# Outreach and People with Disabilities from Diverse Cultures: A Review of the Literature



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### Acknowledgments

The National Council on Disability expresses its appreciation to Theda Zawaiza, Ph.D. and Claudia Gordon, Esq., for drafting this paper, with research assistance from Phuonglinh Dang.

#### **Executive Summary**

Overview. People with disabilities who are also from diverse cultures are significantly hampered in realizing outcomes of full participation in all aspects of society due to a host of barriers to the benefits of civil and human rights. A small but growing body of research on this issue indicates that barriers include the lack of culturally appropriate outreach, language and communication barriers, attitudinal barriers, and the shortage of individuals from diverse cultures in the disability services professions (National Council on Disability, 2000b). While strategies for reaching out to people with disabilities exist (Hasnain, Sotnik, and Ghiloni, 2003; Edwards and Livingston, 1990), research-based evidence is sparse regarding interventions aimed at eliminating barriers. Even more scant is research on outreach as a compelling strategy and its degree of efficacy in engaging people from diverse cultures and ultimately, improving outcomes.

The objectives of the review were to articulate the principal themes of outreach, describe outreach models, illuminate the many challenges to effective outreach, and to document the nature and prevalence of national disability/diversity outreach by the federal government. The research literature was systematically searched and a preliminary scan of nine federal agencies' disability/diversity outreach activities was conducted using a resource mapping inquiry.

Background. For over a decade, the National Council on Disability (NCD) has worked to make national disability policies, laws, programs, and services more responsive to people with disabilities from the broad array of cultures that enrich our country. Despite concerns regarding the prevalence of disabilities and health disparities among people with disabilities from diverse cultures, there remains a significant gap in the empirical knowledge base about promising practices in delivering effective services to these diverse groups. As a part of its Cultural Diversity Initiative (CDI), NCD sought to answer fundamental questions about outreach: What is it? What are current outreach definitions, themes, models, and challenges? What is the state of disability/diversity outreach at the national level by the federal government? This review of literature was one of three projects of the NCD CDI, along with an outreach forum held in July 2003, designed to

inform the development of the third component - an outreach toolkit for use by federal agencies to enhance their outreach efforts.

**Findings.** The review showed a paucity of empirical studies of outreach as an intervention and few studies evaluating the effectiveness of outreach activities. While there is an extensive body of literature documenting and reporting on racial and ethnic health disparities, there were relatively few studies on outreach as an intervention. The review identified operational definitions of outreach and principal outreach themes found in the literature. Types of outreach were described, and examples provided. The challenges of outreach are discussed within the framework of barriers to access and appropriate services for full community integration and independent participation by people with disabilities from diverse cultures. Major findings include:

- 1. Outreach, as an intervention, is a frequently recommended strategy designed to improve services to underserved groups, but about which little is known empirically. Proponents claim various outreach models show promise, but the lack of consistency across studies makes it difficult to generalize about the effectiveness of any given approach. Rarely is the term "outreach" operationally defined or empirically studied, making it an elusive, yet ubiquitous construct.
- 2. Although outreach efforts are highly eclectic, some major themes were found to recur in the literature, including: value placed on target population, assessment of needs, advocacy, transformation of social behaviors/attitudes, dissemination of information and the strengthening of communities.
- 3. The models of outreach found in the literature were categorized as: the *community-based model*, wherein focus is placed on building the capacity of current community organizations; the *grassroots model*, often using indigenous, native-speakers in venues not typically used by service organizations; the *train-the-trainer model*, in which trusted community members are trained so that the community maintains the needed knowledge after outreach workers have departed; the *peer-to-peer model*, which emphasizes the mutual understanding of contemporaries; the *partnership model* which builds on the partner's expertise

- and community trust, and the *support socialization model* which couples outreach with popular events to attract the community.
- 4. Challenges to comprehensive outreach activities include the lack of culturally appropriate outreach; failure to engage local leaders; the lack of needs assessments; language and communication barriers; attitudinal barriers, and the shortage of individuals from diverse cultures in disability services professions.
- 5. Self-reports by the nine participating agencies did not fully capture the depth and breadth of current national disability/diversity outreach efforts in those agencies. Several agencies used outreach as an intervention strategy extensively while others only utilized it periodically, if at all. Methodological limitations constrained the ability to make definitive statements about the nature and prevalence of outreach programs to people with disabilities from diverse cultures.
- 6. All of the federal agency programs and activities addressed disability and/or diversity separately. With a single exception, the federal agency responses to NCD's inquiry represented only one of several offices, divisions or branches within each agency (e.g., the U.S. Department of Health and Human Services (DHHS) Office of Civil Rights (OCR) responded only for OCR; however, absent were responses from other DHHS offices with established work and track records in the area of cultural sensitivity and outreach programs such as in the mental health area.) Not all definitions of outreach were consistent with NCD's operational definition provided as a part of the information given to each agency. Finally, agency information was not always responsive to the areas of inquiry. The combined effect of these observations posed a challenge for a systematic analysis of the information collected.
- 7. Research syntheses are needed to systematically identify and evaluate outreach programs for people with disabilities from diverse cultures. The scarcity of such research precludes empirically based decisions about the efficacy and effectiveness of outreach efforts. Research syntheses are useful in that they increase the accessibility of the research and facilitate its interpretation and use in the field (Gersten, 2000).

The purpose of this review was to explore what research literature tells us about outreach and its feasibility as a viable method to reach under-served populations. It is intended to be a resource for federal agencies and parties interested in national outreach to people with disabilities from diverse cultures. This data provide a preliminary, albeit spotty, scan of the state of disability/diversity outreach at the national level by nine federal agencies. This data can be used to encourage future dialogue and federal interagency collaboration wherein agencies may share their promising practices with each other and by so doing, enhance their programs and ultimately increase involvement of people with disabilities from diverse cultures in their programs. One of the goals of the inter-agency dialogue on outreach to this population will include developing a reliable and valid set of baseline data for each agency on programs, policies, products, and procedures that agencies can share with each other and the public, possibly in the form of a regularly-updated CD-Rom toolkit containing resources helpful in developing comprehensive outreach programs. The review pointed out several gaps in the knowledge about outreach, its effectiveness and its limitations. The following recommendations are offered to address those gaps in knowledge.

#### Recommendations.

- 1. **Outreach Feasibility Studies:** The feasibility of federal agencies using outreach as a reliable and valid strategy to reach people with disabilities should be systematically analyzed. The prevalence of disability in diverse cultures is significant and, in most cases, disproportionately high. Equal representation of people with disabilities from diverse cultures in federal programs can be enhanced by reaching out to these populations in culturally sensitive ways, evaluating the effectiveness of the efforts, disseminating the results and encouraging replication of promising practices.
- 2. Assessment of Federal Outreach Competencies: Federal agencies should be encouraged to undertake a comprehensive self-assessment of their outreach competencies, and a thorough inventory of outreach practices to gauge future training and development needs and to share promising practices, policies, products and procedures with other federal agencies.

- 3. Support Interagency Outreach Collaboration: Interagency agreement and funding on outreach knowledge information dissemination and exchange should be encouraged. A technical expert panel comprised of interagency representatives and grassroots leaders should be formed to develop and pilot cultural competence standards and outreach guidelines for federal agencies and their partners. Agencies should ensure the meaningful participation of people with disabilities from diverse cultures in the development of programs and strategies.
- 4. **Efficacy Research:** Research is needed to weigh the comparative effectiveness of specific strategies, including comprehensive outreach, and improving services, access and protections for diverse populations with disabilities.

The review provides a summary of findings from the literature, a discussion of challenges to outreach and recommendations to address the information and research gaps identified.

# Outreach and People with Disabilities from Diverse Cultures A Review of the Literature

#### I. Introduction

People with disabilities who are also from diverse cultures are significantly hampered in realizing outcomes of full participation in all aspects of society due to a host of barriers to the full benefits of civil and human rights. A small but growing body of research on this issue indicates that barriers include the lack of culturally appropriate outreach, language and communication barriers, attitudinal barriers, and the shortage of individuals from diverse cultures in the disability services professions (National Council on Disability, 2000b). While strategies for reaching out to people with disabilities exist (Hasnain, Sotnik and Ghiloni, 2003; Edwards and Livingston, 1990), research-based evidence is sparse regarding strategies aimed at eliminating barriers. Even more scant is evaluative research on strategies such as outreach and its degree of efficacy in improving outcomes for people with disabilities from diverse cultures.

A common notion in federal disability laws and policies developed over the past twenty-five years (e.g., Individuals with Disabilities Education Act and the Vocational Rehabilitation Act of 1973, as amended) is 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 society. Community integration and self-determination are policy concepts endorsed further in President Bush's New Freedom Initiative, Executive Order 13217 and legislative proposals. However, the promise of these policies has not been realized by people with disabilities from underserved populations.

The purpose of this review was to explore what research literature tells us about outreach and its feasibility as a viable method to reach under-served populations. The review is an

informational piece designed to raise awareness and understanding regarding a strategy that is highly recommended, about which little is known empirically, designed to improve services to under-served groups. It offers a classification schema to explore the concept and practice of outreach. The target audience is federal agencies and parties interested in federal outreach to people with disabilities from diverse cultures. This review can serve as a preliminary research base for the development of technical assistance and training on outreach strategies.

Rationale for a Focus on Outreach. Recurring themes in National Council on Disability (NCD) literature include the observation that federal programs are failing to adequately serve people with disabilities and that people with disabilities from diverse cultures are sorely under-served. For over a decade, NCD, in its advice to Congress, has recommended actions such as outreach and interagency collaboration. Now it has reviewed the outreach literature to provide federal agencies with an informational base from which they can develop and/or enhance their provision of services and their ability to reach underserved people.

The choice of outreach as the focus of the review was not random; rather, it was arrived at through methodical deliberation. Outreach is a strategy often recommended, anecdotally perceived as promising (according to anecdotes of grassroots, disability constituencies), and legislatively required for at least one cabinet-level department (Department of Education). The disparities in health, education, employment and independent living of people with disabilities from diverse cultures are significant, well documented, and persistent despite years of general acknowledgement. The impetus for selecting outreach as a compelling strategy to explore was spawned by the facts of those disparities and the confluence of several other factors: (1) repeated recommendations for outreach in the testimony of grassroots, disability constituencies (e.g., poor, rural, urban); (2) recommendations from the U.S. Commission on Civil Rights in its *Ten-Year Check-Up: Have Federal Agencies Responded to Civil Rights Recommendations?*; (3) the mandate for community living (and by extension, live-able communities) found in the Supreme Court's *Olmstead* decision and the subsequent Executive Order 13217 directing

its swift implementation; and (4) the trend in the federal government toward increased program accountability.

Civil Rights. Last year, the U.S. Commission on Civil Rights (USCCR) reprised its recommendations in which it expressed concern that people in particular areas and communities were not being reached by federal programs. "The Commission asked federal agencies to ensure that their programs reached participants and beneficiaries in rural and inner-city areas as well as underserved populations, such as African Americans, Asian Pacific Americans, Hispanic Americans, Native Americans, migrant and seasonal farm workers and their children, and women. It asked federal agencies to find alternate or innovative methods of reaching such areas and groups" (USCCR, 2002, p.31). The Commission requested that "...federal agencies mount inter-agency coordinated outreach" (Ibid, p.33).

Olmstead. In the Olmstead case, the Supreme Court found that, in certain instances, the Americans with Disabilities Act (ADA) requires states to provide services in the community for persons with disabilities and finds unwarranted institutionalization of a person with a disability discriminatory under the ADA. "The Executive Order [13217] required federal agencies to promote community living for persons with disabilities by providing coordinated technical assistance to states; identifying specific barriers in federal law, regulation, policy, and practice that impede community participation; and enforcing the rights of persons with disabilities" (NCD, 2003a, p.4). The same NCD report, entitled Olmstead: Reclaiming Institutionalized Lives, points out that agencies' reports on their programs show obstacles to community-living still exist. Outreach was offered as one of many viable agency options.

**Program Accountability**. As more people with disabilities from diverse cultures live in communities across the country instead of in institutions, federal agency programs will be pressed to be responsive to a more diverse constituency. Over a decade ago, Congress enacted the Government Performance and Results Act of 1993 (GPRA) to, among other things, "improve federal program effectiveness and public accountability by promoting a

new focus on results, service quality, and customer satisfaction" (GPRA, 1993, p. 1). GPRA required programs to have performance standards and indicators and other means of accountability. Taken together, these factors gave ample and compelling reason to undertake this effort.

*Background*. The Cultural Diversity Initiative (CDI) is a NCD response to begin addressing problems highlighted in the findings and recommendations of earlier NCD reports on the inadequacy of current systems and methods in reaching people with disabilities from diverse cultures. CDI is designed to provide opportunities for federal agencies and other stakeholders to jointly identify promising outreach efforts and strategies for including un-served and under-served populations in the development of federal policies, programs, and activities.<sup>2</sup>

This project includes a review of the literature on outreach and people with disabilities from diverse cultures, identification of salient variables in current outreach efforts and a summary of challenges to outreach. In this paper, *people with disabilities from diverse cultures* refers to people with disabilities of African-American, Hispanic/Latino, Asian/Pacific Islander, American Indian, or Alaska Native heritage. People with disabilities from these under-served populations often reside in inner cities or rural, tribal and/or remote communities. They may also be economically poor, linguistically diverse migrant or seasonal farm workers, and recent immigrants. "People in these communities historically have been overlooked in research, poorly served in policy and practice and consequently, underachieve on all traditional measures of success and well-being" (Zawaiza et al, 2002, p. 4).

*Method and Scope*. The extant research and literature was reviewed and analyzed for information on outreach. NCD conducted several searches of published literature in ERIC databases, Emory University on-line library, Questia on-line library and other on-line databases scanning studies from 1988-2003 that met the inclusion criteria (i.e., focused on and/or included the key words outreach, minority, disability and/or diversity). NCD's

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search topics included: outreach to people with disabilities from diverse cultures, outreach to people with disabilities, outreach to people from diverse cultures and outreach to various under-served populations (e.g., people who are homeless).

Other advanced searches included specific disability categories (e.g., diabetes) and specific races and ethnicities. NCD conducted searches of the web sites of the nine agencies included in the CDI project, and sites for people with disabilities from diverse cultures to identify relevant unpublished studies, progress reports, briefing papers, and position statements. NCD also searched publications of several national databases. A pool of relevant literature was scaled down to include only those publications in which an outreach intervention was implemented or recommended for an under-served group. Studies conducted in other countries or written in a language other than English were excluded

The paper identifies and discusses outreach definitions, themes, models, and challenges. Models are included as examples and should not be considered endorsement of any particular approach. Further, systematic evaluation of these examples to determine effectiveness is beyond the scope of this review; however, NCD recognizes the importance of evaluative research and the need for sets of criteria against which outreach approaches can be viewed. NCD found few pertinent publications on outreach programs that targeted people with disabilities from diverse cultures and even fewer reports that evaluated the effectiveness of any particular approach to outreach. In essence, the available studies on outreach did not use as their primary subjects people with disabilities from diverse cultural backgrounds. Because such outreach information is sparse, this review examines outreach studies from a broader perspective.

#### **II. Prior NCD Diversity Reports and Findings**

"Effective outreach programs, which are important vehicles for communicating public policy and involving underserved groups in the public policy process, can not be initiated, implemented and/or sustained without respect, understanding, and sensitivity

toward racial, ethnic and geographic diversity" (National Council on Disability, 1997, p. 2).

NCD's leadership in exploring effective ways of addressing issues and concerns of people with disabilities from diverse cultures has been accomplished through national and regional opportunities for information collection from grassroots community-based groups and individuals. For example, in 1992 NCD convened a national conference attended mostly by persons from diverse racial and ethnic backgrounds who considered a wide range of disability issues. Policy recommendations were developed for improving the lives of people with disabilities from diverse cultures and were reported to the public. In August 1998, NCD held a series of follow-up public hearings in San Francisco, Atlanta and New Orleans to develop recommendations for improving the ability of federal policies and programs to serve diverse communities effectively.

Grassroots witnesses in the series of public hearings reported that:

[T]he 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 Vocational Rehabilitation Act, IDEA, the Fair Housing Act) and how best to exercise those rights when a violation occurs (National Council on Disability, 1999, p. 3).

In another report, *Lift Every Voice – Modernizing Disability Policies and Programs to Serve a Diverse Nation*, NCD highlighted a recommendation with particular potential to promote joint, culturally responsive federal policies, products, practices and programs. The recommendation called for representatives from the U.S. 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 to work collaboratively. These federal agencies were challenged to develop and implement a large-scale outreach and training

program targeted to people with disabilities from diverse cultural backgrounds and their families that would provide information (including that referenced above as well as information on other opportunities) directly to the target audiences through a series of forums, workshops, and seminars across the country. At the writing of this paper, there was no evidence of this recommendation having been implemented.

NCD has generated the following reports that include specific recommendations regarding implementation and enforcement of the civil and human rights of people with disabilities from diverse cultures: ADA Watch - Year One: A Report to the President and the Congress on Progress in Implementing the Americans with Disabilities Act (April 5, 1993); Meeting the Unique Needs of Minorities with Disabilities: A Report to the President and the Congress (April 26, 1993); Achieving Independence: The Challenge for the 21st Century – A Decade of Progress in Disability Policy – Setting an Agenda for the Future (July 26, 1996); Outreach to Minorities with Disabilities and People with Disabilities from Rural Communities (August 4, 1997); Grassroots Experience with Government Programs and Disability Policy (October 1, 1998); Lift Every Voice – Modernizing Disability Policies and Programs to Serve a Diverse Nation (July 26, 1999); Back to School on Civil Rights: Advancing the Federal Commitment to Leave No Child Behind (January 25, 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 (August 23, 2000); Closing the Gap: A Ten Point Strategy for the Next Decade of Disability Civil Rights Enforcement (August 10, 2000); Implementation Plan for Executive Order 13166 – Improving Access to Services for Persons with Limited English Proficiency (December 12, 2000); and, People with Disabilities on Tribal Lands: Education, Health Care, Vocational Rehabilitation, and Independent Living (August, 2003). According to an NCD synthesis of its seven reports addressing disability and diversity that were issued between April 1993 and January 2000, "people with disabilities from diverse cultures have not been full participants in our country's effort to eliminate disparities, remove barriers, and to protect civil and human rights through enactment of federal laws and initiatives" (National Council on Disability, 2000b, p. 2)

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Subsequently, in May 2000, NCD convened Think Tank 2000: Advancing the Civil and Human Rights of People with Disabilities from Diverse Cultures. In initiating Think Tank 2000, NCD indicated, "years of technical assistance and model programs have not changed the status of the most disenfranchised. Across the board, people with disabilities from diverse cultures receive unequal protection and unequal benefit under the same federal laws being implemented in the larger disability community." Think Tank 2000 was a meeting of representatives from diverse cultural, professional and disability backgrounds charged with developing action steps for fully implementing disability rights laws at the community level for people with disabilities from diverse cultures and other under-served groups. Effective outreach to people with disabilities from diverse cultures was among the key issues addressed by the group.

Within a month of this meeting, NCD convened a second group of participants in the Civil Rights Retreat, to build upon the Think Tank 2000 plan of action and the *Unequal Protection Under Law* series of reports.<sup>3</sup> These participants, also from diverse cultural, professional and disability backgrounds, were charged with mapping out the elements of a ten-point strategy for more effective civil rights enforcement. In summarizing the ten point strategy, the group acknowledged that the greatest civil and human rights laws of this country have spurred a new era of progress for the nation, but they also recognized that much greater progress depends upon overcoming systemic and other artificial barriers.

**Select NCD Diversity Findings**. The following is a sampling of NCD diversity findings provided to highlight the wide spectrum of challenges that exist in disability services policy and practice relative to race and ethnicity. These are just a few of the NCD documents addressing areas of interest to this report. In *The Well Being Of Our Nation*: *An Inter-Generational Vision of Effective Mental Health Services and Supports* (NCD, 2002), language and cultural barriers were noted as follows: "Most state mental health systems still lack the ability to serve people of color and language minorities in their own

traditions and their own language. The Surgeon General recently reported 'striking disparities' in mental health care for racial and ethnic minorities, and that these disparities 'impose a greater disability burden on minorities,' and that people from diverse cultures collectively experience a greater disability burden from mental illness than do whites. This burden is directly attributable to the fact that people from diverse cultures systemically receive less care and poorer quality of care, rather than from their illnesses being inherently more severe or prevalent in the community."(p. 16)

Investing in Independence: Transition Recommendations for President George W. Bush (NCD, 2001) addressed cultural diversity by saying:

The United States consists of a diverse population and we must make a conscious effort to meet the needs of all our people. The Bush Administration must establish an inclusive agenda for America that makes ongoing and emerging issues that impact people with disabilities from diverse cultures an integral part of all work regarding federal agency program administration and implementation, public policy, and legislative/regulatory work.

The *Investing in Independence* report made the following recommendations to effectively address cultural diversity among people with disabilities:

[T]he best way to empower minorities with disabilities and their families is to provide them with easy-to-understand culturally appropriate information about what their rights are under various federal laws...

A federal interagency team should develop and implement a large-scale outreach and training program targeted to people with disabilities from diverse cultural backgrounds and their families. (p. 7)

Reorienting Disability Research (NCD, 1998) called for a refining of current data:

Ensure that the broadest range of people with disabilities (including children, those with hidden disabilities, and minorities with disabilities) are sampled. To understand the unique aspects of all people with disabilities, it is critical that all groups be adequately sampled. Frequently, too few people with a particular

disability or of a particular age or ethnicity are sampled to allow for statistically sound analysis.

The report also recommended, with regard to the development of new data collection instruments, that policy makers "[E]nsure that any new disability questions reflect variations in ethnic cultural understanding of disability." (p. 6)

In *Improving the Implementation of the Individuals with Disabilities Education Act*: *Making Schools Work for All of America's Children* (NCD, 1995), testing in the student's native language and mode of communication was recognized as a critical factor in a culturally sensitive evaluation.

Other Findings on Services to People with Disabilities from Diverse Cultures. NCD's contention that people with disabilities from diverse cultures are under-served is supported by other research and reports conducted over the decade of the 1990s. For example, researchers Feist-Price (1995) and Kundu (1993) found that barriers such as lack of information about resources, few culturally competent service providers, limited inclusion in policy making, rehabilitation, or other service provider training, and discrimination related to language, low socio-economic status, or national origin, are not encountered to the same extent by others in the general population or other people with disabilities. As such, the quality of service and outcomes is less favorable for people with disabilities from diverse cultures across our nation.

The next section of this paper presents a summary of outreach definitions, themes, and models from a broad perspective. This information can be used to inform the development and/or expansion of outreach policies and strategies.

#### III. Definitions of Outreach

Outreach is conducted on many social levels by numerous organizations, communities, governments, and educational institutions. These endeavors range from disability rights training, health education, international aid, and projects for the homeless, to college

recruitment of people from diverse cultures. Although the term "outreach" is used to describe all of these programs, a definition of the word is seldom found in the literature. The scarcity of efforts to define outreach in the literature makes it an elusive term. As a result, entities that employ outreach often interpret and define the concept as it fits into their specific programs. A typical dictionary definition of outreach is "a systematic attempt to provide services beyond conventional limits as to particular segments of a community" (American Heritage Dictionary, 1984). Other definitions emphasize particular parts of this generic one and elaborate on various themes; for example, definitions in the next sections - the U.S. Department of Agriculture definition and the Advocacy definition of outreach - both stress the under-served nature of the targeted group. The last definitions described - categorical definitions - emphasize the activity to be undertaken; for example, education outreach to teach a particular skill.

**U.S. Department of Agriculture**. The U.S. Department of Agriculture (USDA) defines "outreach" as "a way of conducting business to ensure that underserved individuals and groups throughout the United States and its territories are made aware of, understand and have a working knowledge of . . . programs and services. Outreach will ensure that these programs and services are equitable and made accessible to all" (USDA, 2003, website). Notably, the USDA points out that outreach involves a number of components, including an understanding of the under-served customers; using communication techniques that are most appropriate for the under-served customers; earning the trust and acceptance of the under-served customers; developing partnerships and working relationships with under-served customers and their community organizations.

**Advocacy.** Outreach has also been defined in terms of reaching out and assisting through personal contacts with people excluded from, unaware of, or unreceptive to certain information or services (Bannon, 1973). The agency can be a social service group, local, state or federal government, educational institution, or community group. Advocacy, an essential component of outreach, differentiates traditional forms of community services from programs that are conducted to develop those services. Through advocacy, outreach

programs can extend the endeavors of community services to eradicate the problem, or at least ameliorate the situation.

Categorical. Alternatively, Penn State University at Erie (2003) defined outreach by dividing the concept into three categories: research, education, and service. Research outreach refers to the dissemination of a discovery's results or the gathering of information for a discovery. This can include technology transfer, policy reviews, and creative works in the arts. Educational outreach is characterized by teaching or demonstrating an expertise in a particular subject to increase the "potential of individuals or groups" (Penn State University at Erie, 2003, p.1) Programs such as diabetes nutrition classes for African Americans, mobile dental units in low-income communities, and smoking cessation classes for incarcerated individuals are all examples of educational outreach. Service outreach focuses on performing a function that benefits the targeted population. These services may include HIV testing, needle exchange for IV drug users, and prenatal care for teenage mothers.

The definitions of outreach described above (USDA, Advocacy and Categorical) illustrate the broad range of specifications that organizations use to describe their efforts to connect with under-served people. According to Edwards and Livingston a comprehensive outreach approach has eleven features:

- 1. Target audience(s)
- 2. Needs assessments of the target audience(s)
- 3. Short and long term goals and objectives for responding to the needs
- 4. Outreach activities that address those needs
- 5. A timetable
- 6. A coordinator of outreach activities
- 7. Accurate, updated mailing lists with a specific individual named
- 8. An evaluation plan to monitor success
- 9. Outreach messages and materials that are current, easily understood, positive, structured in such a way as to lead the receiver to "the next level" of information, need or services, and highlight something unique and realistic

- 10. Repetition of distinct messages in varied forms to maximize outreach to the targeted audience
- 11. Ongoing research, both formal and informal, for effective outreach (Edwards and Livingston, 1990)

Outreach efforts need not contain all eleven points to be meaningful. Differences in definitions and applications of outreach have enabled programs and projects to fit within broad parameters. As such, producing a single, all-inclusive working definition of outreach may have limited utility and may not be feasible since the concept of the word outreach differs among organizations. However, the literature includes recurring themes that characterize outreach. These themes may prove to be practical ways to describe and discuss outreach efforts as presented in the section that follows.

#### IV. Principal Themes of Outreach

Similar to defining the term "outreach," pinpointing principal themes may be challenging or problematic, given the variability of definitions. Although the literature shows that outreach efforts are highly eclectic, major themes include: value placed on target population, assessment of needs, advocacy, transformation of social behaviors/attitudes, dissemination of information, and the strengthening of communities.

Value Placed on Target Population. The particular population for whom the outreach program is intended must be aware that efforts are made to welcome and include their perspectives and respect their customs. Outreach projects usually start with the identification of a population that would benefit from a certain knowledge or skill (Edwards and Livingston, 1990). From the outset, the organization conducting the outreach typically has a special interest in the population and believes that the population is a valued constituency.

**Assessment of Needs.** After the population of interest is identified, an assessment of needs is conducted to evaluate the type of outreach that would be most beneficial to the community (Wood, 2003). The community may be dealing with numerous concerns. The

outreach project must determine which issue has the greatest impact on quality of life and which is most likely to be addressed effectively through outreach activities.

**Advocacy.** Whether it is teaching caregivers how to cope with family members affected by Alzheimer's or educating seniors on proper vision care, outreach projects are designed to disseminate certain information or provide particular services. Bannon (1973) states that advocacy serves as the distinguishing factor between "benign forms of community help" and outreach. Thus, outreach programs are created on the basis of promoting a message that would result in transformation of lives (Edwards and Livingston, 1990).

**Transformation of Social Behaviors/Attitudes.** The goal of many outreach projects is to transform social behaviors and/or attitudes of the target population. Since some people with disabilities from diverse cultures may have negative perceptions of governmental agencies, access to programs, services or information may be limited (Kramer, 1992; Burroughs, 1998). Therefore, appropriate information regarding the purpose of the outreach can break down negative views that can act as barriers to change.

**Dissemination of Information.** Dissemination of the most current and accurate information can be accomplished in several ways. Local organizational newsletters, community calendars of events, print media, radio and TV shows, and public service announcements are some of the commonly used venues that organizations have found to be successful for spreading information widely about an outreach project (Edwards and Livingston, 1990). For the distribution of information to be effective, attention to language and the cultural relevance of the materials is crucial to the perceived value of the information. Even when the information is current and accurate, it may be considered useless if it does not adhere to the cultural and social context of the audience.

**Strengthening Communities**. Strengthening communities is another principal theme of outreach. In order to achieve stated goals, outreach projects emphasizing this theme must develop and/or strengthen the communities that can be responsible for maintaining desired behavioral transformations. Communities can include organizations, agencies,

coalitions, families, social groups/clubs, and extended support networks such as the church. These six themes are evident in the outreach models described in the next section.

#### V. Outreach Models

Based on analyses of available published papers, NCD determined that the information on outreach could be grouped into six categories. The models in each category have common traits; however, they are included as examples and should not be considered an endorsement of any particular approach. Further, systematic evaluation of these examples to determine effectiveness is beyond the scope of this review. Among the models of outreach described in this paper are: the *community-based model*, the *grassroots model*, the train-the-trainer model, the peer-to-peer model, the partnership model, and the support socialization model. More specifically, the community-based model is one wherein focus is placed on building the capacity of current community organizations. The grassroots model often uses indigenous, native-speakers in venues not typically used by service organizations. The train-the-trainer model trains trusted community members who then train other members of the community so that the community maintains the necessary knowledge after outreach workers have departed. The peer-to-peer model emphasizes the mutual understanding of contemporaries. The partnership model builds on the community partner's expertise and trustworthiness, while the support socialization model couples outreach with popular events to attract the community. What distinguishes the models from each other is the degree to which they are designed to transform systems, communities, and lives. Each is described as follows:

Community-based Model. As the most common method of outreach, community-based projects focus on creating relationships with the existing networks of organizations in the community prior to conducting outreach. Members of the community are encouraged to be involved with all aspects of the project including its design, implementation, and maintenance. The involvement of community leaders and organizations provides a level of credibility to the outreach project that can enable it to be trusted by the population (Wood, 2003). Community members serve as the most valuable resource to outreach workers since they are aware of current issues and problems people in the community are

facing. The community-based projects are usually site-specific so that people's cultural backgrounds can be well accessed and built into the project.

When outreach projects seek full community participation in strategies for increasing knowledge or changing behaviors, capacity building is enhanced and the community can continue the outreach after the project is over. A community adopts the outreach model if value is seen in the results. Incorporating existing community groups into the outreach project also builds a network of organizations focused on a particular topic or concern. (Fife, 2001). Examples of community-based projects are church-based outreach programs to African Americans, Project DIRECT, and the Tribal Connections Project. A description of these projects is included under examples of outreach programs, models, and strategies in Appendix A.

Grassroots Model. The grassroots model overlaps the community-based model in that it also taps into the existing network of organizations to promote outreach efforts. However, the grassroots model has a strong emphasis on building the innermost circles of the under-served population's support system. This is in addition to the community level support found in the community-based model. Informal gatherings at places such as laundromats, beauty parlors, neighborhood meeting venues, and local small businesses are used to spread information about the outreach project. Spreading information through word of mouth is also common within this model because many of the outreach workers are members of the community.

An intensive effort is required to mobilize the underserved groups to spread information in the community. As one example, the El Portal: Latino Alzheimer's Project was able to increase the number of people served through extensive grassroots efforts in Latino communities. The community members were reached through brochures, hotlines, and extensive residential mailings (Aranda, 2003). Although significant resources must be dedicated to the project for the grassroots model to produce desired results, it can be a meaningful way to get the whole community involved in promoting outreach efforts.

**Train-the-Trainer Model.** The train-the-trainer model refers to a strategy that outreach workers use to ensure that communities will be able to continue working toward the goals of an outreach project once the project is over. In this model, the outreach workers teach a specific skill or information to trusted members of the community. In turn, those trusted members then teach the desired skills to other people. Thus, even after the outreach workers are gone, the community can maintain the knowledge needed to address certain concerns or needs.

The Families Who Care project adapted the train-the-trainer model to teach people living in rural areas, and African American caregivers how to take care of elderly people who are living with conditions associated with aging. Religious and community leaders were trained during a two-day course on Alzheimer's and dementia, and on the support needed for caregivers. The trained leaders returned to their own communities and held training sessions for caregivers (Coogle, 2002). This model can address cultural adaptation since local leaders, who understand the community, are used as the trainers.

**Peer-to-Peer Model.** The peer-to-peer model of outreach uses contemporaries of the under-served population to conduct the outreach. The peer-to-peer model is based on people's tendency to learn from their familiar colleagues rather than from outside groups. Peers tend to share the same age-related concerns, cultural barriers, and attitudes that foster a mutual understanding and respect for each other.

Project INSIGHT adopted the peer-to-peer model in outreach efforts to educate older adults on vision loss and the benefits of vision rehabilitation. Senior volunteers were trained to run educational programs that promoted healthy vision care, support services, and information on rehabilitation. The volunteers were able to educate and motivate their contemporaries because they were experiencing similar vision issues and were accepted for their ability to relate (Buonocore, 2002). Using the peer population as outreach workers minimizes the need to devote resources to addressing cultural, linguistic, and attitudinal barriers since the outreach workers are already knowledgeable about the people who need to be contacted about receiving the services.

**Partnership Model.** The partnership model provides an opportunity for proponents of outreach programs to work with trusted local, regional, public, and private organizations, and agencies at all levels of government to address the needs of the population of interest. For the partnership model, outreach efforts are centered on developing and expanding the existing services that the collaborating entities offer (Fleisher, 1998). By partnering with various organizations and agencies, the outreach program is able to reach underserved populations using the partner's expertise and community trust.

For example, through the partnership model the nationally coordinated Cancer Information Service Outreach program teamed with organizations and government agencies to distribute information on cancer, especially to people from diverse cultures and other underserved populations. The CIS staff provided technical assistance tailored to the cultural and regional needs of the partners. Coalition building, media placement, and access to the most up-to-date cancer information were some of the technical assistance services offered to partners (Fleisher, 1998). Through these partnerships, the CIS Outreach program was successful in reaching under-served people in order to provide culturally and regionally appropriate cancer information.

**Support Socialization**. Support socialization refers to identifying crucial social activities that are popular among the target population and then using these activities as an intervention point for the outreach program. The activities are endorsed and supported so that the outreach agenda can be coupled with the activities. The activities serve as a "hook" that brings people into the outreach project (Hartmann, 2003). The social force of the activities appeals to the population's interests and passions and thus creates the stage for social intervention.

An example of support socialization is the creation of after-school and summer sports programs to keep young adults away from drugs and crime. Program developers use sports as a social intervention method to teach young people the value of teamwork, perseverance, and responsibility. Although the level of impact remains unclear regarding

whether sports alone can alter the mindset of at-risk youths, the data suggested that sports coupled with other non-sports-based programs could provide the comprehensive intervention necessary to improve the future of this population (Hartmann, 2003).

Arguably, other appealing social activities can be coupled with outreach activities to increase the number of people reached and enhance receptivity of the message being conveyed. According to the World Wrestling Entertainment, Vince McMahon has teamed up with Russell Simmons of the Hip Hop Summit Action Network to promote voter registration among young people. Using a support socialization model, they plan to sponsor entertainment events coupled with on-site voter registration using the catchy phrase, "Two million more by 2004!" (World Wrestling Entertainment, 2003).

**Examples of Legislatively Mandated Federal Outreach.** Outreach by a federal agency to people with disabilities from diverse cultures was legislatively mandated in the Individuals with Disabilities Education Act (IDEA) and the Vocational Rehabilitation Act of 1973, as amended, in the early 1990s. Under the IDEA authority, the U.S. Department of Education was instructed by Congress to use agency funds to assist minority institutions in building their capacity to compete for special education personnel preparation grants. The Department currently funds the Monarch Center that uses the partnership outreach model. It provides technical assistance and dissemination to promote access to and participation by predominantly African American, Hispanic/Latino, and other institutions the Department of Education identifies as "minority" institutions in discretionary programs authorized by the Individuals with Disabilities Education Act (IDEA). According to their project description: "technical assistance services are provided by a nationwide cadre of content experts and trainers through workshops, seminars, conferences, individual mentoring, and follow-up coaching. Additionally, partnerships and cooperative activities are established with a range of [Office of Special Education Programs, Technical Assistance & Development] providers, research and development projects, national centers, and organizations." (Office of Special Education Programs, 2003, p. 1)

Outreach services to entities serving people from diverse cultures to expand research capacity were also mandated by IDEA legislation. Two projects of note are located at the University of South Florida. The first, Linking Academic Scholars to Educational Resources (LASER), will ensure the development and implementation of a research agenda on urban special education, with the ultimate goal of improving schooling for urban children and youth with, or suspected of having disabilities. The project description summarizes their mission as follows: "to: 1) develop cadres of faculty and graduate students in minority institutions who will conduct and sustain urban special education research/scholarship; 2) develop a national strength-based model that documents strategies for enhancing individual and institutional research capacities; and 3) define and coordinate a national agenda that narrows the gap between research and urban school practice." (Ibid, p. 1)

The second project, Engaging Cross-Cultural Leadership in Preparation for Special Education (Project ECLIPSE), "is a four-year project designed to recruit and prepare a cross-cultural cohort of ethnic minority and majority scholars for careers as urban special education researchers and teacher-educators. The project will provide competitive research fellowships, opportunities for collaborative research and mentoring seminars, and tiered formal and informal mentorship experiences." (Ibid, p. 1)

The University of Texas - El Paso (UTEP) in western Texas will implement Project AIMED (American Indian Masters degree) to train highly qualified educators to work with American Indian students with disabilities. "The purpose of this project is to recruit and train 40 teachers to provide culturally and linguistically appropriate educational programs to students with disabilities who are American Indian, and to graduate qualified educators who will implement a high-quality bilingual special education program on four different American Indian reservations: the Tigua of western Texas, the Tortugas of southern New Mexico, the Apaches of eastern Arizona, and the Apaches of eastern New Mexico." (Ibid, p. 1) These are just a few of the legislatively mandated, federal outreach programs that can provide viable, sustainable changes in under-served communities across the country.

It is NCD's contention that federal agencies must reach out to customers with disabilities from diverse cultures to ensure equality in opportunities for program and service awareness as well as participation. To assure that programs and services are sensitive to cultural differences, federal agencies should undertake a self-assessment. Programs and services need to be systematically evaluated to determine their efficacy in serving people most in need. Broadly, such self-assessments should look at how an agency is prepared to adjust systems and operations within the context of the country's changing demographics. Some agencies have done just that and are in the vanguard of those interested in culturally sensitive and responsive service provision (e.g., Office of Minority Health's Culturally and Linguistically Appropriate Services, CLAS). Some other agencies are just beginning this assessment and can learn from the experiences of other agencies.

#### VI. Summary of Findings of the CDI Resource Mapping Project

As a part of its Cultural Diversity Initiative launched in fiscal year 2003, the National Council on Disability (NCD) requested the cooperation of nine federal agencies in a resource-mapping project. The resource-mapping project was designed to engage each agency in a self-assessment of internal and external outreach efforts for broad inclusion of people with disabilities from diverse cultures in federal agency-sponsored programs, services, products, and activities. NCD asked each agency for assistance with documenting outreach efforts already underway within the federal government.

The self-assessment addressed five areas through responses to an NCD inquiry and included: (1) funding, (2) disability and diversity, (3) evaluation plans, (4) information accessibility, and (5) ongoing agency research. At the time this paper was developed, NCD had received responses from eight of the nine selected agencies.

Based on review and analysis of the data, NCD made several observations that might impact (a) the expansion of these or similar efforts to include additional federal agencies, (b) the focus of a planned follow-up dialogue with the federal agencies, as well as (c) the design of future data collection work in this area. First, all of the federal agency programs and activities addressed disability and/or diversity separately. Second, with a single

exception, the federal agency responses to NCD's inquiry represented only one of several offices, divisions or branches within each agency. For example, the U.S. Department of Health and Human Services (DHHS) Office of Civil Rights (OCR) responded only for OCR; however, absent were responses from other DHHS offices with established work and track records in the area of cultural sensitivity and outreach programs such as in the mental health area. Third, not all definitions of outreach were consistent with NCD's operational definition that was included as a part of the information provided to each agency. Finally, agency information was not always responsive to the areas of inquiry. The combined effect of these observations posed a challenge for a systematic analysis of the information collected. While the data summaries may not reflect the full scope of each agency's outreach efforts, the information reported in this paper serves as a starting point - paving the way for future inquiries and follow-up activities at the discretion of the participating agencies.

For the purposes of the resource mapping inquiry, outreach was defined as "a systematic attempt to provide services beyond conventional limits, to particular segments of a community." The "...particular segments of a community" referred to people with disabilities from racially and ethnically diverse cultures in the United States and "services" encompassed anything the named federal agencies do in fulfilling, advancing, and/or furthering their mission; i.e., the full range of services, programs and activities that the named federal agencies undertake, including informing their consumers of their rights under the ADA as they pertain to that agency.

Prior to reviewing published articles from the literature search or reviewing the results of the resource mapping inquiry, NCD was, to a great extent, informed of the numerous and long-standing outreach efforts initiated within the federal government, particularly in a number of offices within the Department of Health and Human Services (including the Office of the Surgeon General, the Office of Minority Health and the Office of Indian Health), and within the Department of Education (the Office of Special Education and Rehabilitative Services). The outreach by these offices to various people with disabilities from diverse cultures has often taken the form of a high-priority campaign (e.g., to

eliminate health disparities by a time certain). Various programs under HHS exemplify each of the outreach models described above and many HHS reports cite the unique challenges of reaching people from diverse racial and ethnic backgrounds (US Surgeon General, 1999). Outreach strategies are recommended and used frequently, yet are rarely systematically analyzed or compared.

For example, in 1998 the Office of Minority Health (OMH) initiated an assessment of the health infrastructure for people from diverse cultures in selected states and territories and examined the capacity of these jurisdictions to address health disparities by race and ethnicity. The study examined data collection and analysis, cultural competence, access to health care and health professions development. Using information from site visits and interviews, and information gathered from key informants, the study revealed "outreach to the minority communities was the most frequently used approach to engage minorities in prevention or health care. Connected to outreach were efforts to provide health education through the development of culturally and linguistically appropriate health education and promotion materials and through social marketing campaigns" (OMH, 2003, p. 6) Again, a systematic evaluation of these efforts was not a part of this study.

The General Accounting Office (GAO) was recently asked by Congress to identify promising approaches to address racial and ethnic health disparities, and noted that outreach is among the many interventions used to address these disparities. "HHS has focused on racial and ethnic disparities in health access and outcomes in six areas: cancer screening and management, cardiovascular disease, diabetes, HIV infection/AIDS, immunizations, and infant mortality. HHS offices and agencies, researchers at philanthropic foundations, and private organizations such as employers and health plans have efforts underway to try to address racial and ethnic disparities in health care, using interventions such as disease management programs, disease prevention programs, health literacy and language service projects, and education and outreach programs." (GAO, 2003, p. 1)

The following is a brief summary of the initial resource mapping inquiry findings. This data provide a preliminary scan, albeit spotty, of the state of disability/diversity outreach at the national level by the federal government. This data can be used to encourage future dialogue and federal inter-agency collaboration wherein agencies may share their promising practices with each other and by so doing, enhance their programs and ultimately increase involvement of people with disabilities from diverse cultures in agency programs.

**Funding**. In the eight agencies NCD reviewed, five earmarked funds for disability outreach and two agencies earmarked funds for diversity outreach. The Department of Transportation (DOT) submitted ten separate responses for its ten divisions; therefore, DOT warranted an independent assessment. Eight of the ten DOT divisions earmarked funds for disability outreach and six of the ten divisions also earmarked funds for diversity outreach. DOT has a one-stop shop Disability Resource Center (DRC) that provides services, technical assistance and training to ensure that applicants and employees with disabilities in DOT can participate fully in all aspects of DOT work, programs, and services. A number of DOT divisions specifically noted in their responses that they contribute funds annually to support DOT-DRC. It is not clear if all DOT divisions are required to do so.

Outreach funding levels vary widely across the eight agencies. The levels of outreach funds ranged from \$0 to \$16.5 million. Agencies based their calculation of outreach funds on various factors and such factors varied widely across the eight agencies. For instance, a number of agencies provided a breakdown of funds devoted to certain outreach programs and activities while other agencies accounted for salaries of Full Time Equivalents (FTE) focusing on disability and/or diversity issues within the agency. Additionally, disability and diversity related grant awards by agency was the basis of the response provided by one agency. It is also worth noting that the disability outreach funds listed by a number of DOT divisions were specifically noted as the funds that the particular division contributed annually to support DOT-DRC.

A recurring explanation of disability and/or diversity outreach being integrated into an agency's day-to-day work and that such funds are incorporated in the overall agency's outreach budget was echoed by agencies with no funds earmarked for disability and/or diversity outreach.

**Disability and Diversity Outreach**. The agencies used various strategies to reach out to people with disabilities and people from diverse cultures. For example, the Department of Housing and Urban Development (HUD) spearheads a diversity outreach program known as Community Development Work Study Program (CDWSP). The CDWSP program is designed to ensure that graduate students from economically disadvantaged and diverse cultural backgrounds pursue careers in community and economic development. The Department of Labor (DOL) offers millions of dollars in federal grants supporting strategic planning and implementation of activities designed to improve the employment and career advancement of people with disabilities. A number of the DOL grants specifically target the development of model demonstration programs that will enhance the capacity of DOL to serve youth with disabilities. Likewise, the Equal Employment Opportunity Commission (EEOC) conducts extensive technical assistance and training on the Americans with Disabilities Act (ADA) and other disability laws and issues to a wide variety of employer, advocacy, legal and general audiences. The Department of Education hosts mentees from the DOL sponsored National Disability Mentoring Day program as an outreach effort to individuals with disabilities. The program provides an opportunity for individuals with disabilities to spend a day learning about the Department of Education and the kind of employment opportunities available at the agency.

DRC is a division within DOT that serves as the agency's internal one-stop technical assistance resource to all of DOT's programs. DOT-DRC conducts extensive disability outreach such as training and educational workshops to DOT's staff/employee and consumer/customers. In addition to the DOT-DCR outreach efforts on behalf of DOT as a whole, the other nine DOT divisions provided comprehensive summaries of their respective efforts in disability and diversity outreach. An overview of the outreach efforts and activities of each of these DOT offices is beyond the scope of this summary; however, commonalities included targeted recruitment programs designed to reach

people with disabilities and people from diverse backgrounds, disability and diversity awareness education for transportation personnel, dissemination of awareness building and technical assistance information ranging from safety, security, nondiscrimination and access that target air travelers with disabilities from diverse cultures, including those with limited English proficiency, through informational websites, fact sheets, telephone hotlines, employee trainings and the sponsoring of employee attendance at conferences.

**Evaluation Plan**. The agencies use various informal evaluation plans to measure the success of their respective outreach efforts. EEOC was the only agency that illustrated a formal evaluation plan that measures the success of its strategic objectives. The most common evaluation approach among the other agencies was the assessment of whether the recruitment of targeted individuals results in an increase in the applications as well as the hiring of persons with disabilities and people from diverse cultures. DOT Federal Transit Administration (FTA) measures effectiveness based on reduction in the number of complaints received and the increase in the number of requests for technical assistance. The Department of Justice (DOJ) relies on its Equal Employment Opportunity (EEO) report as a method of measuring the success of its outreach efforts.

Accessibility of Agency Information. All eight agencies that responded to NCD's inquiry indicated to a certain degree that they accommodate various types of disabilities and language modes in the ADA and agency information they disseminate. Specifically, this entails making print reports, brochures, CD-Roms, videotapes and the agency's Web site accessible through various means, such as the TTY, captioning for audio output on the Internet, alternative formats such as Braille, and languages other than English.

**Ongoing Research**. Only two of the ten DOT offices and three of the seven other agencies responded affirmatively to NCD's inquiry regarding studies in place or in FY04 budget requests to examine the nature of the participation of people with disabilities and people from diverse cultural groups in an agency's programs, services and activities. EEOC pointed out that while it conducts no formal disability or diversity related studies, the agency documents data regarding the disabilities most frequently cited in complaints. For ongoing research relating to diversity, SSA noted that the agency is conducting a study on how to improve its hiring, promotion and retention of employees with disabilities. The Department of Education indicated that most of the agency's studies address diversity in some way and other studies target disability. HUD cited various ongoing studies by that address disability and/or diversity. One such study examines the trend towards greater integration into the community by providing mainstream housing opportunities for persons with disabilities. Another HUD study, the Housing Discrimination Study, involves an ambitious effort to measure the extent of housing discrimination in the United States based on race or ethnicity. DOT Federal Transit Administration listed four ongoing assessment studies: 1) Fare Increase (studies that examine if a fare increase is discriminatory and whether equity issues were taken into consideration when planning for change); 2) Multilingual Information and Signage; 3) Equitable Allocation of Resources; and 4) Service Changes. These studies assess specific areas that appear to be recurrent concerns with transit customers who file Title VI complaints or lawsuits. Finally, DOT Federal Highway Administration indicated that it is engaged in a Multi-Year Affirmative Employment Task Force to assess the status of the Agency's current employment posture, identify barriers and under-representation, and set goals consistent with the Agency's responsibilities under various Presidential initiatives to employ Hispanic/Latino Americans, Asian Americans, and Americans with disabilities.

**Observations.** The key elements of each agency's response to the NCD Resource Mapping Inquiry varied across the agencies. Although NCD provided a working definition of outreach for the purpose of the NCD Cultural Diversity Initiative (CDI) project, instances of varying interpretations of outreach were evidenced in some aspects

of the agencies' responses. There were also several instances where information provided was not responsive to the particular inquiry. Readily visible from the eight responding agencies' outreach information was the absence of any form of outreach that simultaneously targeted people with disabilities from diverse racial and ethnic backgrounds. The outreach programs and activities accounted for were all either within the disability category or the diversity category. It is also important to mention that the inquiry responses, with the exception of DOT, represent only one of several offices, divisions, or departments within each agency. All of this together poses a challenge for NCD to systematically analyze the information collected. Therefore, findings in this summary do not necessarily reflect the full scope of each agency's outreach activities. Next steps in the NCD CDI project include making the data from each agency more complete through inter-agency collaboration and further dialogue. One of the goals of the ongoing dialogue among agencies on outreach to people with disabilities from diverse backgrounds will include developing a reliable and valid set of baseline data for each agency on programs, policies, products, and procedures that agencies can share.

#### VII. Challenges to Outreach

This section discusses several factors identified in the literature as challenges and/or barriers to outreach efforts. These factors are similar to NCD's findings and recommendations on the overall unmet needs of people with disabilities from diverse cultures. Among those factors are the lack of culturally appropriate outreach; failure to engage local leaders; the lack of needs assessments; language and communication barriers; attitudinal barriers and the shortage of individuals from diverse cultures in disability services professions.

Lack of Culturally Appropriate Outreach. Based on the multicultural make-up of the United States population, outreach programs must make a careful evaluation of a particular group's culture before the start of any endeavor. Differences in culture reflect more than a person's ethnic and racial background. Other relevant factors include place of residence and the demographics of people living in the area--age, health status, occupation, religion, sex, societal status, and so forth. These group characteristics must

be addressed so that the project design is sensitive to cultural factors. Otherwise, untailored projects may result in a community backlash towards the program or organization. For example, with the high prevalence of certain diseases, such as diabetes, among different ethnic groups, certain pharmaceutical companies set out to improve the health status of people from diverse cultures by advertising medications. In their publicity campaign, the pharmaceutical companies used multilingual transit ads to gain presence in communities. Although these ads do circulate in major ethnically diverse areas, their success is very limited due to the community's distrust of the healthcare system. Many people with disabilities from diverse cultures feel that the pharmaceutical companies' interests lie in company pocketbooks and not in alleviating community health problems. Therefore, without a credible, long term, grassroots-implemented campaign, many outreach projects will not yield the desired results (Goetzl, 2000).

Limited Funding. When only limited funding is available, project leaders are unable to gain meaningful entry into the community, translate materials into different languages, hire culturally competent coordinators, or distribute information in the most useful manner. For instance, to decrease the undesired teenage pregnancy rate among members of an identified group, written pamphlets and brochures have been found to be unsuccessful in changing behaviors. However, intergenerational programs with limited funding that focus on oral traditions were much more helpful in decreasing the incidence rate of pregnancy for this population (Fife, 2001).

Lack of Needs Assessment. To ensure an appropriate foundation is formed prior to starting a project, a comprehensive needs assessment must be conducted by the outreach program proponents. The literature identified several elements that outreach organizers have found to be essential to this process. The project Wood and his colleagues conducted (Wood et al, 2003) was geared toward facilitating access to the Internet and thus to health information available on the Web, to American Indians living on tribal lands. However, the fourteen elements that Wood, et al identified as key elements of a tribal community needs assessment may be beneficial to other project leaders entering a community. The elements are as follows:

- 1. Stop, look, and listen; enter with respect.
- 2. Develop a mental image or picture of the community; onsite visits are essential.
- 3. Do your homework; review in advance what is known about the demographics, health status and issues, local leadership, technical infrastructure, etc.
- 4. Your goal is to understand the local community- its history, governance, members, interests, needs, priorities, and spirit.
- 5. Identify, search out and connect with local organizations, leaders, and advocatesboth health and information technology (IT)-related.
- 6. Understand the health information needs and users in the community and the facilitators and barriers to use.
- 7. Benchmark the current technical infrastructure (computers, local/wide area networks, Internet connections, IT staff support) in the community and specifically the health sector and related organizations (e.g., schools, libraries).
- 8. Get feedback through discussions with leaders, key contacts, elders, and users.
- 9. Look for partnership opportunities; be creative, work across boundaries.
- 10. Create a partnership plan- with emphasis on sustainability and capacity building.
- 11. Prepare technical, training, and outreach plans in collaboration with community leaders, and the health and IT staff. Remember it is their community, not yours.
- 12. Build on already existing community initiatives and activities (e.g. health fairs, disease-specific patient groups, wellness programs) to the extent possible.
- 13. Be prepared to be adaptive, iterative, supportive, and open-minded, yet be honest and realistic; balance vision with practicality.
- 14. Build flexibility into the project schedule; the pacing and timing should give priority to the community's needs, capabilities, and readiness.

Overall, the fourteen elements emphasize the importance of respecting and understanding the community's "needs, capabilities, and readiness." Furthermore, it was deemed important to focus on working with community members to create a mutual understanding as the basis for a partnership created to produce a mutually beneficial project.

Failure to Engage Local Leaders. Outreach projects that utilize the community-based model can break down barriers to reaching the targeted population by working with local prominent and/or trusted leaders. Since many leaders have an understanding of the population, they can be valuable resources during the planning and implementation of the project. In addition to their expertise, the community leaders and the groups they represent can provide a bridge to gaining the trust and acceptance of the people who will benefit from outreach. In Burroughs' research on maximizing African Americans' participation in diabetes research, he cites the benefits of using leaders and local social groups for a Community Advisory Board (CAB) that acted as the "guardians" of the project. The CAB was created to ensure the community's interests were served first and that the people conducting the outreach were mindful of what the community wanted from the outreach efforts (Burroughs, 1998).

Failure to Use Peers. Another model of outreach that has the goal of cultural accommodation built into its approach is the peer-to-peer model. In this method, peers of the targeted group are hired to conduct the outreach so that the project employees are people ready to work in a manner that acknowledges and respects the culture. The success of the "Buddy Project" relied on caseworkers who were mental health survivors and who were once homeless reaching out to homeless people with psychiatric disabilities. "Outside" caseworkers that tried to reach this homeless population to encourage treatment met unreceptive people. The peer caseworkers were able to connect on the basis of their own experiences with similar mental and social states (Fisk, 2002). Although the sample in the outreach project was small, it nevertheless illustrates the promise of using peers of a target population to administer an outreach effort.

Language and Communication Barriers. Once outreach organizers have a strong grasp of the environment, they can then disseminate information and communicate their objectives to the people who will be involved in the project. When organizers enter a community without listening to what the people want, projects will not reflect the interest of the people (Johnson, 1996). Thus, the outreach organizers must make communication a priority, since the meaningful outcome of the project can be determined by the degree

of open interaction and understanding among the people conducting the outreach and the people intended as beneficiaries. Projects for serving non-English speakers, people with low-level reading/writing skills, or who have disabilities, must give additional attention to removing language and communication barriers. For example, it would be counterproductive to reach out to these groups through written materials that are in English only and/or that have complex vocabulary and highly technical terms.

With the rapidly changing demographics of the United States, multilingual information has become even more essential and critical than ever. Non-English and non-native English speakers face barriers to outreach projects when the informational materials and communication efforts have not been properly translated into an appropriate language. Translation may be a difficult task for projects that attempt to reach ethnic groups that have numerous subgroups with different languages and dialects. For instance, one translation would not suffice for the American Indian population. As an example, in Los Angeles, California, this population includes over eighty tribes and languages (Kramer, 1992). Another example nationwide is the Chinese population that also speaks numerous dialects and languages such as Mandarin, Cantonese, Gan, Min, Xiang, and Hakka.

Knowing how to communicate with a particular population and through appropriate language is imperative if outreach providers are to communicate their objectives and information without seriously compromising a project. In order to customize a project to the best interests of the population, resources must be adequate and used to create a communication approach that would enable meaningful dialogue.

Attitudinal Barriers. Misperceptions held by outreach providers and/or by the target population can significantly hinder the progress of an outreach project. With negative perceptions of the "system" prevalent among people from diverse cultures, a sense of distrust is common when outsiders enter communities to provide information or to change behaviors without establishing trust and credibility. Along with negative, mistrustful views toward the system, some attitudes about disability and people with disabilities are barriers that breed prejudices or stereotypes and must be deconstructed.

Historical events have also impacted levels of trust and respect. For example, some American Indians living in urban areas are reluctant to approach government agencies for any kind of aid because of the treatment they receive from workers. According to Kramer (1992) and NCD (2003), most government workers are unaware of American Indian culture and values, so they have been seen as "disrespectful at best or outright hostile at worst" (Kramer, 1992, p. 49). Similarly, Hanley (2003) states that, for African Americans, under-utilization of mental health services can be attributed, in part, to the racist manner in which services are provided by staff. Additionally, African Americans' distrust of the U.S. government and its agencies may be attributed to experiences such as slavery and its impact on family and economic opportunity, as well as inhumane treatment of group members in studies such as the infamous Tuskegee Project. Hence, for outreach projects to survive and prosper among African Americans, the outreach administrators must understand what people have encountered and the attitudes towards "outsiders" who seek to implement programs (Pickett-Schenk, 2002).

Besides addressing attitudes towards outsiders, outreach workers themselves must become knowledgeable about diverse views on disability. Cultural perceptions of disabilities such as diabetes must be acknowledged before the outreach project creates its plan of action. For instance, families may conceal diabetes if it carries a social stigma (Burroughs, 1998). In some diverse cultures, having a disability designates a person as an outcast: someone who is incapable of being a functioning member of society. The disability may be viewed as the result of bad karma or a form of chastisement resulting from the family's wrongful actions. For example, Tsao (1999) cites the stigma of being a "triple minority", a Chinese woman with a disability, in a society that does not value differences.

Community and partnership models of outreach can alleviate the pressures of attitudinal barriers when outreach proponents work with community members to strengthen service possibilities. When outreach projects work within the existing community to build a

network of services, the outreach projects are able to contribute to a lasting change in people's lives, including integration into the broader community.

## Shortage of Individuals from Diverse Cultures in Disability Services Professions.

The lack of diverse service professionals can compromise the quality of service delivery to people from diverse cultures. Issues arise when culturally insensitive service providers are unaware of offensive actions. However, people with disabilities from diverse cultural groups often have demonstrated different levels of trust in service professionals of similar backgrounds.

For instance, one community may perceive a physician as a "figure of legitimized authority and power," (Aranda, 2003, p. 264) while another community may be more trusting of nurses than doctors. For the El Portal: Latino Alzheimer's project, doctors were encouraged to provide information and education on Alzheimer's disease to Latino families. This inter-organizational, community-based project utilized the most influential person in the Latino community to administer the outreach (Aranda, 2003) rather than assume doctors were always the professionals to provide this type of outreach.

In another example, the Community Partnership Primary Care project (CPPC) required physicians and nurse practitioners to acquaint themselves with the community and to develop a dialogue with the members of the community (Courtney, 2003). Even though the project did not require the health professionals to come from diverse backgrounds, it did emphasize the need to learn about the community. The Rural Elder Outreach program used nurses as caseworkers instead of social workers or psychiatrists to conduct outreach visits that linked families caring for elderly citizens to appropriate support services (Abraham, 1993).

Lack of staff from diverse cultures may not only hinder services, but it may also close doors for people who need service benefits. In rehabilitation counseling, the absence of a bilingual counselor could result in a vague or completely inappropriate assessment of an individual's capabilities, if the counselor is unable to communicate with the consumer.

Misunderstanding of the consumer's cultural background could also prevent the counselor from being sensitive to family support issues and cultural perceptions of disabilities. Translators may be hired for assessment purposes, but the third party may inhibit the consumers from expressing real concerns out of fear or embarrassment (O'Brien, 1996).

Lack of Information about Resources. Obtaining information about necessary resources has been one of the barriers that prevent people from accessing services. Since there are already few services available specifically for people with disabilities from diverse cultures, information about existing services in the mainstream needs to be made widely available and culturally sensitive. For example, American Indians living in cities tend to be overlooked by service agencies because there is no centralized community mechanism to connect members of the population to services (Kramer, 1992).

It is also difficult for people living in rural communities to spread information about resources because of secluded and difficult to reach areas. To reach out to the rural population, outreach programs must focus on building a community network support system that would act as a resource center to disseminate information and provide support (Abraham, 1993).

Lack of Coordinated Services. This can further exacerbate the access gap because people receive fragmented instead of comprehensive solutions and services. In addition, resources may be duplicated or incomplete when there is no service coordination and this leads to frustration and lack of access to, and/or under utilization of, existing services. For example, lawyers providing "pro bono" work have difficulty contacting people who need their services. Without a proper strategy to match people with lawyers, people who are economically disadvantaged may be left with huge attorneys' fees or succumb to the legal charges against them. Even when lawyers want to volunteer their time to provide free services to their communities, their good intentions are often wasted by the lack of usage (Fiorella, 2003).

As another example of coordination needs, the El Portal: Latino Alzheimer's project cited fragmented services as a barrier to people receiving comprehensive care for Alzheimer's. It was reported that patients were often transferred to different providers and services that required different applications and methods of payment. As a result, patients often forgo care or settle on fragmented care instead of enduring the frustrations of dealing with these systems (Aranda, 2003).

Limited Use of Client Focused Services. Assertive outreach has been reported to be quite successful in ensuring complete care for people with mental health disabilities. NCD noted in an earlier report, *From Privileges to Rights*, that this also applies to people who are mental health survivors (NCD, 2000). Under the client focused method, caseworkers focus on the client's overall quality of life and not just health issues. The client-focused approach may be costly since time limits are not set with clients. However, the advantage is in improved outcomes where coordination of care for mental health patients is important (Winchester, 2002).

Coordination of services through a community center has been reported as especially useful for people living in rural areas. Fife and colleagues suggest: 1) the most successful and long-lived programs are those that include community participation in their conception, design, and implementation, 2) those programs that are most convenient for participants to access will be the best received, and 3) feedback from participants and modification of these programs in accordance with this feedback should be part of any successful program. (Fife, 2001)

Person-centered planning is one way of providing services that is gaining popularity due to its culturally responsive strategies. Hasnain, Sotnik and Ghiloni (2003) made three outreach recommendations to connect people with disabilities from diverse cultures with employment services and supports. They are:

Increase marketing efforts in ethnic communities to identify and address the
unmet needs of underserved and unserved groups due to the lack of outreach to
these populations by disability-related agencies.

- Use non-traditional outreach methods to inform ethnic and underseved communities of vocational rehabilitation service options, such as conducting informal presentations at community events and festivities, placing job notices with grassroots entities, and using ethnic cable stations and radio programs.
- Conduct focus groups to identify the authentic employment and vocational needs
  of racial and ethnic individuals with disabilities and to incorporate them into
  future programs.

The person-centered planning project used the following outreach strategies and found they contributed to improved outcomes.

# Marketing Strategies

- Provide examples/stories to explain abstract concepts
- Take services to the community
- Work with community-based organizations and identify a contact person as a collaborator
- Identify a gatekeeper (a representative of the community)
- Consult with consumers and their communities
- Avoid pushing American values of individualism into practice
- Encourage community ownership
- Avoid service acronyms and jargon

#### Family and Cultural Influences

- Spend extra time getting to know the family
- Note family dynamics
- Include extended family members and kin relationships
- Address both the needs of individual and family
- Be prepared to spend time with the family after the meeting
- Accept refreshments or insistent dinner invitations

## Communications Strategies

- Be sincere, patient, and take the time to listen
- Avoid ethnic stereotyping
- Build relationships and trust
- Avoid rushing or giving that impression because it can lead to distancing
- Respond in a nonjudgmental way
- Give people time to respond to questions
- Provide language and other related accommodations
- Avoid the use of jargon and service delivery terminology
- Note non-verbal communication cues and gestures
- Make regular phone calls and meetings

### **Building Capacity**

- Use cultural informants to assist in working with their communities
- Use the media to inform the community (via ethnic newspapers, ethnic cable and radio stations)
- Work with existing entities where people gather (e.g., community centers, religious affiliations, public library)
- Use a community liaison to gather information and to generate possible referrals
- Use network of consumers/parents to educate and inform other families about person-centered planning

--Outreach Strategies for Working with Consumers and Families from Culturally Diverse Backgrounds (Hasnain, Sotnik and Ghiloni 2003, p. 40)

**Demographics**. A compelling factor influencing the feasibility of outreach is the rapidly changing demography of the United States. Leung (1993) addressed the changing demographics and its effect on federal and state service delivery systems' capabilities concerning people with disabilities from diverse cultures. During the last two decades (1980-2000), the population of the United States has changed significantly with regard to its ethnic, racial, and cultural portrait; it has become more diverse and will continue to do so. Because of this shift, federal and state service delivery programs must respond to different needs that accompany demographic changes.

Census 2000 data revealed that there were 281,000,000 people residing in the United States. One of every three Americans is of Hispanic/Latino, African, Asian, Hawaiian or Alaska Native, or American Indian descent. The rate of disability for persons from diverse groups is substantially higher than for the general population. Therefore, the representation of these groups among the overall disability population is disproportionately high in comparison to their national Census count. One can reason that this disparity will likely continue to increase given the rapid growth of diverse racial and ethnic groups nationwide.

**Limited Attention to Interconnectivity**. Another challenge of outreach is raising awareness about the interconnectivity of disability and other civil rights laws. People with disabilities from diverse cultures have experienced some of the worst outcomes in terms of self-sufficiency. Yet, civil rights groups rarely take on disability issues and

disability groups seldom broach diversity issues as routine agenda items. The literature also shows a need to equalize opportunity for benefits among people with disabilities from diverse cultures and implicates the mentioned barriers to access as well as disparities in quantity and quality of services. People with disabilities from diverse cultures need to become a focus of federal agency policies, programs, activities and outreach efforts.

People with disabilities from diverse cultures have not realized the promise of full inclusion and equal opportunity, although civil rights laws designed to prohibit discrimination are in place. For example, "the ADA placed disability discrimination on a par with race or gender discrimination, exposed the common experiences of prejudice and segregation and provided clear rationale for the elimination of disability discrimination in this country" (NCD, 2000a, p. 1). Still, discrimination persists and is compounded for people with disabilities from diverse cultures. The phenomena of "double jeopardy" and "triple jeopardy" have also been documented in the literature on civil and disability rights (Zawaiza et al, 2002).

As with other civil rights laws, the ADA has created greater recognition and understanding of the manner in which the environment can pose discriminatory barriers. However, there remain vestiges of misunderstanding which thwart efforts to bring movements (i.e., disability rights and civil rights) together in a synergistic partnership. Similar to the authority of earlier civil rights laws, "federal agencies have a key responsibility to advance the interpretation and implementation of the ADA and other disability laws through enforcement actions, policy guidance, and participation in the development of precedent-setting court decisions" (NCD, 2000a, p. 1).

Federal agencies can enhance the effectiveness of programs and, ultimately, the lives of consumers, by systematically reaching out to various constituencies in ways that support empowerment. Besides the fact that reaching all potential customers is good customer service, federal agencies that administer programs and services are required by law to serve all Americans, including individuals with disabilities. Other benefits of outreach

include increased customer satisfaction, a more positive public relations image in the target market and increased market volume.

There has yet to be a comprehensive multi-agency outreach campaign to connect programs and services to people with disabilities from diverse cultures. Such a campaign could provide:

- 1. Linguistically and culturally appropriate information about programs, services, products and contact information.
- 2. Opportunities to raise awareness about protections through training and notices of civil and due process rights under pertinent federal laws in appropriate formats.

Cultural Competence. Research on diversity outreach reports advantages for organizations to achieve a measure of cultural proficiency in order to improve customer service. The term "cultural competence" was coined by Cross (1989) to describe a level of proficiency necessary to engage customers effectively. According to Goode (2001), there is no one definition of cultural competence. Goode explains further that the definitions of cultural competence have evolved from diverse perspectives, interests, and needs and are incorporated in state legislation, Federal statutes and programs, private organizations and academic settings (Goode, 2001). With slight variations, Cross (1989), Soriano (1995), and Goode (2001) define cultural competence as "a set of congruent behaviors, attitudes, and policies that come together in a system, agency or among professionals and enable that system, agency or professionals to work effectively in cross-cultural situations. The word culture is used because it implies the integrated pattern of human behavior that includes thoughts, communications, actions, customs, beliefs, values and institutions of a racial, ethnic, religious, or social group. The word competence is used because it implies having the capacity to function effectively." (Goode, 2001, p. 1).

The four common elements found among the various definitions and concepts of cultural competence include: 1) valuing diversity 2) having the capacity for cultural self-

assessment 3)having the ability to institutionalize cultural knowledge 4) having the capacity and willingness to adapt service delivery, reflecting an understanding of cultural diversity.

The dominant characteristics of programs that exemplified culturally competent principles/values were: (1) clearly defined philosophy and policies; (2) staffing patterns that reflect the ethnic makeup of the population served; and (3) an emphasis on training, education, and curriculum development to address cultural issues (Cross et al, 1989, p. 39).

Similarly, in adapting the work of Cross et al., Goode (2001) listed several values and principles that are considered integral to a culturally competent system of services and supports. The list includes: a service delivery system that is driven by culturally preferred choice, not by culturally neutral or culturally free interventions; working in conjunction with natural, informal support and helping networks within culturally diverse communities (e.g., neighborhoods, civic and advocacy associations, local/neighborhood merchants and alliance groups, ethnic groups, social and religious organizations, spiritual leaders and healers); and, extending the concept of self-determination. The National Center for the Dissemination of Disability Research (NCDDR, 1999) referred to empowerment as the most critical element of cultural competence. Accordingly, empowerment involves an orientation towards partnership with clients or consumers rather than assistance bestowed upon a passive recipient. NCDDR also cited Kalyanpur and Rao's contention (1991) that, "Empowerment signifies changing the role of a service provider from that of an expert to that of an ally or friend who enables [individuals] to articulate what they need . . . It involves caring, which builds supportive relationships; respect, which builds reciprocity; and the acceptance of differences, which builds trust" (NCDDR, 1999, p. 35).

**Different Cultural Constructs of Disability**. Among the factors that deter people with disabilities from diverse cultural backgrounds from seeking services are the different cultural conceptualizations of disability. Several authors reported that the term

"disability" is a socially constructed concept (Harry, 2002) and is culturally derived (NCDDR, 1999). "There is no uniform definition of disability since the government agencies define disability differently" (Smart and Smart, 1997, p. 2). Similarly, Groce (in press) observed that all societies do seem to recognize individuals with a disability as having some physical, psychological or sensory attribute that distinguishes them from other non-disabled members of that society. Gallagher (1990) describes this as an "otherness." However, it is the cultural interpretations of this "otherness" that are of concern and these cultural interpretations vary significantly from one society to the next.

Collectivist vs. Individualistic Orientations. Different interpretations of the etiology and meaning of disability and of statutory concepts such as "independence" can affect the extent to which people with disabilities from diverse cultures avail themselves of federal services and supports. NCDDR (1999) pointed out that individualism is one of the most dominant values operating in mainstream American culture. Further "such value is evident in rehabilitation counseling and the work of independent living centers which primarily focus on the individual with the disability; services, procedures, and rules are geared to that person" (NCDDR, 1999, p. 25).

While mainstream American cultures view disability as an individual matter and movement toward independence an appropriate objective, people from diverse racial and ethnic groups largely hold collectivist value orientations that emphasize the importance of family and interdependence. People from diverse cultures have also reported perceptions of disability as a reflection upon and responsibility of the entire family. NCD (1999) found that these cultural differences about concepts such as individual empowerment, self-sufficiency, independent living, control over one's life, and minimal reliance on others, may be isolating and even offensive to a person with a disability from a diverse culture if the concepts are not adequately translated and/or presented in a culturally appropriate manner (NCD, 1999, p. 15).

Examples of findings and recommendations from published research include reports about Asian Americans by Choi and Wynne (1996), African Americans and

Hispanic/Latino Americans by Harry and Leung (1992), Wagner and Tata (1995), and Soriano (1995), and American Indians/Alaska Natives by Harry (1992) and NCD (2003). Commonalities across these reports include recognition of diversity within groups, key roles for families in the lives of people with disabilities, different ways of perceiving disability as a concept, and the role of cultural beliefs, customs and traditions that need to be respected.

### VIII. Findings and Recommendations

**Findings**. The review showed a paucity of empirical studies of outreach as an intervention and few studies evaluating the effectiveness of outreach activities. Major findings include:

- Outreach, as an intervention, is a frequently recommended strategy designed to
  improve services to underserved groups, about which little is known empirically.
  Proponents claim various outreach models show promise but the lack of
  consistency across studies makes it difficult to generalize about the effectiveness
  of any given approach. Rarely is the term operationally defined or empirically
  studied, making it an elusive construct.
- 2. Although outreach efforts are highly eclectic, some major themes were found to recur in the literature, including: value placed on target population, assessment of needs, advocacy, dissemination of information, transformation of social behaviors/attitudes, and the strengthening of communities.
- 3. The models of outreach found in the literature were categorized as: the community-based model, wherein focus is placed on building the capacity of current community organizations; the grassroots model, often indigenous, native-speakers using venues not typically used by service organizations; the train-the-trainer model, in which trusted community members are trained so that the community maintains the needed knowledge after outreach workers have departed. The peer-to-peer model emphasizes the mutual understanding of contemporaries; the partnership model builds on the partner's expertise and community trust while the support socialization model couples outreach with popular events to attract the community.

- 4. Challenges to comprehensive outreach activities include the lack of culturally appropriate outreach; failure to engage local leaders; the lack of needs assessments; language and communication barriers; attitudinal barriers and the shortage of individuals from diverse cultures in disability services professions.
- 5. Self-reports by the nine participating agencies did not fully capture the depth and breadth of current national disability/diversity outreach efforts in those organizations. Several agencies used outreach as an intervention strategy extensively while others only utilized it periodically, if at all. Methodological limitations constrained the ability to make definitive statements about the nature and prevalence of outreach programs to diverse people with disabilities.
- 6. All of the federal agency programs and activities reported addressed disability and/or diversity separately. With a single exception, the federal agency responses to NCD's questionnaire represented only one of several offices, divisions or branches within each agency (e.g., the U.S. Department of Health and Human Services (DHHS) Office of Civil Rights (OCR) responded only for OCR; however, absent were responses from other DHHS offices with established work and track records in the area of cultural sensitivity, and outreach programs in areas such as mental health.) Not all definitions of outreach were consistent with NCD's operational definition provided as a part of the information given to each agency. Finally, agency information was not always responsive to the areas of inquiry. The combined effect of these observations posed a challenge for a systematic analysis of the information collected.
- 7. Research syntheses are needed to systematically identify and evaluate outreach programs for people with disabilities from diverse cultures. The scarcity of such research precludes empirically based decisions about the efficacy and effectiveness of outreach efforts. Research syntheses are useful in that they increase the accessibility of the research and facilitate its interpretation and use in the field (Gersten, 2000).

**Recommendations**. The following recommendations are offered to address the apparent gaps in knowledge about outreach and people with disabilities from diverse cultures.

- 1. Outreach Feasibility Studies: The feasibility of federal agencies using outreach as a reliable and valid strategy to reach people with disabilities should be systematically analyzed. The prevalence of disability in diverse cultures is significant and, in most cases, disproportionately high. Equitable representation of people with disabilities from diverse cultures in federal programs can be enhanced by reaching out to these populations in culturally sensitive ways, evaluating the effectiveness of the efforts, disseminating the results and encouraging replication of promising practices.
- 2. Assessment of Federal Outreach Competencies: Encourage federal agencies to undertake a comprehensive self-assessment of outreach competencies and a thorough inventory of outreach practices to gauge future training and development needs and to share promising practices, policies, products and procedures with other federal agencies.
- 3. Support Interagency Outreach Collaboration: Encourage interagency agreement and funding on outreach knowledge information dissemination and exchange. Form a technical expert panel comprised of interagency representatives and grassroots leaders to develop and pilot cultural competency standards and outreach guidelines for federal agencies and their partners. Ensure the meaningful participation of people with disabilities from diverse cultures in the development of programs and strategies.
- **4. Efficacy Research:** Research is needed to weigh the comparative effectiveness of specific strategies, including comprehensive outreach, in improving services, access and protections for diverse populations with disabilities.

**Future Outreach Research**. Organizations looking to enhance their outreach activities could benefit from exploring the challenges to outreach presented here in tandem with issues relevant to people with disabilities from diverse cultures. Future research in this area might include recommendations discussed in a recent report (Zawaiza et al, 2002) on infusing issues of people with disabilities from under-served communities into a transdisciplinary research agenda in the behavioral and social sciences such as the following:

- Study the degree of awareness in the field of disabilities (e.g., researchers, providers, consumers) of cultural factors that impact services, treatment, families, consumers, and the community.
- Research the correlation between program capacity, increased cultural
  competence, and outcomes (e.g., in educational achievement, economic selfsufficiency, social and community involvement) of people with disabilities from
  diverse cultures.
- Examine various training models for personnel preparation to identify salient features and promising practices.
- Analyze why the existing body of research regarding promising practices has not made a difference in the employment and self-sufficiency of people with disabilities from diverse cultures.
- Explore to what extent health, poor health care, and subsequent development of secondary conditions play a role in the ability of people with disabilities to secure and maintain employment.
- Does the effectiveness of programs improve for people from diverse cultures as diverse professionals move into professional service systems?
- What role might under-utilized venues and leaders, e.g., community churches and ministers, play in improving outcomes for people with disabilities from diverse cultures?
- 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?

Conduct a meta-analysis and synthesis of studies aimed at understanding the complexities and special needs of people with disabilities from diverse cultures.

#### IX. Conclusions

NCD, in its role of advising and assisting the executive branch, undertook this review to continue collaborating with federal agencies working to enhance their outreach efforts. This paper identified several definitions of outreach and the principal outreach themes found in the literature. Models of outreach were described, creating a common lexicon of terms and meanings with examples of outreach types or models that elaborated on these descriptions.

Over the past twenty-five years, the landscape of disability policy has become rich with consumer rights, protections, and opportunities, yet the systems in place to serve people with disabilities from diverse cultures still are unable to provide appropriate services. During the years covered by research addressed in this paper, national administrations have sought to provide an inclusive, representative government that values this country's diversity and fosters access to the mainstream of American life. Despite these efforts, inequalities in education, employment, housing and other areas persist as central issues.

This report has clear implications for research and policy focused on people with disabilities from diverse cultures. It identifies outreach themes and models that may have a positive impact on some of the more intractable obstacles facing people with disabilities from diverse cultures and the federal agencies mandated to serve them. Future contributions to the outreach knowledge base can only serve to further articulate the principal themes and models of--as well as illuminate the many challenges to--outreach.

NCD intends to continue to help ameliorate this dismal situation. In addition to facilitating inter-agency dialogue on outreach to this population (see, http://www.ncd.gov/newsroom/advisory/cultural/forum\_summary.html), NCD's Cultural Diversity Initiative will include the development of a toolkit containing resources helpful in developing comprehensive federal outreach programs.

"I am not an advocate for frequent changes in laws and constitutions, but laws and institutions must go hand in hand with the progress of the human mind. As that becomes more developed, more enlightened, as new discoveries are made, new truths discovered

and manners and opinions change, with the change of circumstances, institutions must advance also to keep pace with the times." -- Thomas Jefferson

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## Appendix A

## **Examples of Outreach Programs, Models, and Strategies**

American Indian Elders Outreach Project- A demonstration outreach program created to assess the needs and concerns about aging and service delivery to American Indians living in Los Angeles, CA. Contact information: Josea Kramer, Los Angeles Department of Community and Senior Citizens Services, 3175 W. 6<sup>th</sup> St, Los Angeles, CA 90020, (213) 738-2671 (Kramer, 1992).

Assertive Outreach- A client-focused approach to mental health that sends workers into the community to contact people in their own environment. The service focuses on working together to build on clients' strengths – not simply on providing treatment, but also on improving each client's quality of life and standard of living and improving community awareness and acceptance (Winchester, 2002).

The Buddy Project- A support socialization project that employed formerly homeless persons with psychiatric disabilities in a community-based mental health outreach team to participate in social activities with "difficult to engage" homeless persons with psychiatric disabilities. This interaction is particularly important in community reintegration (i.e. housing, clinical and rehabilitative services) of this population. Contact information: Deborah Fisk, Connecticut Mental Health Center, 235 Nicoll St., New Haven, CT 06511, (203) 789-6912 x 306 (Fisk, 2002).

Cancer Information Service Outreach Program- A nationally coordinated outreach program that uses the partnership model to establish an alliance with government, nonprofit, and private organizations to reach underserved and minority populations (Fleisher, 1998).

- Church-based Support Groups- Utilizes church as an intervention setting to reach out to African American families coping with mental illness (Pickett-Schenk, 2002).
- El Portal: Latino Alzheimer's Project- An inter-organizational, community based collaborative model that is aimed at enhancing the community's capacity to provide culturally and linguistically competent educational, medical, social, and support services for Latinos affected by dementia, and their caregivers. The project coordinated mainstream and ethnic agencies in Los Angeles County to provide appropriate services to Latino families affected by dementia (Aranda, 2003).
- Families Who Care Project- A train-the-trainer approach to outreach designed to educate African American and rural family caregivers in dealing with dementia in a culturally competent way. (Coogle, 2002). Contact information: Constance L. Coogle, Virginia Center on Aging, Virginia Commonwealth University, P.O. Box 980229, Richmond, VA 23298-0229
- Health-Peers- Utilizes retired senior volunteers to conduct programs designed to teach seniors how to reduce their risk factors for cardiovascular disease, cancer, osteoporosis, and injuries (Buonocore, 2002).
- Healthy Living, Healthy You- An educational program in Canada that identifies the specific health needs of immigrant women and then effectively presents the requested information. Although the information was presented only in English, the extensive use of audiovisual aids and translators enabled the project to educate the women on numerous health concerns (Murty, 1998).
- Peer-driven Intervention Model- Uses people from the target population as the caseworkers who are responsible for achieving the goals of the project. This

insures a built-in cultural and ethnic accommodation to the entire population of interest (Broadhead, 1995).

Project DIRECT (Diabetes Interventions Reaching and Educating Communities Together)- A community-based outreach to maximize participation of African Americans in diabetes research. This project used a Community Advisory Board to build trust in the community and to ensure that the project would give back to the people (Burrus, 1998).

Project InSights- A community vision education and outreach program that uses adult volunteers to educate their peers about age-related vision loss and the benefits of vision rehabilitation for the visually impaired (Buonocore, 2002)

Project TAP outreach- A program funded by the U.S. Department of Education. This project provided outreach services to day care center staff to provide appropriate services to children with developmental delays who are from diverse cultures. (U.S. Department of Education).

Radio Outreach- Use of the radio as a mode of outreach to different target populations through the eclectic variety of stations. This type of marketing provides the outreach with mass exposure while being cost effective (Ingerstoll, 2003).

Rural Elder Outreach Program- A health oriented outreach program that links formal and informal community-based services, volunteer efforts, and academic resources to strengthen the ability of the communities in the rural South to care for their elderly (Abraham, 1993).

Seniors Teaching Seniors Program- Trains older adults to become teachers, leaders, and organizers of a broad range of educational programs for their peers (Buonocore, 2002).

- Sport as a Social Intervention- Use of sports as an intervention method to encourage minorities, particularly African American youth, to improve their progress in school (Hartmann, 2003).
- Stay Well Program- Trained senior volunteers to conduct health promotion programs at senior centers, libraries, and other sites where older adults congregate (Buonocore, 2002).
- Targeted Outreach- A peer sponsored outreach program aimed at increasing minority's awareness and interest in student organizations. This technique was used by a peer counselor organization to recruit people of color (Garman, 1997).
- Tribal Connections Project A National Library of Medicine initiated community based outreach program that established or improved Internet connections on Indian reservations and Alaska Native villages to develop tribal access to health information available on the Internet (Wood, 2003).

#### **Endnotes**

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<sup>&</sup>lt;sup>1</sup> MiCASSA and HR 2032 and S 971, Medicaid Community-based Attendant Services and Supports Act.

<sup>&</sup>lt;sup>2</sup> The research project reviewed the outreach efforts of the following departments: The Departments of Education, Labor, Transportation, Justice, Health and Human Services, Housing and Urban Development and the Social Security Administration, Equal Employment Opportunity Commission, and the Federal Communications Commission. <sup>3</sup>A series of NCD reports documenting findings and recommendations on the Air Carrier Access Act (ACAA), the Individuals with Disabilities Education Act (IDEA), and the Americans with Disabilities Act (ADA). Each showed that despite great strides toward equality, people with disabilities still deal with major ongoing barriers of discrimination and the consequences of weak federal enforcement.