's disability, one's race, one's language, one's culture, one's ethnicity, or a combination of these, at bottom the sting of rejection is just as painful. As we mark the ninth anniversary of the signing of ADA, the declaration of equality made in 1990 remains hollow for many people with disabilities from diverse cultural backgrounds as they continue to struggle against the persistent barriers of poverty, inequality and dual discrimination.

On August 5, 1998, the National Council on Disability (NCD) held a public hearing in San Francisco, California on "Meeting the Unique Needs of People with Disabilities from Diverse Cultural Backgrounds." This hearing was part of a series of hearings and forums NCD is conducting to develop recommendations to improve the ability of federal policies and programs to serve diverse communities effectively. The San Francisco hearing was preceded by a roundtable in Atlanta, Georgia, and a hearing in New Orleans, Louisiana. In part to ensure greater input from the Asian/Pacific Islander and Hispanic communities, the San Francisco hearing was conducted simultaneously in Spanish, English, and Cantonese to encourage the participation of non-English speakers. Although the hearing participants were from California and Hawaii, the issues raised have application at the national level.

Throughout the six hours of testimony at the 1998 NCD hearing in San Francisco, over 60 witnesses identified several barriers to full participation by minority individuals with disabilities and their families. The three main barriers that emerged from the testimony were:

- (1) Having a Seat at the Table: Barriers to Employment, Public Accommodations, Transportation, and Culturally Competent Service Delivery;
- (2) Getting in the Door: Barriers to Citizenship; and
- (3) Being Recognized: Barriers to Accurate Demographic Data.

This report follows up on a groundbreaking 1993 NCD report entitled Meeting the Unique Needs of Minorities with Disabilities. Many of the findings reported in 1993 remain true six years later. Notwithstanding federal efforts to improve service delivery to minorities and other underserved groups, NCD has been told by grassroots consumers that little has changed that has resulted in tangible improvements in their day to day lives.

This report is not a comprehensive treatment of policy issues affecting minorities with disabilities. Rather, it is intended to spark a dialogue about how best to learn from our experiences in the last several years and bring the federal disability policy agenda to a new level of inclusiveness and effectiveness, resulting in better outcomes for people with disabilities from diverse cultural backgrounds and their families. This report captures priority issues identified by the minorities with disabilities and others who testified in San Francisco, many of whom were native Spanish speakers and native Cantonese speakers. Although a great number of the issues raised in San

Francisco echoed themes NCD had heard in public hearings and meetings in Atlanta and New Orleans, some of the issues raised elsewhere were not emphasized at the San Francisco hearing and some of the priority issues raised in San Francisco received less attention elsewhere.

In part to broaden the scope of the policy agenda contained in this and other reports NCD has released in recent years, NCD will be hosting a think tank in the Spring of 2000 to further refine a public policy agenda that will be responsive to the needs of all minorities with disabilities, their families and communities. Likewise, in Fall 1999 and Winter 2000, NCD plans to issue reports on federal enforcement of the Individuals with Disabilities Education Act (IDEA) and ADA, respectively, which will include a number of recommendations specifically geared toward making those laws more effective for minorities with disabilities and their families.

NCD looks forward to working with the broader disability and civil rights communities in the coming months and years to elevate the voices it heard in San Francisco, New Orleans, and Atlanta, and thereby make the policy landscape more inclusive and responsive to the needs of this important population. Although the pages that follow include many important recommendations for improving service delivery for minorities with disabilities, NCD wishes to highlight one recommendation in particular that will enhance the positive impact of current policies and programs.

NCD has learned from grassroots witnesses that the best way to empower minorities with disabilities and their families to take full advantage of federal laws, programs and services is to provide them with easy-to-understand, culturally-appropriate information about what their rights are under various federal laws (e.g. ADA, the Rehabilitation Act, the Individuals with Disabilities Education Act, the Fair Housing Act, etc.) and how best to exercise those rights when a violation occurs.

To address this issue directly, NCD recommends that an interagency team comprised of representatives from the Departments of Education, Labor, Health and Human Services, Justice, and Housing and Urban Development, along with the Equal Employment Opportunity Commission, Small Business Administration, and Federal Communications Commission, develop and implement a large-scale outreach and training program targeted to people with disabilities from diverse cultural backgrounds and their families that will provide such information directly to the target audiences through a series of trainings, forums, and seminars across the country. These trainings should be repeated periodically so that new people are trained each year and materials are routinely updated.

This interagency team should work with the disability communities, minority communities, and the disability, minority, religious and other interested organizations to develop a workplan, timetables, and appropriate stakeholder consultation as they begin their work. In addition, NCD recommends that the interagency Team recruit, train, and contract with a core group of people with disabilities from diverse cultural backgrounds and their family members to help develop the written materials and programs that will be used for the trainings, translate them into many languages with sensitivity to cultural appropriateness of terminology, and conduct the trainings once the materials are produced. The federal partners should make efforts to include and accommodate often-overlooked groups among the people to be trained and the core group of trainers, including but not limited to young adults with disabilities, people living on Indian reservations and other rural or isolated locations, people with mental disabilities, and people with limited English proficiency. Finally, NCD recommends that the federal sponsors of the trainings eliminate any potential financial barriers to participation so that the population trained will truly represent the population to be served.

[Note: In the spirit of our 1998 hearing, NCD will not release the full report until translations of the full report are available in Spanish and Cantonese. NCD is releasing only the Executive Summary of this report today, along with culturally appropriate Spanish and Cantonese translations of the Executive Summary. Also, throughout the Executive Summary, for ease of reference, NCD recommendations appear in italics.]

I. HAVING A SEAT AT THE TABLE: BARRIERS TO RESOURCES

A. BARRIERS TO EMPLOYMENT

NCD found in 1993 that "persons from minority backgrounds with disabilities...do not have appropriate training and career development opportunities." NCD believes this finding is still applicable today. Based on the flat

employment numbers for minorities with disabilities and the testimony presented at the 1998 NCD hearing in San Francisco, it is apparent that minority individuals with disabilities still experience tremendous difficulty accessing culturally appropriate job training and career development opportunities. Although these barriers can occur for all people with disabilities, they are more persistent and more pronounced for people with disabilities from diverse cultural backgrounds.

While the labor force participation rate for people 18 to 64 years old who do not have disabilities is nearly 83 percent, it is only about 52 percent for those with disabilities, and only about 38.6 percent for non-whites with disabilities. For people with severe disabilities, the labor force participation rate is about 30 percent for whites, 21.2 percent among Hispanics, and 17.8 percent among blacks.

Based on the testimony and data reviewed, it seems that in spite of the Rehabilitation Cultural Diversity Initiative begun in 1992, significant racial disparities continue to exist in the delivery of vocational rehabilitation services. In California, these disparities are particularly apparent in the areas of job training and placement services. Moreover, minority individuals with disabilities often experience tremendous difficulty obtaining employment with minority-owned businesses due to the stigma attached to disability within many minority communities. In some racial and ethnic communities, as in some white communities, people with disabilities are viewed as bad for business, not worth investing in as employees or courting as customers, and in some cases bearers of bad luck.

NCD's 1993 finding that "persons from minority backgrounds with disabilities...are unable to take full advantage of the ADA and other disability policies because of a lack of economic opportunity" is still applicable today. According to witnesses at the 1998 hearing, there are few opportunities available to minority individuals with disabilities for economic independence, particularly entrepreneurial opportunities. Many minority individuals with disabilities experience significant language and communication barriers when seeking employment, which are often the result of discrimination based on a potential employer's fear and ignorance.

Family members of minority individuals with disabilities have unique needs and experience unique barriers to employment that have a direct impact on the provision of services for the minority with a disability. For the most part, the unique needs of family members of minority individuals with disabilities have not been incorporated into the larger disability policy agenda, and this has had a direct effect on the lives of minority-group members with disabilities. Recommendations for Improving Employment Opportunities:

- The Department of Labor, Small Business Administration, and the Department of Education should expand funding for culturally appropriate job training and career development opportunities, and should require all such federally-funded programs to demonstrate their ability to meet the language, culture, and disability needs of the whole population in their service area.
- The Rehabilitation Services Administration (RSA) should address the racial disparities apparent in the vocational rehabilitation system, particularly in the areas of job training and placement services.
- RSA should strengthen and increase the number of interventions outlined in section 21 of the Rehabilitation Act, which requires vocational rehabilitation agencies to take action to better address the needs of underserved groups within their service areas.
- RSA should conduct compliance reviews of all state departments of rehabilitation to determine the extent to which their efforts to comply with section 21 of the Rehabilitation Act have produced better outcomes for minorities with disabilities in their state.
- The Small Business Administration, working with the Presidential Task Force on Employment of Adults with Disabilities, should provide more entrepreneurial opportunities for minority individuals with disabilities to promote economic independence.
- Federal, State, and local policy-makers should incorporate the unique needs of family members of minority individuals with disabilities into the larger disability policy agenda, particularly in the area of employment.

One barrier to employment for family members of minority children with disabilities that was repeatedly mentioned at the 1998 hearing was the prevalent lack of accessible, affordable, and integrated child care and after-school

programs. There are very few after-school programs available in California, let alone programs that are affordable, integrated, and accessible. In addition, the programs that match this criteria tend to have waiting lists that exceed a year. Existing programs are also rarely staffed with employees trained to work with children of varied abilities and cultural backgrounds. Due to the lack of accessible, affordable, and integrated child care and after-school programs, parents of minority children with disabilities are foregoing valuable employment opportunities. Parents who cannot afford to stay home with their children testified about their need to turn to extreme measures such as locking their disabled children in their rooms, a practice which was noted by a substantial number of witnesses at the 1998 hearing. Put simply, the child care shortage in California and other states has reached crisis proportions for low-income parents of children with disabilities, many of whom are minorities.

Recommendations for Improving Access to Child Care:

- The Department of Justice should prioritize investigations to assess compliance with Title III access mandates among social service center establishments serving children.
- The Department of Education and Department of Justice should prioritize investigations of school district compliance with IDEA least restrictive environment requirements in the implementation of district-provided after-school programs.
- Congress should appropriate funding to increase the supply of accessible, affordable, and integrated child care and after-school programs; and should require that all federally-funded programs not only meet federal disability access standards but also demonstrate the capacity to meet the language, culture, and disability needs of their entire service population.
- The Departments of Education, Justice, and Health and Human Services, including the federally-funded legal services programs and protection and advocacy systems, should increase outreach efforts to parents of minority children with disabilities regarding their rights under ADA, IDEA, section 504 of the Rehabilitation Act, the Fair Housing Act, and other federal disability civil rights laws.

B. BARRIERS TO ACCESSING PUBLIC ACCOMMODATIONS

NCD's 1993 finding that persons from minority backgrounds with disabilities...have greater difficulty...gaining access to public accommodations...than do other Americans with disabilities, is still applicable today. More than 20 percent of the witnesses who testified at the 1998 NCD hearing in San Francisco stated that they experienced multiple barriers when trying to access public accommodations such as restaurants, markets, and other popular local establishments, particularly in their own cultural communities (such as Chinatown in San Francisco). Minority individuals with disabilities and their family members who testified at the 1998 hearing attributed the continued lack of access to public accommodations to a prevalent lack of compliance with existing access mandates in Title III of the ADA and little knowledge of those requirements among protected individuals and covered entities in minority communities.

There are a variety of serious gaps in the legal protections afforded minority individuals with disabilities and their families, particularly in the area of access to public accommodations. Unlike the Individuals with Disabilities Education Act, which has specific language supporting the rights of ethnic minority families whose primary language is other than English, the ADA and most other disability laws and policies fail to address the unique language and communication needs of minority individuals with disabilities and their families for whom English is a second language. Moreover, many American Indian tribes have no civil rights law for tribe members with disabilities.

Recommendations for Improving Access to Public:

Accommodations:

- Congress Should Require Federal Enforcement Agencies like DOJ, EEOC, DOT and HUD to Demonstrate Their Effectiveness in Serving People with Disabilities from Diverse Cultural Backgrounds.
- Federal enforcement agencies should work together to develop a multi-agency outreach and technical assistance strategy that would constitute a national campaign to increase knowledge of civil rights protections and how to file complaints among protected communities, focused on underserved groups like language, racial and ethnic minorities, youth, and rural residents with disabilities and their families.
- Congress should ensure that civil rights enforcement agencies have adequate financial and staffing resources to effectively address the needs of their entire service areas.
- Congress and the Bureau of Indian Affairs should provide federal financial support and assistance for the development of tribal disability rights legislation.

BARRIERS TO TRANSPORTATION:

NCD's 1993 finding that persons from minority backgrounds with disabilities...have greater difficulty...gaining access to...transportation than do other Americans with disabilities is still applicable today. Almost one in five witnesses who testified at the 1998 NCD hearing in San Francisco stated that they experienced multiple barriers when trying to access public transportation. One issue repeatedly discussed at the hearing was the perceived unwillingness on the part of public transportation personnel to accommodate minority individuals with disabilities and implement existing access requirements with regard to public transportation. Several parents who testified at the hearing indicated that this is a particular problem for minority children with disabilities. According to these parents, public transportation personnel are largely unwilling to assist minority children with disabilities in getting on and off the bus, and finding the appropriate stop. Minority individuals with disabilities who speak English as a second language also face additional language and communication barriers when attempting to access public transportation. Some respondents testified that public transportation personnel seemed less willing to assist minority individuals with disabilities who were limited or non-English speaking.

There are a limited number of transportation options available to minority individuals with disabilities who live in isolated areas and rural communities, especially in the Pacific Islands. Although most Americans with disabilities occasionally have to wait long periods of time for public transportation, witnesses at the 1998 hearing asserted that because of their disability and racial identity, drivers were even less likely to pick them up. Witnesses at the hearing stated that they were often forced to wait somewhere between four and six hours before public transportation personnel would finally stop and pick them up. As a result of this prolonged wait and discrimination, many minority individuals with disabilities often miss important medical or other appointments.

Recommendations for Improving Access to Transportation:

DOT and/or DOJ should investigate the extent to which local compliance with ADA transportation requirements are influenced by race and ethnicity.

Congress should ensure that transportation civil rights enforcement agencies have adequate financial and staffing resources to maintain an adequate presence with covered transportation entities to ensure compliance.

DOT should make funds available for local transportation providers to provide on-going diversity and disability awareness training for all public transportation personnel, as well as specific training on the public transportation provisions of ADA. DOT should create incentives for local transportation providers to increase efforts to hire bilingual public transportation personnel in service areas with high concentrations of non-English speakers.

BARRIER TO CULTURALLY COMPETENT SERVICE DELIVERY:

1. MINORITY REPRESENTATION IN DISABILITY SERVICE PROFESSIONS

NCD's 1993 finding that one of the main barriers to culturally competent service delivery for minority individuals with disabilities is the lack of minority representation in disability service professions is still applicable today. Approximately one half of the participants at the 1998 NCD hearing testified about the difficulty they experience accessing culturally competent services due to the shortage of minority individuals in disability service professions.

One area where the lack of minority representation is particularly apparent is in the field of disability counseling services. Several respondents at the hearing stressed the tremendous need for cultural identification between clients and counselors in order to provide culturally appropriate counseling services. In a recent national study funded by a grant from the National Institute on Disability and Rehabilitation Research, 82 state rehabilitation agencies (general and blind) were surveyed regarding the racial and ethnic composition of their workforces. Within the 56 agencies responding, 87.4 percent of state offices staff were reported as Caucasian American, 7.7 percent as African American, 1.9 percent as Hispanic American, 2.9 percent as Asian American and Pacific Islander, and 0.1 percent as other. Within district offices, which tended to have lower salaries across the board, the staff were reported as 79.5 percent Caucasian American, 13.3 percent African American, 4.8 percent Hispanic American, 1.7 percent Asian American and Pacific Islander, and 0.5 percent Native American. The same recent study found that professionals of minority backgrounds are significantly under-represented nationally.

Another area where there is a tremendous shortage of minority service personnel is in the field of special education. Witnesses at the hearing testified that there are few bilingual/bicultural school personnel in all areas of special education. According to statewide special education data, more than half (57%) of the students enrolled in special education in California are from minority communities, while less than 15 percent (14.9%) of the special education teachers in the state are minority and almost 85 percent (84.3%) are White. Several hearing participants felt that this racial imbalance leads to conflicting expectations and poor parent-teacher communication, particularly in rural areas. Witnesses at the hearing also testified that there are few, if any, special education mediators and hearing officers of color, particularly African-Americans. According to the one California special education hearing office, there are no special education mediators of color in the state, and out of the eight hearing officers, only three are persons from minority communities.

Furthermore, no special education mediators or hearing officers in California are African-American. Since contract preferences have been deemed unconstitutional as a result of Proposition 209, the hearing office referenced above has made no effort to conduct targeted recruitment and hiring of minority individuals and women. According to a number of hearing participants, one aspect of representation that is largely overlooked in the discussion regarding culturally competent service delivery is the lack of disability service personnel who are not only members of racial and ethnic minority groups, but also people with disabilities. Just because someone is bilingual or bicultural does not necessarily mean they will understand and be sensitive to the needs of people with disabilities from minority communities, particularly given the stigmas attached to disability within many diverse cultures. Several witnesses who were recent immigrants noted that this issue is further complicated by generational differences and immigration status.

Another aspect of representation that impacts culturally competent service delivery is the absence of minority individuals with disabilities within positions of decision-making power. According to witnesses at the hearing, this problem is particularly apparent in the composition of the general and administrative staff for California's network of independent living centers. According to the Section 704 Report for 1997, over 50 percent of the general staff for the state's independent living centers are members of minority communities, and at least 60 percent are people with disabilities. Over 60 percent of the decision making staff, however, are White. Of the 18 current State Independent Living Council members in California, furthermore, only 1 representative is a person from a minority community. Section 705(b)(4) of the Rehabilitation Act of 1973 requires that a majority of all SILC members be persons with disabilities, but there is no similar requirement in the law to ensure appropriate minimum minority representation.

Recommendations for Improving Diversity of Disability Service

Providers:

The Departments of Education, Health and Human Services, and Labor should increase incentives for minority individuals, particularly minority individuals with disabilities, to enter disability service professions, and to be afforded educational and professional development opportunities after entry. For example, the Department of Education should enhance funding for scholarships funded through the Office of Special Education and

Rehabilitative Services to minority institutions of higher education to increase the number of qualified graduates of culturally diverse backgrounds, especially those with disabilities.

RSA and the Office of Special Education Programs should continue their efforts to increase the number of minority professionals working in vocational rehabilitation, special education, independent living, and related services, and other disability service agencies should create similar initiatives. For example, Rehabilitation Capacity Building initiatives should be utilized to develop new programs in Historically Black Colleges and Universities, Hispanic Serving Institutions, Native American Serving Institutions, and Asian American/Pacific Islander Serving Institutions, which will increase the number of qualified rehabilitation personnel of diverse cultures in the system.

RSA and other federal funders should require disability service providers to have a demonstrated commitment to workplace diversity and family-friendly Policies. Along these lines, RSA should mandate hiring of a higher percentage of graduates (RSA scholarship recipients) of the programs mentioned above each year to fulfill the Comprehensive System of Personnel Development needs of every agency.

Congress should appropriate adequate funding to EEOC, DOJ, HUD, DOT and Education to enable them to conduct disability rights training to minorities with disabilities, their family members, and bilingual individuals, with the goal of creating a core group of culturally diverse individuals in every state who can train additional individuals in the requirements of federal civil rights laws and how to use those laws when a violation occurs. The Department of Education should issue a policy memorandum mandating targeted recruitment and hiring of bilingual and bicultural special education staff at all levels. OSEP, along with the Office for Civil Rights at the Education Department, should investigate the racial and ethnic composition of special education mediators and hearing officers nationally, and the extent to which race and ethnicity influence mediation and due process outcomes.

Federal funding agencies like Education, HHS and DOL should encourage voluntary public disclosure of diversity data for entities receiving federal funds. In addition, federal agencies like RSA should require an annual cultural competency assessment for every state agency and maintain a national database containing the following personnel information: position, ethnicity, gender, disability status, education, certification/licensure, and salary. NIDRR should fund a longitudinal study on participation of culturally diverse professionals in the rehabilitation system. In addition, NIDRR should fund research on rehabilitation outcomes, educational outcomes, etc., as a function of counselor/teacher ethnicity, gender, disability, education, and professional competency.

2. CULTURALLY APPROPRIATE OUTREACH

NCD's 1993 finding that minority individuals with disabilities and their families are largely unaware of the services and resources available to them because there have been insufficient outreach efforts to these individuals by federal, state, and local agencies, is still applicable today. More than four in ten of the participants at the 1998 NCD hearing asserted that minority individuals with disabilities and their families are still unaware of the services and resources available to them due to the inadequacy of culturally appropriate outreach efforts to these populations.

Participants in the 1998 hearing noted that there is a tremendous lack of awareness among minority populations about the existence of the Americans with Disabilities Act, and the specific rights guaranteed under the act. One group that has tremendous difficulty gaining access to necessary information and resources are parents of minority children with disabilities, particularly those who are limited or non-English speaking. According to several witnesses at the hearing, the lack of access to information and resources substantially limits the ability of parents of minority children with disabilities to exercise their rights and responsibilities under the law, and obtain necessary services for their children.

According to a large number of hearing participants, the lack of awareness among minority individuals with disabilities and their families largely stems from the failure of federal, state, and local agencies to provide information in a way that is culturally and linguistically appropriate, and takes into account the fundamental differences that exist between majority and minority cultures.

Many U.S. minority groups have collectivistic orientations which emphasize the importance of family and interdependence. This is in direct contrast with the U.S. majority culture, which is highly individualistic and places tremendous value on personal autonomy and independence.

Due to these cultural differences, concepts such as individual empowerment, self-sufficiency, independent living, control over one's life, and minimal reliance on others may seem offensive and isolating to a minority individual with a disability if not adequately translated and presented in a culturally appropriate manner.

There are significant cultural differences in the perception and impact of disability on the individual and the family. In many U.S. minority cultures, disability is seen as a reflection upon and responsibility of the entire family.

U.S. majority culture, on the other hand, tends to view disability primarily as an individual matter. According to witnesses at the hearing, the sense of family responsibility for disability within many minority cultures stems from the negative perception of disability that exists within those cultures. For a large number of minority group members, disability is typically viewed as a shameful or negative reflection upon the whole family.

There is a tremendous need for education and outreach to minority individuals with disabilities, to their families, and their communities, in order to provide support in dealing with the impact of disability, and in turn, increase awareness about available resources and ways to integrate the experience of disability into one's life, one's family, and one's community without shame or unnecessary sacrifice of one's goals.

Awareness about disability issues needs to be increased within minority communities, but there is an equally profound need to increase awareness about minority cultural issues within the mainstream disability community. According to witnesses at the hearing, most disability organizations know very little about how to promote linguistic and cultural access for minority individuals with disabilities. Linguistically and culturally appropriate outreach is often hampered by the failure of federal agencies to renew grant funding specifically earmarked for this purpose. Culturally appropriate outreach requires a long-term commitment and a continued presence in minority communities in order to establish the required sense of trust that is necessary for outreach efforts to be successful. When funding is not renewed, outreach efforts are substantially and negatively impacted.

Recommendations for Improving Culturally Appropriate Outreach:

Congress should amend the definition of Minority Entities under Section 21 of the Rehabilitation Act to once again include Community-Based Minority Organizations. Congress should ask GAO to investigate the cultural and linguistic appropriateness of public information activities related to the ADA, IDEA, the Fair Housing Act, and other federal disability civil rights laws. Education, HHS, DOT, HUD, DOL and SBA should require their grantees and field offices to develop a culturally appropriate outreach plan which takes into account the fundamental differences that exist between majority and minority cultures. The National Institute on Disability and Rehabilitation Research should require its research and training centers with emphasis on minority populations to develop and test guides describing the services provided by independent living centers that use appropriate cultural and linguistic terminology for diverse populations. Once these guides are produced, RSA should require CILs and SILCs to use these guides to improve their outreach and service delivery to diverse populations. Federal agencies funding outreach efforts should encourage initiatives directed not only toward minority individuals with disabilities, but also toward their families and racial and ethnic community organizations. Federal agencies conducting or funding outreach should emphasize that successful outreach requires an awareness of the perception of disability and related issues like independent living that exists within a particular cultural community.

3. LANGUAGE AND COMMUNICATION BARRIERS

NCD's 1993 finding that one of the main barriers to culturally competent service delivery for minority individuals with disabilities is the failure to address their language and communication needs is still applicable today. Approximately four in ten of the participants at the 1998 NCD hearing testified about the difficulty they experience accessing culturally competent services due to language and communication barriers.

For minority individuals with disabilities who are limited or non-English speaking, the language barriers, in particular, are a major obstacle to accessing necessary resources due to the prevalent lack of bilingual service providers, interpreters, and language appropriate materials. The lack of language capacity among many disability service providers was noted by several witnesses at the hearing, who stated that this barrier significantly limits access to information about rights, benefits, employment programs, and other support services and opportunities. The need for bilingual service providers is particularly apparent in the area of special education. According to witnesses at the hearing, parents of children with disabilities who are limited or non-English speaking face significant language barriers when attempting to enroll their children in special education, obtain related services, and participate in everyday, informal communication with school personnel. The lack of access to interpreting services was noted by a large number of participants at the hearing. Difficulties included evaluating interpreter

skills, finding and paying for an interpreter with the particular language(s) needed, and having interpreters available when needed. Cheryl Wu and Nancy Grant, of the Hearing Society for the Bay Area, also noted that interpreting/translation often addresses only words, and does not take into account the need for translation of cultural concepts, behaviors and body language, expectations about relationships, and jargon (medical terms, educational and legal acronyms). When dealing with service providers, minority individuals with disabilities often experience significant communication problems due to cultural differences in body language and communication styles.

Other language and communication barriers discussed at the 1998 hearing include a lack of direct telephone access due to English-only answering systems, limited funding for translation and interpretation services, and the absence of translated materials in alternative formats like braille, audiocassettes, and large print. Based on the results of a follow-up study conducted after the hearing, Kathy Abrahamson and Kathy Knox, of the Rose Resnick Lighthouse for the Blind in San Francisco, concluded that an additional language and communication barrier for people from diverse cultural communities who are blind or visually impaired is the complete absence of language appropriate materials available in alternative formats, particularly from governmental agencies.

Recommendations for Removing Language and Communication Barriers:

- Education, HHS, HUD, DOT, DOL, and SBA should require that their field offices and grantees conduct targeted recruitment and hiring of minority individuals who are bilingual and bicultural, especially minority individuals with disabilities.
- The Office of Special Education and Rehabilitative Services should issue a policy memorandum mandating targeted recruitment and hiring of bilingual special education staff at all levels.
- RSA should include language interpreter information and referral as a core service at all centers for independent living serving significant populations of non-English-speaking people within their service areas.
- RSA should require all CILs with significant non-English-speaking populations in their service area to develop language/communication action plans that include the following:
 - The establishment of contacts within minority community agencies who can assist in facilitating communication with ethnically diverse populations;
 - The development of a language interpreter referral database that is available in multiple languages and alternative formats, and also on the world wide web;
 - Sending all existing or new translated materials to the state independent living council for widespread distribution to other centers for independent living and related agencies/organizations in the state; Sign language and other language interpreter/translator training programs that provide instruction on translation of cultural concepts, behaviors and body language, expectations about relationships, and other technical disability-related terms (medical terms, educational and legal acronyms).
 - Provide Language-Dedicated Telephone Lines in Spanish and other languages, and Information in Bilingual Formats on Web Pages.
- Education, HHS, HUD, DOL, DOT, and SBA should make available adequate funding to all field offices and grantees for translation and interpretation services.
- Congress should ask GAO to investigate the quality of service delivery for minority individuals with disabilities and their families in terms of language and cultural competence.

II. GETTING IN THE DOOR: BARRIERS TO CITIZENSHIP

The United States has a long and well-documented history of discouraging and actively restricting the immigration and citizenship of people with disabilities, especially those from certain racial and ethnic communities. The historical pattern of discouraging and actively restricting the immigration and citizenship of people with disabilities has continued on into the 1990s through a more indirect, yet equally exclusionary practice of denying immigrants with disabilities their right to reasonable accommodations in the naturalization process. In the wake of the 1996 welfare reform law, many immigrants with disabilities throughout the United States faced the possibility of losing necessary Social Security and food stamp benefits if they did not become U.S. citizens. In California, almost 74 percent of the legal non-citizens in the state stood to lose not only Supplemental Security Income (SSI) and food stamp benefits, but also Medicaid and In-Home Supportive Services (the State name for home-based personal

assistance services) as a result of categorical eligibility requirements, if they failed to naturalize and attain U.S. citizenship prior to enactment of welfare reform.

At the time of NCD's hearing in 1998, citizenship continued to be withheld from many qualifying immigrants with disabilities due to the denial of reasonable accommodations and policy modifications by the Immigration and Naturalization Service (INS) in three particular stages of the naturalization process: the naturalization interview, fingerprinting, and the execution of a meaningful oath of allegiance. Only in the last year has INS begun to take its obligations under the Rehabilitation Act seriously by forming a national working group with community-based organizations that is helping INS develop needed field guidance and policy modifications for naturalization processing and adjudication. On April 7, 1999, INS issued comprehensive new guidance to its field adjudicators that is intended to simplify and streamline the review of form N-648, which exempts persons with certain disabilities from the English language and U.S. civics knowledge requirement for naturalization. INS also is revising the N-400, the naturalization application, and is planning to include a new section on the revised form which will allow applicants to indicate that they will need a reasonable accommodation during their interview (e.g. sign language interpreter, home visit, etc.). In addition, INS has announced a new fingerprint waiver procedure that will become available during summer, 1999. It will waive the fingerprint requirement for applicants who cannot produce classifiable fingerprints due to a disability; instead, they will be instructed to obtain a local police clearance memorandum.

The April 7, 1999 memorandum also included guidance to field adjudicators concerning the determination of whether certain applicants with severe disabilities understand the oath of allegiance. The guidance instructed adjudicators to communicate with the applicant through a family member, if the family member can aid in communicating with the applicant; to use yes or no questions that the applicant might more readily be able to answer; and to accept whatever form of communication the applicant uses, including blinks and nods.

Recommendations for Improving the Naturalization Process:

- Congress should ask the General Accounting Office (GAO) to conduct a study of INS compliance with disability access mandates under federal law, examining in part whether the changes put in place in the last year have resolved the longstanding problems identified in this report.
- INS should conduct training for field staff regarding the new procedures and policies outlined in its April 7, 1999 memorandum. Such training should be completed by October 1, 1999.
- Congress should amend the Immigration and Nationality Act to provide for a disability waiver for the oath of allegiance requirement. INS should ensure timely processing of naturalization applications for applicants with disabilities.
- The Disability Rights Section of the Civil Rights Division of the Department of Justice, NCD, and INS should work together to monitor implementation of INS recent efforts to address longstanding problems with its naturalization process regarding access for applicants with disabilities, and to address ongoing problems as they occur. To further this effort, DOJ should institute an 800 number staffed with trained multi-lingual employees where anyone experiencing problems with accommodations in the naturalization process could raise those issues in a central location that would track the nature of the problems and take steps to address both individual and systemic issues identified. This 800 number should be publicized in numerous languages in every INS office and on INS forms and materials.

III. BEING RECOGNIZED: BARRIERS TO ACCURATE DEMOGRAPHIC DATA

Over the past thirty years, the United States has experienced significant changes in the racial and ethnic makeup of its population. Many of these changes were felt first and most powerfully by California, a state that has proven to be a harbinger of what other large states will encounter. By the year 2000, California will become the first continental state in America with a majority population made up of racial and ethnic minorities. This shift has substantial political, economic, and social ramifications. Within the federally-funded disability service provider network in California, there will be a need to revisit assumptions about the prevalence of disability among Hispanic and Asian/Pacific Islander populations and subpopulations, and the relative emphasis placed on service delivery for individuals with disabilities in those communities. This need will expand beyond California as other States undergo similar population shifts. The importance of accurate demographic data is underscored by the reliance on such data,

particularly census data, by state and county agencies in planning for eligible recipients under Medicare, Medicaid, and SSI programs; by rehabilitation agencies in distributing funds and developing programs under the Rehabilitation Act, by HUD in distributing funds for housing for people with disabilities, etc. In short, census information is used by all levels of government to guide the annual distribution of \$180 billion dollars in critical services to people with disabilities and their families. According to the national estimates, the rate of disability within Hispanic and Asian/Pacific Islander populations is significantly lower than in any other racial or ethnic group in the nation, including Whites. Some researchers, however, believe that these estimates do not accurately reflect the reality of the prevalence of disability within Hispanic and Asian/Pacific Islander populations and subpopulations due to a variety of socioeconomic factors and acculturation variables, including immigration status and the perception of disability within a particular culture. All of these variables have an impact on the self-reported rate of disability within Hispanic and Asian/Pacific Islander populations and subpopulations. Due to the wide-spread publication of the national figures, the tendency within the service delivery system nationally has been to focus on the needs of Whites, African-Americans, and Native-Americans with disabilities, while little attention has been directed toward serving the needs of Hispanics and Asians/Pacific Islanders with disabilities. This oversight appears to have substantially hampered the effectiveness of service delivery for Hispanics and Asians/Pacific Islanders with disabilities.

Recommendations for Improving the Accuracy of Demographic

Data:

The Census Bureau and the Bureau of Labor Statistics, working with the National Institute on Disability and Rehabilitation Research and the National Center for Health Statistics, should develop alternative methods for tracking the prevalence of disability within racial/ethnic minority communities nationally and at the state and local levels.

The Census Bureau should make affirmative efforts to hire minority and bilingual individuals with disabilities as part of the workforce that will assist with Census 2000.

NIDRR and other federal research entities should conduct studies that explore the intra-ethnic experience and prevalence of disability.

NCD believes that every person with a disability should have the opportunity to realize the promise of freedom and equality made in ADA, regardless of their race or ethnicity. The importance of racial and ethnic diversity needs to be recognized as a key component of the disability civil rights movement in the new millennium. These recommendations are submitted in the belief that they will promote that recognition, and in so doing begin the process of tearing down the shameful wall of exclusion that continues to prevent minority racial and ethnic individuals with disabilities and their families from participating fully in all aspects of American society.