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ABSTRACT

This literature review discusses the need for rehabilitation organizations to become culturally competent and for rehabilitation research to reach and be utilized by minority populations. Sections address the incidence of disability in minority populations, the socially constructed nature of race, culture, and disability, cultural power and the perpetuation of inequity, cultural and other considerations that can influence effectiveness within the rehabilitation system, and characteristics of effective systems and relationships. Following suggestions for developing culturally competent organizations, recommendations for research are provided and include: (1) grounding decisions about research purposes and hypotheses in a thorough knowledge of potential user audiences; (2) examining assumptions inherent in the goals, hypotheses, and methods of the intended research; (3) exploring a variety of research methodologies; (4) defining all variables fully; (5) using sampling techniques that provide adequate representation among all targeted audiences; (6) structuring data collection activities to ensure an appropriate rate of return for all targeted subpopulations; (7) carefully considering within-group as well as between-group differences; (8) seeking input and feedback from representatives of target audiences in identifying data collection procedures and instruments, analyzing data, and drawing conclusions; and (9) using multiple dissemination strategies and media. (Contains approximately 115 references.) (CR)

Disability, Diversity, and Dissemination:

A Review of the Literature on Topics Related to Increasing the Utilization of Rehabilitation Research Outcomes among Diverse Consumer Groups

April 1999

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Disability, Diversity, and Dissemination: A Review of the Literature on Topics related to Increasing the Utilization of Rehabilitation Research Outcomes among Diverse Consumer Groups

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Introduction: Seeing and hearing "from a different position"

Linking disability research outcomes with the people who can use them is a complex task under any circumstance (NCDDR, 1997). The task is further complicated by, on the one hand, the enormous diversity in terms of broad demographic characteristics among people with disabilities and their families, and on the other hand, the relative homogeneity among rehabilitation researchers and service providers (Smart & Smart, 1997; Bradsher, 1995). Circumstance, race, culture, language, experience, and belief can influence people's access to information and services; their roles in and treatment by agencies and by other individuals; their goals for rehabilitation and independent living; and the kinds and sources of information they find to be credible and useful.

Communicating effectively — including both giving and receiving information, so that researchers and service providers clearly understand the needs and circumstances of those they seek to help, and so that consumers understand the uses, requirements, limitations, and benefits of research outcomes and rehabilitation services — is one of the most difficult elements in this equation. As the writer Hannah Arendt (1958, cited in Greene, 1993, p. 13) once observed, each person "sees or hears from a different position," and sometimes what individuals see and hear can diverge strongly.

Another way of considering this concern is to think of information as "culture specific." According to Cochrane and Atherton (1980, cited in Metoyer-Duran, 1991, p. 320) "the proper unit of analysis for considering information services in a culturally pluralistic society should be the 'cultural community,' which is composed of potential users who may have distinct values, beliefs, and attitudes towards external information services." Metoyer-Duran also quotes Menon's (1983) observation that, because information is culture specific it is, consequently, "largely uncommunicable unless it has been 'acculturated'" (p. 320). A major element in the dissemination and utilization process, then, is to find ways of "acculturating" information about rehabilitation research outcomes, a task that includes listening as well as speaking.

Such a task, in some ways at least, may sound deceptively simple: Gather information about a specific culture and tailor the resulting materials and media accordingly. However, there are a number of complicating factors, discussions of which will form the bulk of this literature review:

- Concepts of race, ethnicity, and culture are often intertwined and misapplied, and often in ways that result in stereotyped beliefs about groups and individuals.

- It is problematic to assume that minority groups share a common culture or other characteristics. Rather, it is important to look at subpopulations, seeking to identify commonalities and differences. As Bartolome and Macedo (1997) conclude, "We need to avoid the lumping of multiple identities into a monolithic entity such as race or ethnicity" (p. 224).

- The concept of culture refers not only to groups of people who can be distinguished by a common geography, bloodline, language, and/or set of customs. One can also speak of what Mason (1994) describes as "non-ethnic cultural groups," including, for example, "lesbians and gays, elders, women, people with disabilities, religious minorities, and others" (p. 1).

- As Sonia Nieto observes, "culture is often thought of as a characteristic rather than a process" (Kenyatta & Tai, 1997, p. 176). However, it is in reality fluid, constantly evolving.

- It is often difficult to sort out factors that are related to culture rather than to socio-economic status or other life circumstances.

- The issue of power — of institutionalized patterns of inequity that lead some groups to be subordinated to a dominant, "mainstream" group — is one of the greatest barriers to the development of a rehabilitation research and service system that is responsive to the needs of all people with disabilities. The volatility of this issue makes it extraordinarily difficult to examine and address.

Many reports addressing the topic of diversity consist primarily of lists and descriptions of characteristics that differentiate "minority" cultures from that of mainstream U.S. culture, and discussions of ways that researchers and rehabilitation professionals can become more sensitive to those differences. This review will address some of those descriptions. But a broader conceptual orientation is necessary in order to get to the most persistent barriers and misunderstandings.

As noted above, diversity is a broad concept. However, the rehabilitation-related literature on this topic is limited, particularly literature that is grounded in empirical research. Material that does exist focuses almost entirely on racial and ethnic groups rather than on "non-ethnic" cultural groups. The scope of this literature review, therefore, is largely restricted to discussions related to racial and ethnic diversity. Another limitation is the lack of systematic information about the characteristics and processes of rehabilitation research environments. Where the rehabilitation literature does address diversity issues, the focus is almost exclusively on service delivery, primarily via rehabilitation counseling. There is a small but growing body of material regarding the implications of cultural diversity for research and knowledge utilization in more general contexts, but little or none of this work specifically addresses the rehabilitation field.

Given the restricted research base, it is difficult to draw firm conclusions about many aspects of disability, diversity, and the dissemination process. Where possible, however, this report attempts to incorporate relevant information from other disciplines, particularly the literature on minorities and public health services, and educational and sociological inquiries into relations between minority and majority groups. And the report attempts to apply the available information to the process of linking rehabilitation research outcomes with potential users, suggesting implications for the activities of identifying research needs, designing and conducting research, disseminating research outcomes, and promoting the utilization of those outcomes among targeted users.

The scope of concern

Incidence of disability among minority populations

Race and ethnicity are among the factors that have "the strongest association with disability" (Smart & Smart, 1997, p. 13). Bradsher (1995) notes that, whether one is considering the overall disability rate in the United States, rates for people ages 15-64 (i.e., what is often considered "working age"), or rates of severe disability, African Americans and American Indians consistently have the highest rates of disability. Drawing on data from 1991-92, Bradsher reports the following statistics:

Percent of Americans with a disability/severe disability
1991-1992, by racial/ethnic group

	African American	American Indian	White	Hispanic Origin	Asian/Pacific Islanders
Percent with a disability	20.0	21.9	19.7	15.3	9.9
Percent with a disability, ages 15-64	20.8	26.9	17.7	16.9	9.6
Percent with a severe disability	12.2	9.8	9.4	8.4	4.9
Percent with a severe disability, ages 15-64	12.7	11.7	7.4	9.1	4.5

Source: Bradsher, J.E. (1995). Disability among racial and ethnic groups. *Disability Statistics Abstract*, 10, 1-4.

Bradsher also reports that women in each of these racial/ethnic groups, except for American Indians, have a higher rate of disability than men. However, when considering persons of working age, "there are no significant differences observed between disability rates for men and women aged 15-64, overall or within any racial/ethnic group" (p. 2).

Walker and Brown (1996), analyzing data from the National Center for Health Statistics, found African Americans and Hispanic Americans to be overrepresented in all disability categories, including chronic health conditions; physical, sensory, and language impairments; and nervous and mental disorders. Similarly Walker et al. (1996), using data from the 1990 federal census, report that although African Americans represent only 12.1 percent of the total U.S. population, they represent 14 percent of all persons with disabilities in this country. Among African Americans who have a disability, 71.8 percent have a severe disability, as opposed to only 52 percent of white Americans with a disability. In addition, 78.2 percent of African Americans with disabilities are unemployed or not working, and 41 percent are at or below poverty-level income. Among Hispanic Americans with a disability, 67.8 percent have a severe disability, and 27 percent live at or below poverty-level income.

Smart and Smart (1997) observe that "most Asians and Pacific Islanders do not fit the disability or socioeconomic profile of other minorities" (p. 10). However, recent immigrants, including Hmongs, Laotians, Vietnamese, and Cambodians, are exceptions; many of these are refugees and tend to be both poorer and less well educated than other Asians in the U.S. According to Leung (1996), "Asian Pacific Americans are the fastest growing population in the United States today, with the primary growth of the last decade due to immigration" (p. 2).

An examination of data on public health reveals similar disparities in risk rates between white and minority populations. For example, in announcing a new health initiative last year, the White House released the following statistics:

> Infant mortality rates are twice as high for African Americans as for white Americans. African American men suffer from heart disease at nearly twice the rate of whites. African Americans are more likely to die from breast cancer and prostate cancer. Overall, cancer fatalities are disproportionately high among both Latinos and Blacks. And Hispanic rates for diabetes are twice the national average; Native American rates are three times the national average. . . Asian Americans suffer from Hepatitis B in greater numbers than other groups. Vietnamese women are five times as likely to have cervical cancer, Chinese Americans four to five times as likely to have liver cancer. (Brooks, 1998, p. 11)

It is likely that race or ethnicity is not the root cause for the higher incidence of disabilities and chronic or life-threatening health problems among minority groups, but rather "is fundamentally a measure of exposure to health risks" (LaVeist, 1996, p. 24). As Ficke (1992, quoted in Smart & Smart, 1997, p. 13) warns, "It is important to note that the issue of causality between. . . demographic factors and disability often cannot be determined at all from the data."

LaVeist (1996) concludes that "at the core of race-associated differences in health status are social and political factors" (p. 23). McNeil (1993, cited in Smart & Smart) found that, among adults aged 25 to 64, the incidence of severe disability was 22.8 percent among persons who did not complete high school, but among college graduates, the rate was only 3.2 percent. Smart and Smart report that "African Americans, Hispanics, and Native Americans are consistently found to lag behind the general U.S. population in the number of years of school completed. . . This is also true of some subgroups of Asians and Pacific Islanders" (p. 12). Similar statistics can be cited regarding income levels among minority populations. Education, income, and discrimination (which often results in disparities in employment, education, and income) may be more primary influences on disability than race or ethnicity *per se.*

Inequitable treatment of minority populations

As the National Council on Disability noted in its report to the President and Congress (Wright & Leung, 1993), "Many minority persons with disabilities face discrimination on the basis of both minority status and disability" (p. 2). Considerable evidence exists that people with disabilities who are African American, Hispanic, American Indian, or Asian Pacific American do not have the same opportunities for assistance, employment, or income as their white counterparts. Findings from Section 21 of the 1992 Amendments to the 1973 Rehabilitation Act (quoted in Flowers, Edwards, & Pusch, 1996), conclude that:

> Patterns of inequitable treatment of minorities have been documented in all major junctures of the vocational process. As compared to White-Americans, a larger percentage of African-American applicants to the vocational rehabilitation system are denied acceptance. Of the applicants accepted for service, a larger percentage of African-

> American cases are closed without being rehabilitated. Minorities are provided less training than their white counterparts. Consistently, less money is spent on minorities than on their white counterparts. (p. 22)

These findings are supported by a series of studies conducted by the Howard University Research and Training Center for Access to Rehabilitation and Economic Opportunity (Walker & Brown, 1996; Walker, et al., 1996). One study found that "white clients tended to have more money spent on their program services than did any other group" (Walker & Brown, p. 31). Santiago, Villarruel, and Leahy (1996) conclude that "rehabilitation in the United States can be a very selective process whereby only individuals identified as being most likely to succeed are referred to, and participate in, services" (p. 11). Standards regarding who is "most likely to succeed" tend to be based on white, middle-class perspectives. For example, Locust and Lang (1996) describe an incident in which "an Indian man, dignified and proud of his long braids, was told that vocational rehabilitation services for him would not begin until he cut his hair" (p. 6). Smart and Smart (1992) describe a state rehabilitation program in which "Anglo clients are often asked if they would be willing to relocate in order to facilitate job placement, but Hispanic clients are routinely assumed to be unwilling to do so and, therefore, are not asked about the possibility of relocation" (p. 30).

LaVeist (1996) describes discriminatory treatment in medical care, noting that "several studies have demonstrated race differences in clinical diagnosis as well as race differences in the intensity of medical services provided for a similar diagnosis" (p. 26). Research on utilization of mental health services among minority populations reflects similar patterns of inequity. Ridley (1989, quoted in Leong, Wagner, & Tata, 1995; see also Mohr, 1998; and Yamashiro & Matsuoka, 1997) concludes:

> Compared to White clients, ethnic minority clients are more likely to receive inaccurate diagnoses; be assigned to junior professionals, paraprofessionals, or nonprofessionals rather than senior professionals; receive low-cost, less preferred treatment consisting of minimal contact, medication, or custodial care rather than individual psychotherapy; be disproportionately represented in mental health facilities; show a much higher rate of premature termination; and have more unfavorable impressions regarding treatment. (pp. 417-418)

Leong, Wagner, and Tata further note that "African Americans are disproportionately hospitalized" even though "studies have found no racial differences in the prevalence of psychological disorders among African Americans." They conclude that "the misuse of hospitalization for African Americans is probably due to clinician bias and/or problems in misdiagnosis (e.g., African Americans are more likely to be misdiagnosed as experiencing schizophrenia)" (p. 418).

Minority populations — particularly African Americans and American Indians — also are underserved by the national network of independent living centers (ILCs) (Richards & Smith, 1992; SEDL, 1997). In a survey of 32 independent living centers in six midwestern states (including Illinois and Michigan, states with substantial proportions of African Americans and other minority populations), Flowers, Edwards, and Pusch (1996) found that 58 percent reported having no plans or programs "focusing on outreach to culturally diverse consumers." Of those who did, only three ILCs stated that they "felt that their plans were effective" (p. 26). The centers reported serving more than 8,000 people in the preceding year. Of the approximately 4,600 for whom racial/ethnic demographic information was reported, 89 percent were listed as "Caucasian." African Americans, at seven percent, were the largest minority group served.

The ILC survey also found that fewer than 20 percent of the centers' administrative staff (which include clerical staff and office managers as well as executive and finance directors and other professionals) were identified as members of culturally diverse groups. Twenty-two percent of direct services staff were from "diverse cultural backgrounds," as were 12 percent of members of the centers' boards of directors.

In terms of employment, Leung (1993) reports:

> The statistical data for Blacks with disabilities indicates that while they constitute 19% of all persons of working age with disabilities, they constitute just 8.6% of year round full-time workers with disabilities. Similarly, Bowe (1992) indicates that adults with disabilities of Hispanic origin constitute 7.5% of all persons of working age who have disabilities, yet they are just 5% of year round

> full-time workers with disabilities. . . James et al (1993) utilizing data from the National Spinal Cord Injury Statistical Center, found that Black persons with SCI were less likely to be employed than their White counterparts. (p. 94)

Walker and Brown (1996) found that, in three of four major categories of disability, "African Americans had the highest proportion of persons who were not in the labor force. Hispanics were also hard hit by unemployment" (p. 30). The authors also found a "consistent tendency for minority persons across disability categories to be at the bottom of the economic ladder and for whites to be at the top" (p. 29). Seelman and Sweeney (1995), in discussing the fact that people with disabilities tend to have lower incomes than nondisabled people, observe that "White persons with disabilities are generally in the low income ranks ($18,000), but not as destitute as Hispanics ($12,000) or African Americans ($8,000), whose family income levels fall below the poverty index reported in the latest census ($12,091)" (p. 3).

Some studies indicate that collateral factors such as education and income may contribute to differential treatment. Santiago, Villarruel, and Leahy (1996) conducted a "pilot survey" of 124 disabled working-age Latino adults in 1990-91 and found that "respondents who were high school graduates had 4 times higher odds of receiving MRS (Michigan Rehabilitation Services) services than respondents with less than high school degrees" (p. 15). Similarly, a study by the Howard University Research and Training Center found that "clients with higher education levels and more economic independence at program entry had higher weekly earnings at closure and had more services provided to them during the program" (Walker & Brown, 1996, p. 31). As noted earlier, it is important to keep in mind that minority populations, whether disabled or nondisabled, continue to face discrimination in both education and employment.

Although most of the data regarding the treatment of specific populations within the rehabilitation system focus on racial or ethnic minorities, there is some evidence that women suffer inequitable treatment as well. Westbrook, Legge, and Pennay (1995) conclude that:

> Compared to men with disabilities women are more likely to be stigmatized, have poor self concepts, be unmarried, condemned for having children, left by their partners following disablement and denied access to education, employment, and financial assistance. . . Discrimination against women with disabilities is also apparent in health care. Research. . . has indicated that such women are less likely than men to receive rehabilitation. (p. 26)

The socially constructed nature of race, culture, and disability

At the core of this literature review is a consideration not only of the differences among people, but of the ideas humans construct about those differences, the ways in which those who fit most easily into the dominant culture of U.S. society tend to value and devalue certain differences, and the impact of the dominant cultural perspective on minorities with disabilities. Such a consideration must begin with an understanding that the very definitions of terms like *culture, race,* and *disability* are grounded in a particular time, place, and perspective. Rather than mirrors that precisely reflect reality, definitions of these terms and ideas about them are imperfect human constructs (Kenyatta & Tai, 1997; Scheurich, 1993).

Concepts of race, ethnicity, and culture

Defining culture. The term *culture* has been defined as "a learned system of meaning and behavior that is passed from one generation to the next" (Carter & Qureshi, 1995, p. 241), and as "all the customs, values, and traditions that are learned from one's environment" (Sue & Sue, 1990, cited in Sodowsky, Kwan, & Pannu, 1995, p. 132). According to Sodowsky et al. (1991, cited in Sodowsky, Kwan, & Pannu, 1995) in every culture there is a "set of people who have common and shared values; customs, habits, and rituals; systems of labeling, explanations, and evaluations; social rules of behavior; perceptions regarding human nature, natural phenomena, interpersonal relationships, time, and activity; symbols, art, and artifacts; and historical developments" (p. 132). Culture, then, acts as "a unifying influence. It combines the different aspects of life into a logical whole" (p. 132).

Cultures are constantly evolving in response to changes in the environment; as Venkatesh (1995, p. 30) notes, "no culture stands still." Moreover, because culture is a learned phenomenon, "individuals and groups can and do change their ethnic or cultural identities and interests through such processes as migration, conversion, and assimilation or through exposure to modifying influences" (Smedley, 1993, quoted in Carter & Qureshi, 1995, p. 241). In bicultural or multicultural contexts, such as are prevalent in the United States, the interaction between cultures often acts as a modifying factor. Life events, psychological characteristics, and other factors also can mediate cultural influences.

Harry (1992) argues that the most important thing to understand about culture is that "standards of social behavior are culturally derived." She also observes that "the closer one is to one's original culture, the harder it is to recognize the culturally specific, rather than universal, base of accepted norms for behavior" (p. 57).

Defining "race" and "ethnicity." The concepts of race, ethnicity, and culture are sometimes used to describe the same things. Wright, et al. (1983, quoted in Harry, p. 5) attempt to distinguish among these terms: "Ethnic groups will be so defined if they share a common sociohistory, have a sense of identity of themselves as a group, and have common geographical, religious, racial, and cultural roots. The central core of each ethnic group, welding it together with the thread of belief, styles of being, and adapting, is culture. . . Race is, at this point, a dubious biological designation" (p. 13). Tatum (1997), in supporting this last point, notes that "race is a social construction. Despite myths to the contrary, biologists tell us that the only meaningful racial categorization is that of human" (p. 16).

A number of scholars in the fields of sociology and education discuss the particular function of the concept of race in the United States. Takaki (1993) points out that, in the U.S., race "has been a social construction that has historically set apart racial minorities from European immigrant groups" (quoted in Kenyatta & Tai, 1997, p. vii). Harry observes that, in this country, "the use of the term *minority* essentially represents an attempt to categorize by race, not by culture. Yet the specifics of race are only important on one dimension: whether one is White or not" (p. 3). Analyzing the racial categories used by the U.S. Office of Civil Rights (OCR) and other institutions, she notes that:

> the U.S. interpretation of White [is] as a pure, unmixed racial group, so that to be, for example, one-quarter Black is to be Black, while a person who is one-quarter White would also be Black. While Latin American and West Indian societies, which also share the history of slavery, have built into their view of race the fact of racial mixture, the U.S. interpretation reflects the enduring legacy of a much more oppressive form of the institution of slavery. (p. 47)

Harry analyzes "the political aspects of racial classification" (p. 5), observing that the OCR classifications mix geographic and racial features in ways that seem logically inconsistent but that support the conception of *white* as both racial and geographic (i.e., European):

> The corollary "regardless of race" attached to the definition of Hispanic reflects the anomalous character of this group. The category Asian or Pacific Islander, for example, clearly includes a mixture of racial groups, yet the classification system does not specify "regardless of race" for this group, presumably because Whites are not likely to be among them. . . It is not required, then, to distinguish between the dramatically different racial characteristics of people from India and China. . . Nor does the category Black (not of Hispanic origin) reflect any more logic, since many Hispanics from Caribbean and Central American territories have origins in the Black racial groups of Africa. (p. 6)

The U.S. Office of Management and Budget, responding to concerns about racial classification, recently revised its standards for classifying federal data on race and ethnicity. The new standards set five categories for data on race, including (1) American Indian or Alaska Native, (2) Asian, (3) Black or African American, (4) Native Hawaiian or other Pacific Islander, and (5) White. A separate designation for data on ethnicity includes two categories: (1) Hispanic or Latino, and (2) not Hispanic or Latino. According to these standards, respondents are to be encouraged to select multiple racial categories where appropriate. In modifying the standards, OMB (1998) notes that:

> The racial and ethnic categories set forth in the standards should not be interpreted as being biological or genetic in reference. Race and ethnicity may be thought of in terms of social and cultural characteristics as well as ancestry. (p. 2)

Several scholars note the increasing tendency to substitute *ethnicity* for *race*. Kenyatta & Tai (1997) conclude, "Some researchers and educators use ethnicity interchangeably with race because, we believe, they are still uncomfortable with race, racism, and its role in education" (p. vii). Margaret Andersen, a panelist in a forum on education and ethnicity, also questions this exchange of terms:

> The caution I would put forth. . . is that in abandoning the concept of race, there is a serious tendency to abandon discussions of power, domination, and group conflict. . . I cannot help but notice in works on ethnicity how quickly the discussion there turns to matters of culture and identity, not at all to questions of economic exploitation, political power, and powerlessness. (Kenyatta & Tai, p. 177)

The term *race* provides a good example of the difficulties in determining appropriate terminology to apply in describing particular groups. Some authors note that the word lacks meaning in terms of the physical or biological differences implied in its common usage, while others argue for the term's political and sociological importance. Perhaps the critical point is the necessity to recognize and make explicit the purposes and assumptions that are bundled into the use — or avoidance — of such words.

Disability as a socially constructed concept

Disability, like *race, ethnicity,* and *culture,* is a term whose definitions are culturally derived, even though its meaning in the U.S. has been given what Harry (p. 113) calls "transcendent status." Luft (1995) observes that "disability categories are primarily defined according to middle-class developmental norms" (p. 3). The significance of such norms, she notes, "is in their impact on the procedures used by social institutions in providing services — procedures that tend to be predicated on the clients or recipients behaving according to cultural expectations and standards" (p. 9). Harry concurs; in discussing the concept of disability inherent in the Education for All

Handicapped Children and other federal law, she states:

> Professionals interpret the model [of disability] inherent in the law as actually transcending culture. They come to believe that the definitions of disability deriving from the technological culture of the United States in fact represent universal truths. (p. 237)

Harry concludes that one reason for the assumed universality of ideas about disability contained in U.S. law, policy, and procedures is "its base in the highly esteemed science of medicine." This same esteem leads to the assumption that experts "hold the keys to truths regarding the conditions and needs" of children with disabilities (p. 113) — an assumption that often devalues the perceptions and understandings of the individual, family, and community.

Harry, Luft, and other scholars are not attempting to argue that disabilities do not exist, or even that all responsibility for individual limitations rests with the external environment. However, they do observe that the conditions included in the term *disability* vary in different contexts, and that diagnosis of specific conditions is often subjective and culturally derived, as are judgments about the severity, impact, and appropriate response to those conditions. As Smart and Smart (1997) conclude, "Disability is not caused by disease and injury alone, but is also related to the way in which institutions define and diagnose disability" (p. 12). The following examples illustrate their point:

- Smart and Smart (1997) note that "there is no uniform definition of disability since government agencies define disability differently. . . Further clouding the picture, some health demographers do not define disability as completely as do rehabilitation demographers," excluding for example, conditions such as alcohol abuse and learning disabilities (p. 10). The authors also cite a 1993 study which found that "in Alaska, only 3% of all special education students were classified as retarded, yet, in Alabama, 23% were considered retarded" (p. 12).

- "The arbitrary nature of the term *mental retardation* was dramatically demonstrated by the American Association on Mental Deficiency (AAMD), in its radical revision of the definition from an IQ cutoff point of 85 to a mere 70. Overnight, the population of mentally retarded persons was cut by 13 percent" (Harry, 1992, p. 144).

- "Between the years 1978 to 1990 the category of Learning Disabilities grew dramatically, Emotional Disturbance increased slightly, and numbers of children with Speech and Language Impairments, Hearing Impairments, and Mental Retardation gradually decreased" (Luft, 1995, p. 11).

- Shacht (1997), reporting case history information collected by the American Indian Rehabilitation Research and Training Center regarding American Indian consumers from five states, could not account for the following differences: "The distribution of *Reported Disabilities* varied in unexpected ways [among the 121 cases]: arthritis and rheumatism, and Alzheimer's disease were reported mainly from South Dakota; learning disabilities and emotional/mental disorders were reported mainly from California; various orthopedic disorders and diabetes mellitus [were] reported mainly from Texas; and paraplegia was reported mainly in Arizona" (p. 10).

The ways in which individuals, families and cultures perceive and accommodate disabilities also vary significantly. For example, in their study of young Latino men with disabilities, Santiago, Villarruel, and Leahy (1996) report that "only 37 percent of the 124 respondents in this investigation viewed themselves as having a severe disabling condition. Yet, when the information from the MRS screener was reviewed, 56 percent of these persons were considered to have a severe disabling condition" (p. 16). Schensul (1992), in a study of Alzheimer's disease among elderly Puerto Ricans in the U.S., notes that "elderly Puerto Ricans are aware of the symptoms of cognitive loss and behavioral change [associated with Alzheimer's disease] but tend to view them as normal" (p. 26). And Locust (1988, cited in Harry, 1992, p. 81) "points out that the prevalence of a congenital hip deformity observed among the Navajo is not considered disabling, while surgery to correct it may create a disability because it tends to make riding a horse uncomfortable."

Cultural power and the perpetuation of inequity

Systems of advantage and disadvantage

The common assumptions in U.S. society regarding race, culture, and disability take on greater importance when the issue of power is added to the equation. The idea that one group is dominant while others are subordinate, that "systematic advantage and disadvantage" (Tatum, 1997, p. 9) are prevalent in the United States, is not only abhorrent to most Americans; to many individuals, it may seem unbelievable. (Based on individual experience, some people may believe that disparities are real across one dimension, such as disability, but not across others, such as race or social/economic class.) However, it is a basic sociological principle that societies stratify their members in terms of "power, resources, and status" (Pilisuk, McAllister, & Rothman, 1996, p. 16). An increasing number of scholars and researchers — including sociologists employing "network-analytic" research methods (Stanton-Salazar, 1997) — have begun to examine the ways in which such dominance permeates institutions and relationships in this country, while remaining "invisible" to many members of the dominant group (Scheurich & Young, 1997, p. 12; see also Duarte & Rice, 1992; MacIntosh, 1990; and McLaren, 1995).

Delpit (1995) asserts that inherent in issues of race, culture and class are issues of power. "Those with power are frequently least aware of — or least willing to acknowledge — its existence," while members of subordinate groups are acutely conscious of the disparities (p. 26). Scheurich (1993; see also Maher & Tetreault, 1997) observes that the longer one group is dominant, the more effectively "the styles of thinking, acting, speaking, and behaving of the dominant group. . . become the socially correct or privileged ways of thinking, acting, speaking, and behaving" (p. 7):

> The ways of the dominant group become universalized as measures of merit, hiring criteria, grading standards, predictors of success, correct grammar, appropriate behavior, and so forth, all of which are said to be distributed as differences in individual effort, ability, or intelligence. Membership in a social group and group-related, inequitable distribution of resources and power thus disappear under the guise of individualism. (p. 7)

The pervasiveness of the mainstream American belief in individualism acts as an extremely powerful filter. As Scheurich (1993) describes it:

> Among Whites, the idea that each person is largely the source or origin of herself or himself, that is, individualism, is considered a natural facet of life. Within the frame of this belief, individualism is seen as a naturally occurring, trans-historical, transcultural condition to which all humans naturally aspire. (p. 6)

Stanton-Salazar (1997); (see also McIntosh, 1990; Scheurich, 1993; and Tatum, 1997) characterizes this belief "not only as mythical and extremely simplistic, but also ideologically geared to preserve the status quo" (pp. 6-7). Rather, he observes, children "are raised embedded in social networks" that can either "systematically engineer their advantage" or "undermine the support flowing from family and community sources" (p. 31). Emphasizing the importance of "institutional agents" such as teachers, mentors, and advantaged peers, he concludes:

> The ideological cloak of individualism serves to obscure how the formation of supportive ties to institutional agents. . . rests on knowledge of, facility with, and deference to the cultural rules, communicative conventions, and network orientations that together are rooted in the social character and ethos of the dominant group. (p. 31)

Racism and "the cloak of individualism"

As McLaren (1995) concludes, "Power relations may not always have a conscious design, but they have unintended consequences which define deep structural aspects of oppression" (p. 53). Moreover, some authors note the convenience of the mainstream belief in individual merit. Delpit (1995) observes, "To act as if power does not exist is to ensure that the power status quo remains the same" (p. 39). Those who reap the tangible benefits of privilege have little apparent reason to question what has always been assumed to be true (Tatum, 1997). And, as constructivist learning theory posits, "In order to take on a new viewpoint, one must decide to let go of an old one. There must be a reason to decide to make a shift in thinking" (Shapiro, 1994, p. 7).

Scheurich and Young (1997), among others, discuss the ways in which the individualist perspective within U.S. culture works to obscure racism and to "keep the thinking about equality or equity incomplete" (McIntosh, 1990, p. 36). The fact that "racism in the U.S. is overwhelmingly seen as an individual phenomenon" (p. 5), they conclude, helps to explain why many mainstream Americans so strongly believe that racism is a limited problem, and react with confusion and hurt when others describe them as part of the problem. Most people do not consider themselves racist; they may, in fact, speak and act against racism. However, Scheurich and Young point out that:

> While. . . individualized, conscious, moral or ethical commitment to antiracism is a significant and meaningful individual and historical accomplishment, the fact that it restricts our understanding of racism to an individualized ethical arena is a barrier to a broader, more comprehensive understanding of racism — for society and for researchers. (p. 5)

Scheurich and Young have identified five categories of racism. The first two, "overt racism" and "covert racism," can be defined "as operating at the individual level." "Institutional racism" and "societal racism" are "organizational and social categories" that "create the social context" for individual racism. The fifth category, "civilizational racism," is one which "creates or constitutes the possibility for all of the prior four categories" (p. 4). At institutional and societal levels, racism tends to operate almost invisibly, "like smog in the air" (Tatum, 1997). Differential treatment results not (necessarily) from the conscious intentions of specific individuals, but from the unexamined agreement that "the practices of the dominant group" represent the norms and standards "to which all others must strive" (Aronowitz, 1997, p. 192).

Many scholars and social commentators point out that, in spite of the changes in law and mores in the past four decades, racism persists in all its forms (Lubiano, 1998; West, 1993). Although many mainstream white Americans tend to view violence such as the 1998 murder of James Byrd in Jasper, Texas, as aberrations, such events are, rather, fostered by the less extreme, more covert forms of racism that permeate U.S. society (Scheurich & Young, 1997).

Inequities and the rehabilitation system

Much of the discussion about institutionalized patterns of dominance and subordination is couched in broad social terms. Given the statistics regarding the incidence of disability and imbalances in assistance to consumers, there is no reason to believevom such systematized inequities. Moreover, any efforts to improve outreach to minority populations must consider the cultural and other contexts in which those efforts are embedded.

A few authors have focused specifically on the systems and institutions intended to assist people with disabilities. Duarte and Rice (1992) for example, conclude that "dominant cultural values related to individualism, self-reliance, and work are evident in rehabilitation legislation, policies, and procedures" (p. 12). Similarly, Harry (1992) notes that "the Education for All Handicapped Children Act couches its mandate in concepts that are uniquely Western, both in terms of a medical model of disability and of a framework of services derived from a technological culture" (pp. 23-24).

Schaller, Parker, and García (1998), in discussing rehabilitation counseling services, observe that the meaning of disability may be constructed differently within different cultures. Yet, "despite a growing recognition of a more comprehensive, environmental conceptualization of disability, rehabilitation counseling continues to use definitions of disability based on pathological and statistical models" (p. 41). They further note that:

> Statistical identification of disability lends an air of objectivity in conclusions based on parameters of normalcy defined by a given group. Both the pathological and statistical models of disability, by definition, limit perceptions and interpretations of disability. (p. 41)

Alston and Bell (1996; see also Mohr, 1998) caution that "one attitude that African Americans with disabilities may bring to the rehabilitation process is cultural mistrust" (p. 17). They note that such mistrust is frequently based on negative experiences that African Americans consumers have endured in seeking assistance from the rehabilitation or other service systems. Harry (1992) cites several researchers who have observed "that among low-income Black families, the experience of frequent intrusions by social service workers also contributes to mistrust and unwillingness to cooperate with service providers" (p. 51). She further notes that, "with regard to more ambiguous or mild [disabilities], it has been observed that many African Americans have enduring and well-founded concerns about being misdiagnosed and treated inappropriately by mental health services " (p. 53).

Cultural and other considerations that can influence effectiveness within the rehabilitation system

The complexities of identifying cultural characteristics

Discussions of what are commonly labeled as "cultural differences" between specific groups are inevitably problematic. Most authors focus on what Mason (1994) terms "ethnic cultural groups." "Minority" populations tend to be grouped into the broad categories that, in the U.S., generally are used as racial designations — typically, African American, Hispanic, American Indian, and Asian Pacific American — despite the fact that the categories jumble geographic, racial, ethnic, and cultural characteristics. These groups are contrasted with "mainstream U.S. culture," which is (often implicitly) considered to be white, affluent, and native-born. Race, culture, language, economic and social status, and religious beliefs often are intermingled without explicit consideration of their distinctions or relative importance.

Authors who describe cultural differences generally note that, within each broad category, groups and individuals do vary in terms of nationality, language, religion, and other characteristics. Leung (1996), for example, identifies 47 different cultural groups within the broad category of Asian Pacific Americans. Many also point out that culture is only "one of several significant variables" that influence human interactions (Duarte & Rice, 1992, p. 42). Some reports address other considerations as well, as the following sections describe.

Acculturation. Most authors emphasize that "traditional patterns in all groups may be affected significantly by acculturation" (Harry, 1992, p. 55). Leung (1988, cited in Harry) identifies six factors that appear to most strongly influence acculturation, including "time in the host culture; proximity to the traditional culture, which. . . deters the acculturation process; age; birthplace; gender, with females being more open to acculturation than males; and intermarriage" (Harry, p. 14). To this list Harry adds "the variables of social class and educational level" (p. 14).

Several studies describe frameworks for levels of acculturation; though these vary somewhat, they all outline a continuum moving from immersion in one's traditional culture through a bicultural or "dualistic" orientation to immersion in or accommodation to the host culture, with the last stage variously described as "atraditional" (Ramirez & Castañeda, 1974, cited in Harry, p. 14) or "overacculturation" (Leung, 1988, cited in Harry, p. 14). Soriano (1995) distinguishes between acculturation and assimilation, characterizing *acculturation* as biculturalism, or the capacity to function in both the traditional and the host or mainstream culture, and *assimilation* as absorption into the mainstream.

Immigrant vs. indigenous groups. Harry observes that "the concept of stages of acculturation is more difficult to apply" to African Americans, "whose native culture was forcibly undermined by slavery, with no allowance for a period of continuing traditional belief and practice" (pp. 14-15). Similar problems apply in considering American Indians and their relationships to mainstream U.S. culture, and some Hispanics as well, since many Mexican Americans have deeper roots in U.S. soil than most white Americans.

Ogbu (1992), among others, has conducted research exploring differences among immigrant and indigenous minority cultures in the U.S. He distinguishes among "autonomous" (for example, some Mormon and Jewish immigrants), "immigrant," and "caste-like" minorities, characterizing the first two groups as "voluntary" and the third group as "involuntary" minorities. Ogbu theorizes that voluntary minorities, believing in the possibility of improving their lives in the United States, are more likely to succeed in school and society than are caste minorities who, experiencing persistent discrimination, "tend to try to preserve linguistic and cultural differences as symbolic of their ethnic identity and their separation from the oppressive mainstream culture" (cited in Minami & Ovando, 1995, p. 438). A recent study of immigrant children includes findings that reinforce Ogbu's work. The study takes note of students' "rising awareness 'of the ethnic and racial categories in which they were persistently classified by mainstream society'" (cited in Dugger, 1998, p. A11). Researchers found that study participants who began to identify themselves by ethnic categories such as Chicano or Latino had lower grades and higher dropout rates than other participants. This finding "lends support to analysts who have suggested that children of immigrants who come to identify with American minorities may take on 'oppositional' identities" (Dugger, p. A11).

Some researchers, however, argue that Ogbu's categories "are painted with too broad a brush stroke" (Zentella, 1997, p. 272). Valdés (1997), in discussing children of Mexican origin, notes that both voluntary and involuntary minorities "exist within this single population" (p. 406). Zentella makes a similar observation regarding students she studied in a Puerto Rican neighborhood in New York City, noting further that "any model that polarizes accommodation and resistance cannot capture the ways both coexist in the daily lives" of the students she observed (p. 273). Trueba (1989, quoted in Harry, 1992) also criticizes Ogbu's framework for "its inability to account for the success of many so-called caste-like minorities" (p. 20).

Racial identity development. Considerations of assimilation and of immigrant and indigenous minorities also must take race into account. Harry cites work by Spener (1988), who points out

> that the racial background of immigrants is important because, after the "outward ethnolinguistic markers" are no longer evident, racial differences are. Consequently children of immigrant racial minorities remain minorities, while the children of White immigrants become part of the majority. (Harry, p. 17)

Some researchers, particularly those focusing on African Americans, emphasize racial rather than cultural identity, with cultural considerations being subsumed within those of race. Alston, Bell, and Feist-Price (1996) describe racial identity in terms of four dimensions:

> Racial identity development may be defined as the process through which an individual examines the *psychological* (sense of belongingness and commitment), *cultural* (awareness, knowledge, and acceptance of cultural and social traditions), *physical* (acceptance of physical features of the racial group) and *sociopolitical* (attitudes toward social and economic issues of the racial

> group) aspects of being a member of one's racial group along with the value and emotional significance associated with that membership. (p. 11)

A psychological theory of African American racial identity development described by Cross (1995) is frequently used as a framework for discussions of racial identity. This theory describes "the psychology of becoming Black" (p. 94), a multi-staged process through which individuals move "in the transformation of . . . a nonAfrocentric identity into one that is Afrocentric" (p. 97). This theory has been adapted and applied not only to other minority populations, but also to considerations of racial identity development among whites (Cross, 1995; see also Tatum, 1997).

Distinguishing cultural factors from socioeconomic status. Many scholars discuss "the danger of confusing culture with socioeconomic level," observing that "much of what is thought to be culturally derived is actually a result of economic conditions" (Smart & Smart, 1992, p. 31). As an example, Harry points out that "the stereotype of the absent Black father is tied to economics and class rather than being characteristic of African Americans as a whole" (p. 49). Some reports on cultural differences that influence the effectiveness of rehabilitation services discuss the need for programs that are easily accessible (meaning, in this instance, located within the client community), that offer flexible service hours, or that offer assistance with child care (see, for example, Duarte & Rice, 1992; Flaskerud, 1986). While these are important considerations in improving access to services, they are a function of socioeconomics rather than of culture. Smart and Smart conclude:

> Poverty may lie at the root of many behaviors which could be misdiagnosed as having an internal locus. . . Upon closer inspection. . . it becomes apparent that "free" services are costly when the client must leave work, pay for childcare, pay transportation costs, and provide an interpreter, all problems with an economic basis rather than a cultural or psychogenic basis. (p. 32)

Some writers have suggested that the condition of poverty itself has given rise to a distinctive cultural group. As Luft (1995) describes it, poverty "frequently is viewed as a distinctive subculture of American life, and one that carries with it an intergenerational cycle" (p. 13). However, McLemore (1994) reports that "most of the research conducted to determine whether poor people do, as claimed, possess a specific, distinctive culture has not supported this idea." He further notes, "Many critics see the culture of poverty thesis. . . as an elaborate way to shift the responsibility for social change away from the majority and onto the shoulders of the minority," a process characterized as "blaming the victim" (p. 342).

Facing the dilemma. Given the complexities described above, most authors acknowledge the severe limitations of cultural characterizations but then proceed to make them. The dilemma lies in the question posed by Tatum: "How can I make the experiences of my Latino, Asian, and Native students visible without tokenizing them?" (p. 132). She concludes, as do most scholars pursuing this topic, that "a sincere, though imperfect, attempt to interrupt the oppression of others is usually better than no attempt at all" (pp. 132-133).

Descriptions of mainstream culture in the United States

As noted earlier, the norms and beliefs of mainstream U.S. culture shape the organizational goals, policies, norms, procedures, and interactive styles of most organizations and institutions in this country. Very few reports, however, attempt to profile these characteristics except as they contrast with characteristics identified for other cultures. As is true with other broad cultural categories, "mainstream U.S. culture" is an encompassing term that belies the diversity of those it includes. Descriptions of what it means to be "in the mainstream" generally refer to white, middle-class Americans. Other significant characteristics are often mentioned as well, as the following sections discuss.

"Whiteness." Though a person does not necessarily need to be "white" to participate in mainstream U.S. culture, characteristics of those in the mainstream are inextricably tied to that dubious but powerful racial designation. Maher and Tetreault (1997), citing Thompson et al., attempt to make sense of this apparent paradox by

> distinguishing among "Whiteness as description," referring to the assignment of racial categories to physical features, "Whiteness as experience," referring to the daily benefits of being White in our society, and finally, "Whiteness as ideology," referring to. . . beliefs, policies, and practices. (p. 324)

Individualism. The literature describes *individualism* as one of the most dominant values operating in mainstream U.S. culture. Rehabilitation counseling and the work of independent living centers, for example, focus on the individual with a disability; services, procedures, and rules are geared to that person. However, Leung (1993) notes that "one of the common elements in the value/belief systems of all four major minority groups is the emphasis on the group, rather than the individual" (p. 96). With a "collectivist" rather than an individualist orientation (Gudykunst & Ting-Toomey, 1988, p. 40), decisions may be based on the needs of the family group rather than on those of one particular member. Hong (1995), in discussing Asian Pacific cultures, describes this orientation as *familism:*

> As opposed to individualism in Western cultures, Asian cultures are focused on the family. . . The idea of familism prescribes that the family is more important than the individual. The welfare of the family takes precedence over the welfare of the individual. (p. 60)

The focus on the individual functions not only as a goal but also as an explanation for differences in status and achievement. As discussed earlier, individualism helps to mask social inequities by attributing "success" and "failure" to the behavior and characteristics of each person rather than to patterns of access and opportunity (Scheurich & Young, 1997; Harry, 1992). The pervasiveness of this belief is illustrated in the results of a study by Connor (1988), who examined the approaches used in health promotion and disease prevention programs in a number of western and eastern countries. Connor found that:

> The U.S. programs emphasize changes that the individual is supposed to make in his or her behavior; success or failure is very much dependent on individual effort. Likewise, attributions for success or failure are focused on the individual (good personal will-power, in one case; lack of conviction or self-control in the other), as are the outcomes of success or failure (an improved or diminished self-confidence, for instance). (p. 182)

This orientation contrasts strongly with approaches used in other countries. For example, Connor observes, "In Western European countries, the medical model is mixed with and sometimes superseded by a public health model with more focus on groups and communities and much less on individuals" (p. 182). In eastern countries, there is "a strongly individualist focus, in that different balances are appropriate for different individuals." However, this perspective is

> mixed with a strong community focus, in that complex belief systems surround activities of daily life. . . The respect for individuals which is a part of these systems is very different from the respect for individuals that characterizes the western approach, particularly the strongly-individualistic U.S. approach. Individuals in the Eastern view have limited power to change their current situation; individuals in the Western view are seen as nearly allpowerful in changing their current situation. (p. 183)

High vs. low context. Duarte and Rice (1992) note that the literature of intercultural communication emphasizes "cultural differences related to context," which they characterize as "the information that surrounds events" (p. 17). Harry (1992), among others, cites Hall (1977), who "used the concept of 'high- and lowcontext' cultures to describe the potential of the law in various societies to address human issues in a more or less personalistic manner." Mainstream U.S. culture "is, in comparison to that of many other countries, markedly 'low-context' in its reliance on positivistic criteria for truth and in its tendency to exclude and treat as irrelevant the complexities of human perception and personal interaction" (pp. 111-112). In this country laws, policies, procedures, application criteria, and other requirements are designed to be "low context," independent of circumstance and equally applicable to the full spectrum of the populations addressed. The intent of such an approach is often fairness, for example, stating job requirements as concretely as possible so that all applicants are judged according to the same criteria and none receives preferential treatment. But since mainstream cultural standards are embedded in these requirements, as well as in the expectations and perceptions of the gatekeepers who apply them, the rules become skewed toward those in the mainstream (Scheurich & Young, 1997; Tatum, 1997).

The concept of low versus high context also applies to communicative styles, particularly in organizational or service settings. Harry explains that,

> In high-context communication there is a tremendous reliance on personal delivery, which may include affective as well as factual information, thus making meaning dependent on personal interaction. By contrast, low-context communication relies, according to Hall, on the actual language code isolated from the interpersonal aspects of communication. The goal of this form of communication is a high level of objectivity — on the assumption that such objectivity reflects greater precision in meaning. The latter will only be true, however, if both parties in the communicative act hold shared meanings of the language being used. (p. 172)

Harry further notes that members of the mainstream culture who work in service settings tend to combine a casual, informal style of greeting and speech with a lowcontext, impersonal approach to the content of the conversation. For members of most non-mainstream cultures, "an underlying commonality is a frequent discomfort with the informal and egalitarian approach typical of most White Americans." She recommends that those in professional settings, at least initially, should "approach culturally different families in a polite and more formal manner. . . . while striving to create communication that is personal rather than impersonal" (p. 57).

Valuing reason, science, and technology. Haymes (1995) and others note the emphasis in mainstream U.S. culture on rationality, the positivistic pursuit of scientific "truths," and technological advancements. These beliefs exert a particularly strong influence on approaches to rehabilitation and education (Schaller, Parker, & García, 1998; Scheurich, 1993; Duarte & Rice, 1992).

Attitudes regarding disability. As suggested above, attitudes about the causes and appropriate responses to disability within mainstream U.S. culture are strongly influenced by beliefs in individualism, rationality, and science. The medical model, which is structured to identify "disease" and treat it largely in isolation from other aspects of a patient's life, permeates mainstream perspectives regarding disability (Connor, 1988; Duarte & Rice, 1992; Harry, 1992).

Descriptions of "ethnic cultures" in the U.S.

African Americans. Considerations of culture within the broad category of *African American* are extremely complex. Most African Americans have a long ancestry in the U.S. (Takaki, 1995). For many, however, their position in U.S. society is marginal to that of the mainstream. At the same time, links to their cultures of origin have been attenuated (McLemore, 1994). In addition, African Americans are diverse in terms of education, economic status, religious belief, degree of urbanization, and other characteristics (Tatum, 1997). Lubiano (1992) observes that:

> In our attention to the history of racism in the United States, African Americans have learned to keep in our memory the unrelenting attacks on our existence as a group. . . But blackness is simply too large and unelaborated a category to carry the weight of analysis. (p. 346)

While it is inaccurate to speak of "Black culture" in monolithic terms, African Americans tend to remain in touch with what Lubiano (1992) describes as "a conscious awareness of being part of a group. . . with a particular place in history and a political relationship to other groups within the. . . United States" (p. 330). In addition, some African Americans share affiliations and worldviews that are grounded in elements of traditional African cultures, Protestantism, and adaptations to the experiences of indenturehood, slavery, and subordination in U.S. society (Takaki, 1995; Harry, 1992). Cross (1995), in discussing racial identity development, observes that not all African Americans develop a Black identity. For those who do, however,

> Having a Black identity means that the reference group functions of one's identity are grounded in one's Blackness. . . One's values, cultural preferences, artistic tastes, leisure activities, cooking styles and food choices, secular and religious musical tastes, church affiliation, organizational memberships, and social network or intimate friends are all influenced by one's perceived connection to Black people. In brief, some or a great deal of the meaning and hope one has for living a purposeful life is linked to one's perception of oneself as an African American. . . Whether it is mingled with other identities or singular, being Black plays an important reference group function in the daily life of the person. (p. 119)

Jackson and Sears (1992, cited in Leung, 1993) describe an "Africentric" worldview as characterized by a "group orientation, collective responsibility, cooperation, and interdependence" (Leung, p. 96). Similarly, Harry notes that Protestantism within Black culture "emphasizes group solidarity and collectivity" (p. 48). McLemore (1994) cites a number of sources that emphasize the importance of extended families, noting that "accumulating evidence supports that the extended family, rather than the nuclear family, is the proper unit of analysis" for studies of African American families (p. 328). He reports that "regardless of income level, African Americans are significantly more likely than white Americans to have extended family members living in the household" (p. 330).

In terms of attitudes regarding disability, studies suggest that many African Americans attribute "significantly more importance to spirituality in causing and treating" developmental and other disabilities. Instead of, or in addition to, seeking help through medical or rehabilitation systems, many African Americans rely heavily on community supports, particularly the church (Leong, Wagner, & Tata, 1995, p. 423). Harry, Allen, and McLaughlin (1995, cited in Schaller, Parker, & García, 1998) also point out that African American parents "may hold broader perceptions of normalcy and have a wider range of expectations for developmental milestones of children's behavior" than do many educational professionals (p. 41).

Traditional Hispanic cultures. Soriano (1995), discussing culturally appropriate rehabilitation counseling for Latino populations, observes that "Latinos are highly diverse. . . in terms of culture, ethnicity, and geographic origin, as well as in terms of education and economic levels" (p. 67). However, within this diversity, many scholars find a number of commonalities in customs, beliefs, and worldviews. Harry (1992), for example, lists characteristics common to traditional Hispanic worldviews. She characterizes traditional Hispanic culture as "based on Catholic ideology, with an inextricable interweaving of the ideologies of native Central and South American views of the universe" (p. 26). In Caribbean territories, however, "it is mainly African religious beliefs that have been added to a Catholic base" (p. 26). Other characteristics cited by Harry and others include:

- "the centrality of the concept of 'familia,'" with "'a clearly defined hierarchy of authority'" within the family structure (p. 29, quoting Ramirez & Castañeda, 1974)

- "respeto," also described as "dignidad," "personalismo," or "confianza" (p. 29), all terms referring to "a personalized yet ritualistic respect" that is based on selfhood rather than on achievement, and which "makes it difficult for an individual from traditional Hispanic culture to be comfortable with North American-style 'professionalism,' which assumes due respect on the basis of one's possession of specific skills" (p. 30), and

- devaluation of darker-skinned peoples and placement of a high valuation on social status (p. 30).

As is described for other non-mainstream groups, perspectives on disability among members of traditional Hispanic cultures are influenced by beliefs in the intersection of the physical and the spiritual (Smart & Smart, 1992). Families, which act as a powerful support system (Leong, Wagner, & Tata, 1995) consider some conditions as merely a reflection of individual differences rather than disability, and adapt family and work roles to accommodate those differences. However, severe disability, especially developmental disability, is a stigma for the traditional Hispanic family (Harry, 1992).

Many traditional Hispanic families, though they may seek assistance from mainstream health systems, also may seek help from folk healers and members of the clergy. Leong, Wagner, and Tata, in discussing mental health services, cite findings that "utilization of folk healers is not common, particularly among urbanized, acculturated Hispanics" (p. 427). However, they also cite a study by Martinez and Martin (1966), which found "that approximately 97% of the 75 Mexican American housewives they surveyed were familiar with folk remedies and more than 50% had been treated by a folk healer" (p. 427). Trevino (1991) concludes that:

> To many Mexican Americans both traditional health services and folk healing are important, each addressing different needs in different ways. . . Rehabilitation counselors who serve many Mexican Americans should seriously consider building relations with folk

> healers. After all, they may be viewed as simply another allied health professional offering rehabilitation services from a different cultural perspective. (p. 24)

Traditional Asian Pacific cultures. Leung (1993) notes that "no ethnic group in the U.S. is as difficult to describe as Asian Americans" (p. 95). Harry (1992) also describes "vast racial differences" among groups in this category, as well as differences in religion, language, and culture, but identifies "certain commonalities" (p. 35). She observes that "the essence of Eastern cultures is collectivism and harmony" (p. 35). Quoting Chan (1986), she summarizes the common features in Eastern cultures as

> harmony, social order, rules of propriety, filial piety, benevolence, loyalty, cooperation, reciprocity, and obligation, all of which exist within a system of "prescribed roles and relationships which emphasize subordination and interdependence" . . . A belief in "the supremacy of the universal order over oneself is further manifested in reverence for the past." (p. 35)

In discussing Americans of Chinese descent, Chan, Lam, Wong, Leung, and Fung (1988) contrast the individualistic orientation of U.S. mainstream culture with "the Chinese preoccupation with social order (collectivist orientation). This concern of the Chinese people for harmony-within-hierarchy is strongly influenced by Confucian philosophy and often continues to be an influence on Americans of Chinese descent" (p. 21). They observe that the emphasis in traditional Chinese society on "functioning within well-defined and structured social relationships" may lead some Chinese Americans to "expect the same well-defined structure and role in a [rehabilitation] counseling relationship. The client-centered approach used by many rehabilitation counselors in the United States may be viewed as too ambiguous and 'wishy-washy' by Chinese-American clients" (p. 22). In a similar vein, McFarlane, Farley, Guerrero, and Galea'i (1996), discussing Pacific cultures in areas served by the Rehabilitation Research and Training Center of the Pacific, describe how these differences influence concepts related to independent living: "The concept of independent living when described by such terms as empowerment, advocacy, personal choice, and living independently, goes against Pacific Island cultural practices of respect, being humble. . ., family choice and involvement, and living and being with the family" (p. 24).

As do other authors (see for example, Harry, 1992; Hong, 1995), McFarlane et al. stress the importance in traditional Asian Pacific cultures of family life and the preservation of family honor. They explain that, in traditional Samoan culture, for example, "a person has an identity only so far as that person can demonstrate his/her connections to the *aiga* (extended family). Personal needs, goals, and eccentricities must be downplayed for the good of the family group" (p. 25). They further observe that, "in Samoa and throughout most of the Pacific, there remain strong inhibitions against airing family problems to outsiders" (p. 25). Yamashiro and Matsuoka (1997), discussing the underutilization of mental health services among Asian and Pacific Americans, discuss the concept of "face," which is reinforced by Confucian philosophy. They conclude that traditionally oriented Asian and Pacific Americans "may perceive that losing face because of mental illness in the family would subject the individual or family to a religious or spiritual crisis" (p. 182).

In terms of attitudes about disabilities, Leung (1996) cites Paris (1993), who "found that Asians generally had the least positive attitudes [toward people with disabilities], even when healthcare professionals are the subjects of research" (p. 5). As Hong (1995) explains,

> There are many [Asian Americans] who believe in supernatural or metaphysical forces which could play a role in health and disease, and in fortune and misfortune. Such beliefs have strong implications in the perception of the causes of disability, in the treatment of disability, and in the feelings of guilt, responsibility or shame associated with having a person with a disability in the family. (p. 61)
>
> Traditional Asian Pacific Americans often seek help through sources other than, or in addition to, the western medical or rehabilitation system. Hong observes that "a family will often want to pursue traditional Asian cures, such as herbal medicine, or take certain actions to restore the balance of nature" (p. 61). Liu (1995) notes that "Asian Americans rely more heavily on informal social networks" than do most other minority groups (p. 125).

American Indian cultures. Quoting Trimble (1990), Leung (1993) explains that "the term American Indian can be viewed as 'an imposed social and political ethnic category with little relevant meaning,' and represents 'a range of cultural orientations'" (p. 95). Leung notes the existence of more than 500 tribal groups that have been recognized by the U.S. government. Harry (1992) points out the dangers of ignoring the diversity inherent within these groups as well as other factors. She concludes:

> To the extent that there can be said to exist a Native American culture in the United States, it must be seen as the product of three centuries of contact with U.S. mainstream culture and the imposition of alien forms of government, philosophy, and social organization on varying traditional cultures of Native American peoples. . . Contemporary Native American groups hold certain features in common, which may be, to varying extents, a combination of traditional features, adaptive strategies, and varying levels of acculturation to the dominant culture. These features include an enduring sense of pride in cultural heritage, a belief in the interrelatedness of body and spirit, culturally distinctive communication styles, and a reliance on extended community and kinship networks. (p. 40)

Harry notes among Native American groups "a style of communication that is consistently described in the literature as less verbal and direct than that of mainstream U.S. culture" (p. 44). This indirect style, along with standards of courtesy and appropriate interaction, lead Locust and Lang (1996) to conclude that, "if a [rehabilitation] counselor wished to observe courteous behaviors with an [American] Indian client, the time spent with that one client would double or triple what might be necessary for other clients" (p. 5).

Regarding concepts of disability among American Indians, Locust (1988, cited in Harry) observes "that most traditional Indian languages do not have words for retarded, disabled, or handicapped and, rather than using such categories, may assign names of individuals that are descriptive of the disability, such as One-Arm, or One-Who-Walks-with-a-Limp" (p. 46). The belief in the interrelatedness of body and spirit described by Harry and others contrasts with the beliefs inherent in the mainstream medical model. As is true in other traditional cultures, American Indians with strong roots in traditional tribal culture may seek help from "folk healers" as well as the mainstream medical and rehabilitation systems.

Characteristics of effective systems and relationships

How do we link all of the preceding information to the process of increasing the utilization of rehabilitation research outcomes? Addressing diversity in the knowledge utilization process is not merely a matter of translating materials into Spanish or broadening dissemination channels to include, for example, churches in predominantly African American communities. For most research and development organizations, and for the service agencies that often serve as dissemination channels for them, addressing diversity requires fundamental changes in perspective in order to become knowledgeable about, responsive to, and credible to a diverse set of potential users. There are implications for organizational policy, structures, procedures, and staffing; for what research is conducted, for what purposes, and according to what methodologies; and for strategies for "packaging" and disseminating research outcomes. These implications are discussed in the following sections.

Building "culturally competent" organizations

Most of the literature addressing organizational issues related to diversity focuses on service agencies rather than on research agencies and organizations. However, many of the principles and characteristics described for service agencies also appear relevant to a variety of institutional contexts. This literature includes recommendations for organizational approaches that are variously described as "culture-compatible" (Flaskerud, 1986) or "multicultural" (Duarte & Rice, 1992; Ehiobuche, 1995). A number of authors use the term "cultural competence," a concept derived from the work of Cross et al. (cited in Benjamin, 1992; see also Schaller, Parker, & García, 1998; Soriano, 1995; and Mason, 1994).

Soriano defines cultural competence as "a set of congruent behaviors, attitudes, beliefs, and values that. . . enable [people] to work effectively in a cross-cultural situation" (p. 67). Benjamin notes that developing "culturally competent systems of care" requires "congruence" among policymakers, administrators, practitioners, and consumers; he lists five "essential elements" that characterize culturally competent organizations.

With slight variations, this list is echoed by Soriano:

- valuing diversity "for its own sake" (Soriano, p. 68);
- having "the capacity for cultural self assessment" within the organization (Benjamin, p. 39);
- institutionalizing knowledge about various cultural groups;
- fostering consciousness among all staff as to "the dynamics inherent when cultures interact" (Benjamin, p. 39); and
- having the "willingness and ability to adapt to a diverse and continuously changing cultural mosaic in society" (Soriano, p. 68).

Benjamin and his colleagues conducted a nationwide study to assess organizational characteristics that help to operationalize these elements of cultural competence. They found:

> Some of the dominant characteristics of programs that exemplified culturally competent principles/values were: . . . clearly defined philosophy and policies (the more clearly articulated the program philosophy and policies based on cultural dynamics and inclusion, the more culturally competent the programs tended to be); . . . strong emphasis on the importance of family as defined by the culture; staffing patterns that reflect the ethnic makeup of the population served; [and] an emphasis on training, education, and curriculum development to address cultural issues. (p. 39)

Empowerment vs. assistance. The most critical element of cultural competence, according to some authors, is "empowerment," an orientation toward partnership with clients or consumers rather than assistance that is "bestowed" upon a passive recipient. As Kalyanpur and Rao (1991) explain,

> Empowerment signifies changing the role of a service provider from that of an expert to that of an ally or friend who enables families to

> articulate what they need. . . It involves caring, which builds supportive relationships; respect, which builds reciprocity; and the acceptance of differences, which builds trust. (p. 31)

Wolff (1995), citing the work of Chavis and Florin, summarizes major differences between traditional approaches, in which research, services, or information are provided by outside "experts" *to* an essentially passive recipient audience or clientele, and an empowerment approach, in which providers and clients work as partners. Wolff uses the term "community based" to describe traditional approaches and "community development" to describe empowerment strategies:

Traditional/ Community based	*Empowerment/ Community development*
Problems defined "by agencies, gov-ernment and outside institutions"	Problem defined by the community
Primary vehicles for change are "information, education, and. . . services"	Primary vehicles for change are "building community control and increasing community capacity"
Professionals "are the key and central decision makers"	Professionals "are a resource to the community's problem solving"
Primary decisionmakers are "agency and government representatives and other leaders appointed leaders"	Primary decisionmakers are "the indigenous, informal and elected from the community" (p. 2-17)

Some authors also discuss the need for service agencies to shift their orientation from that of solely addressing the needs of individuals to including a focus on underlying social, institutionalized inequities. For example, Ehiobuche (1995), describes a "multicultural rehabilitation modality" as requiring "an equally balanced focus on the environment and on the individual because disability may stem as much from environmental barriers (cultural racism, poverty, and disadvantaged status) as from the individual's functional limitation" (p. 53). Similarly, Atkins (1988), in discussing mental health services for African American clients, quotes Raphael (1972), who notes that "the counselor is caught between efforts to ameliorate the immediate problems of a particular client and an awareness that only deeper social reform can eliminate the general conditions creating the problems" (Atkins, p. 45). And Brodwin, Orange, and Brodwin (1995), pointing out that people with disabilities are stigmatized in U.S. society, argue that "it is the responsibility of the rehabilitation counselor to tactfully and artfully stimulate various aspects of our society to address the anti-discrimination regulations of the ADA" as well as other provisions designed to prevent discrimination against particular groups (p. 87).

Addressing organizational policy as well as practice. Mason (1994) notes that "the policy element is an often overlooked — yet very important — area" of cultural competence within organizations. "Culturally competent staff attitudes and program practices need to be upheld by policy lest they ebb and flow on the trends of the times" (p. 6). Similarly, O'Brien and Rhoades (1996), in discussing outreach and rehabilitation services for non-English speakers, recommend that agencies that are "serious about improving services to non-English-speaking clients must begin with an organized outreach plan." They stress that "the plan should not be placed solely on the shoulders of one person — for example, the bilingual staff member — but should be a cohesive teamwork effort to which all staff members are committed" (p. 8). Duarte and Rice also address the importance of aligning policy and practice:

> The VR agency should be an organization which values diversity and emphasizes that value in its mission, policy, principles, procedures, and practices. It is critical that organizational leaders demonstrate a commitment to this value in theory and practices which guide agency activity. The integration of this value into the organization is not a "quick fix" process achieved by brief training programs. (p. 43)

Diversifying staff. Perhaps more than any other single characteristic, the literature stresses the need for the staff of culturally competent organizations to reflect the racial, ethnic, and cultural diversity of intended consumers. For example, Atkinson and Lowe (1995), who reviewed research studies on mental health counseling, found "strong evidence" that pairing clients with "ethnically similar" counseling professionals is "associated with more positive counseling process and outcome" than if the client and professional are "ethnically dissimilar" (p. 405). Flaskerud (1986) identified "nine major components of a culture-compatible approach recommended by researchers to the mental health care of Asian, Hispanic, and Black American clients" and then conducted a study to assess the influence of each component on the dropout rate among minority clients within mental health service organizations. The study found that, "of the individual components, language match of therapist and client, ethnic/racial match of therapist and client, and agency location in the ethnic/racial community were the best predictors of dropout status" (p. 136).

McFarlane, Farley, Guerrero, and Galea'i (1996) also emphasize the importance of having staff members who can speak the native language of intended clients or consumers. They quote Vash (1994):

> Language is a critical factor in understanding culture. When you try to understand and analyze beliefs, ethical values, and convictions, there are deep concepts that are very much tied to language. When you rely on translators, you lose a great deal. Individuals who can speak two languages are almost essential. (McFarlane, et al., p. 23)

One strategy that has been used successfully in several contexts is training and employing paraprofessionals drawn from the client community (McFarlane & Fehir, 1994). D'Alonzo, Giordano, and Oyenque (1996) report on a rehabilitation services project in New Mexico which used paraprofessionals drawn from local American Indian tribes to work with American Indian clients. Over a one-year period, the employment rate of American Indian rehabilitation clients more than doubled, from 14 percent to 31 percent, and the unsuccessful termination rate dropped by more than 20 percent. Locust and Lang (1996) report on a similar outreach effort with potential American Indian clients in Florida, a "Native American Technician" program in which "tribal people are employed via a subcontract with a tribe or tribal entity to provide outreach to American Indian people with disabilities" (p. 11). Via this program, the number of American Indian clients in Florida increased from only one to 260 over a four year period. Ultimately, however, as Schaller, Parker, and García (1998) point out, using paraprofessionals is an incomplete answer to the need for greater numbers of rehabilitation professionals from culturally diverse backgrounds.

Diversifying marketing and service strategies. Backer (1994) discusses "social marketing," a strategy drawn from corporate marketing concepts; he notes that "social marketing provides a management framework for systematic efforts to understand a target audience for change" (p. 17). He describes key elements as follows:

> *Audience segmentation,* a key concept of social marketing, involves\ subdividing the targets (e.g., teachers in a large school district) into both "demographic" and "psychographic" groups, based on an understanding of what personal or group characteristics have a bearing on their behavior with respect to [adopting an innovation]. . .
> Learning what the individual differences are requires *audience analysis,* frequently using marketing techniques such as "focus groups." (p. 17)

Similarly, Yamashiro and Matsuoka (1997) describe the need for "culturally sensitive marketing strategies" for mental health service providers. Elements of such strategies, as they describe them, include:

- "removing impediments to services" by assuring procedures that address cultural needs, for example, confidentiality measures that families perceive will protect them from losing "face" (p. 183),
- adopting culturally inclusive perspectives on disability and dysfunction, and
- conducting research and needs assessments to "determine who the prospective clients are and where they reside," so that outreach efforts can be tailored to the concerns and needs of specific audiences (p. 184).

Schaller, Parker, and García (1998), among others, describe changes in practice that contribute to cultural competence. These include showing respect for cultural values and mores, addressing families as well as individual clients, locating services within the client community, assuring language accessibility via both print materials and interpreters, and using culturally sensitive assessment tools.

Issues in conducting research

Research organizations, of course, are not direct service providers. However, concerns for racial, ethnic, cultural, and linguistic diversity among staff, for understanding of cultural dynamics and the diversity between and within specific populations, and for a commitment to empowerment are all relevant to research as well as service agencies. In a research context, "empowerment" relates to the processes through which researchers determine the focus of research; the specific questions they pose; the ways in which they collect, organize, and analyze data; and the ways in which they attempt to get research outcomes into the hands of those who can use them. Wright and Leung (1993), among others, recommend that "minority communities and persons with disabilities should be involved in the process of planning research, implementing research, and interpreting findings of research" (n.p.). Without "cultural competence" as it is described above, research agencies will find it difficult to secure the involvement of minority groups in any meaningful way.

Some scholars concerned with diversity issues have focused a cultural lens specifically on the processes and assumptions of research. They have found "that data are collected, organized, and communicated within a cultural context and with tools that are also products of the culture" (Metoyer-Duran, 1991, p. 320). As Muntaner, Nieto, and O'Campo (1997) observe, the sociology and history of science show that:

> Decisions about basic assumptions guiding research are social phenomena. . . The scientific community determines in part the acceptability of hypotheses for inquiry, publication, and continued funding through a social process in which certain assumptions are uncritically accepted even in the face of empirical refutation. (p. 263)

The following paragraphs describe some of the issues that have been raised in the literature. These range from overarching, epistemological concerns to speficic methodological issues.

Epistemological issues. The examination of cultural beliefs extends not only to methodology, but to the epistemological foundations upon which research methods are constructed. For example, Scheurich and Young (1997) note "a lack of understanding among researchers as to how race is a critically significant epistmological problem in educational research" (p. 4). They point out that "no epistemology is context-free. Yet, all of the epistemologies currently legitimated in education arise exclusively out of the social history of the dominant White race. . . In other words, our 'logics of inquiry' (Stanfield, 1993) are the social products and practices of the social, historical experiences of Whites" (p. 8). Buchman (1982) discusses the fact that researchers and developers often fail to perceive the influence of their own theories and beliefs on the outcomes of their work; he quotes Nisbett and Ross (1980) regarding "the fallacy of misplaced certainty":

> An important step in reducing people's overconfidence would be taken by leading them to recognize that their interpretations of events, rather than being simple read-outs of data, are inferences that make heavy use of theory. Once one recognizes that the same data would look quite different, and could easily support different beliefs, if those data were viewed from the vantage point of alternative theories, the groundwork for a humbler epistemic stance has been laid. (p. 2)

Costa and Bamossy (1995; see also Taylor and Bogdan, 1984) describe common epistemological errors, describing many studies as "parochial," meaning that they "assume similarity" based on characteristics of one culture and pose that similarity as the norm. Costa and Bamossy also describe "ethnocentric research," in which "one culture's 'universal' theories are imposed on another culture"; in such studies, researchers explore differences, but those differences are examined and explained in reference to norms that are assumed to be universal. In contrast to these approaches, the authors recommend comparative studies, which ”search for both similarities and differences" without presuming universal norms or the superiority of one set of cultural characteristics over another (p. 21).

Methodological issues. The literature identifies a host of methodological concerns that can compromise the reliability and validity of research outcomes. As discussed below, these include issues related to research design, sampling and other data collection procedures, and data analysis.

Research design. In spite of some researchers' continuing concerns about the validity and generalizability of qualitative research (Conwal Inc., n.d.), Taylor and Bogdan

(1984), as well as others, suggest the strengths of qualitative or ethnographic research designs over the more commonly used positivist methodologies in exploring questions related to minority populations. For example, Harry (1992) in discussing studies of parents of children with disabilities, states that studies of parental attitudes "will be more reliable if they utilize a recursive, open-ended approach" (p. 103).

Hermes (1998) reflects one trend in qualitative research with minority groups. In her report on research with an Ojibwe Indian tribe, she describes an approach of "reciprocity and mutual respect" in which she sought guidance and feedback from the community she was studying at every step in her research, from identifying research questions to collecting, review, and analyzing data. Noting that her relationships with the community "ordered the methods" of her research, she recommends a "guiding principle": "Be in the community as a member first and a researcher second" (p. 166).

Smart and Smart (1997) describe other research methodologies that appear to hold promise in "unraveling the complex relationship between social conditions and minority status" and assessing strategies for "treatment and prevention of disabilities in minority populations" (p. 12). Citing Adler et al. (1994), they report on promising research designs, including

> the use of tree-structured regression and "grade of membership" analyses. Tree-structured regression techniques partition populations into subgroups and then identify different paths to given outcomes. Their strength lies in their ability to analyze numerous, complex, interrelated variables. . . Likewise, "grade of membership" analysis is able to accommodate larger numbers of variables by developing "ideal descriptions," either theoretically or empirically, of various classes of individuals. This technique becomes more precise with the addition of more and more variables. (Smart & Smart, p. 13)

Identifying and defining variables. Smart and Smart (1997) and others discuss the common problem of "inadequate definition of research variables" (pp. 32-33), particularly the "validity of racial/ethnic classification" (Duarte & Rice, 1992, p. 13, citing Kumanyika and Golden, 1991). Anderson, Wang, and Houser (1993) cite

Hahn (1992), who "believes that the assessment of demographic identity in a society with a culturally diverse and rapidly changing population is extremely difficult." Hahn challenges "the assumption that categories of race and ethnicity are consistently defined when, in fact, terminology and categorization differ from source to source and region to region" (p. 12). Smart and Smart note, for example, that "many researchers have failed to distinguish the various subgroups of the Hispanic population, obscuring important differences between such groups. . . Different definitions of the terms 'Hispanic,' 'Latino,' and 'Mexican American' have yielded different samples, each with varying socio-demographic characteristics" (p. 33). Also challenged is the assumption "that the racial and ethnic categories used by researchers are adequately understood by those being surveyed" (Anderson, Wang, & Houser, p. 12).

Taylor and Bogdan discuss the problems that can arise when research variables are defined in rigid ways that cannot accommodate the realities of life among the populations studies. As an example, they describe a study that focused on conditions within "single-parent" vs. "dual-parent" homes. In collecting data, researchers found that those two categories failed to capture the variety of living arrangements that characterized most of the homes under study, for example, homes that included extended family members who filled parenting roles. However, because of the study's rigid design, researchers were forced to attempt to fit the data to their pre-existing categories.

Sampling and data collection procedures. As noted in the previous paragraph, sampling procedures can be compromised by poor definition of variables associated with the populations being sampled. In addition, a number of authors note that studies involving nonmainstream populations often rely on inadequate sample size (Anderson, Wang, & Houser; see also Duarte & Rice).

Concerns regarding data collection procedures include problems in accessing and obtaining data from a representative sample. Huff (1994), for example, describes the complexities involved in trying to set up a focus group composed of urban African American families: "We have learned that. . . families. . . may not have: (1) an address; (2) a telephone; (3) access to banking services; or (4) transportation" (p. 10). Anderson, Wang, and Houser conducted a needs survey among people with disabilities in Hawaii. Using a mail survey approach, they were unable to obtain an adequate return rate. They concluded that the return rate "may have been affected by the values and traditions within Asian cultures that emphasize the importance of keeping information about the family within its unit" (p. 14).

Researchers' failure to understand and accommodate cultural proprieties can result in the provision of misleading or inaccurate data. Harry (1992) notes that, "given all that is known about power relations between dominant and subordinate cultural groups, it should always be assumed that respondents' initial answers to judgments about the educational system may not be reliable" (p. 103). She quotes Leung (1988), who describes responses to research questions among Asian parents: "Attention and affirmation may only mean courtesy and propriety" (p. 105). Yu (1985, cited in Harry) refers to such patterns of response as "courtesy bias," "which may occur when informants do not yet trust the researcher and when researchers are not aware of the cultural inappropriateness of certain approaches" (Harry, p. 105). Problems also arise in assuring mutual understanding of terms used in survey questions. Taylor and Bogdan caution that "field researchers must start with the premise that words and symbols used in their own worlds may have different meanings in the worlds of their informants" (p. 51).

One major concern in data collection is the use of translators in obtaining data from non-English-speaking subjects. Smart and Smart (1992; see also Harry) describe the problems inherent in the common practice of using friends or other family members to act as interpreters, whether in a research or a service setting:

> The use of family and friends as translators violates the right of privacy of the client. . . When the children of the client are used as translators, the client may be reluctant to fully discuss certain topics or the translator may have a tendency to speak for the client. Use of family members as interpreters alters the family structure. (p. 34)

As noted earlier, the use of interpreters also can result in the loss or misinterpretation of responses. The most effective data collection strategy is for those who conduct interviews, observations, or surveys to speak the respondents' language and to be well oriented to the cultural context in which the research activity is being conducted. The same considerations should apply in settings requiring interpretation for persons who are deaf or hearing impaired.

Data analysis. Two criticisms of data analysis appear most consistently in the literature. The first is misinterpretation based on a lack of cultural understandings or the assumption of normative standards that are, in fact, culturally derived (Duarte & Rice, 1992; Harry 1992). The second is the common failure to account for "within-group differences" when reporting on particular populations. Studies suggest that analyses of racial and ethnic demographics often overemphasize between-group differences and under-emphasize within-group differences, so that differences between groups may be exaggerated, while differences within a specific group may be overlooked (Anderson, Wang, & Houser, 1993; NCDDR, 1996).

Issues in dissemination and utilization

Although information is limited regarding dissemination and utilization (D&U) strategies targeted specifically to minority populations, there is a considerable literature base describing D&U processes in general.* Experts now understand knowledge utilization as a *learning* process in which the potential user, or consumer, is "an active problem-solver and a constructor of his or her own knowledge," not merely "a passive receptacle of information and expertise," as earlier D&U theories had suggested (Hutchinson & Huberman, 1993, p. 2). Knowledge is no longer thought of as an inert object to be "sent" and "received," but rather as a fluid set of understandings that are shaped by those who use it as well as by those who originate it (NCDDR, 1996). The relationships between the potential *user* and the D&U *source, content,* and *media* used are critical determinants of effectiveness, with attention to particular user groups as the most central concern. Findings related to the D&U process that have appear to have particular implications for work with minority persons with disabilities and their families are outlined below.

Credibility and trust. Potential users of research outcomes tend to accept assistance, information, and ideas from sources they know and trust (Carrillo, Lumbley, &

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* See the NCDDR's July 1996 report, *A Review of the Literature on Dissemination and Knowledge Utilization*, for detailed coverage of this topic.

Westbrook, 1990; Fullan, 1985; Robinault, Weisinger, & Folsom, 1980). Users tend to be more concerned about the source of the information that is disseminated than about the specific content of the information (Hutchinson & Huberman). Some studies suggest that the source's perceived expertise is less important to users than trustworthiness in obtaining user support (Marquart, O'Keefe, & Gunther, 1995). Given the findings regarding cultural mistrust (discussed in an earlier section of this report), the importance of establishing credibility and trust with minority populations cannot be overemphasized. And cultural responsiveness is essential to establishing such confidence (Schaller, Parker, & García, 1998).

Utility. If research outcomes are to be used, they must be perceived by potential users as relevant to their needs and daily lives. Dentler (1984), among others, stresses that "the property of knowledge that is essential for [use] is its congruence with the real world of practice" (n.p.). Similarly, a study of Tennessee school systems reported by West and Rhoton (1992) concludes that "the strongest barrier to research utilization statewide was the [perceived] non-practical focus of research reports" (p. 13). For effective D&U, then, researchers must know a great deal about the priorities, needs, environments, and circumstances of their intended users, and must tailor their outcomes and information accordingly.

Cultural responsiveness. To be effective, D&U strategies must be appropriate within potential users' cultural contexts (Duarte & Rice, 1992). This includes understanding and addressing users' perceptions about disability, family, and propriety. Information about research outcomes also must be easily understandable by potential users. Leung (1992), for example, reports that "language differences" are a primary cause of negative attitudes about researchers — not only in terms of English vs. other languages, but in terms of dense, technical descriptions that assume a vocabulary and contextual knowledge most nonresearchers do not possess.

It is also critical to know what dissemination channels are available to, and used by, potential user groups (Edwards, 1991). Leung (1992) notes that one of the most elementary — and important — guidelines for selecting a dissemination medium is that "utilization will not occur if persons with disabilities cannot physically gain access" (p. 299).

Personal contact. Perhaps the most consistent finding in the literature on knowledge utilization is the importance of personal contact for the success of dissemination activities. As Fullan (1991) notes, "The primacy of personal contact in the diffusion of innovations has been known for years" (p. 53). This finding has significant implications for D&U activities targeted to minority populations. To provide for personal contact with potential users, most research agencies must rely on intermediaries. However, relying solely or primarily on intermediaries from government agencies and service providers within the rehabilitation system is likely to prove inadequate. Many people who are oriented to traditional minority cultures tend to seek help outside the established rehabilitation and medical systems, and it is important for researchers to broaden their contact to include these community resources, including, among others, community agencies and organizations, informal community leaders, church personnel, and healers (Schensul, 1992). In addition, persons from lower socioeconomic brackets — who are disproportionately from minority populations — often require special outreach efforts due to their lack of access to mainstream services and resources.

D&U research findings targeted specifically to minority populations. As noted earlier, the research literature contains limited information regarding dissemination media and methods that have proven effective with specific minority populations. However, a few studies exist that suggest promising strategies, at least within the limited contexts studied:

- Metoyer-Duran (1991, 1993) has conducted studies suggesting that "ethnolinguistic gatekeepers" within traditional cultural communities serve as "information and referral agents" (1993, p. 365). Her research suggests "that gatekeepers have greater awareness of and use more information resources than other community members, even when controlling for educational level, employment status, income, and longevity in the community" (1991, p. 325). Metoyer-Duran found that these gatekeepers draw on a number of information sources, including mass media, print, and institutional representatives. However, they are most likely to consult interpersonal sources. To access gatekeepers as potential dissemination channels, she recommends "establishing close relationships with other institutional sources used by gatekeepers" (1993, p. 368).

- Schensul (1992) and colleagues conducted research to help identify dissemination strategies that could effectively deliver information about Alzheimer's disease to elderly Latinos in the U.S.. Among the strategies they tried were presentations in churches, pamphlets left in churches, a community conference, an art exhibit of "symptom depiction cards" drawn by "a wellknown Puerto Rican artist" (p. 21), contact with informal building leaders, botánicas, Spanish radio, Spanish and English neighborhood newspapers, and community outreach via service providers. They found that, of the public media they tried, Spanish radio proved the most effective dissemination channel. The authors found "that most Latino elderly prefer listening to one or two specific stations, and do so regularly throughout the day." The authors recommend appearances on radio call-in shows over the more commonly used Public Service Announcements (PSAs), noting that PSAs "hold limited attention and come on infrequently. More effective are call-in shows, especially those focused on the general problems of Latino elderly. . . The Spanish language call-in show is an extremely important untapped venue for dissemination of health-related information because it is interactive" (p. 23). Regarding the effectiveness of Spanish language newspapers, the study found that they were "widely read, but when questioned, readers did not mention knowledge of Alzheimer's Disease or its management" (p. 23).

- Schensul also reports that, because elderly Latinos tend to fear the diagnosis of Alzheimer's disease, standard presentations on the disease that include discussions of etiology, symptoms, natural history and management, "will not be received and may in fact reduce the likelihood that seniors and their families will report symptoms to a physician. Any technique which uses informal dialogue about daily or historical aspects of participants' lives will be more successful in opening the door to 'discovering' dementia" (p. 26).

- Ward, et al. (1993) describe a study of targeted media campaigns designed to address the underutilization by racial and ethnic minorities of a telephonebased cancer information service. They found that, among all audience groups, television was the most effective medium in increasing the number of telephone inquiries. However, they also found that the effects of the special promotional campaigns, whether via television or other media, tended to be short term.

- Online technologies represent an increasingly important dissemination strategy, but many people still lack access. Although some studies suggest that racial differences in computer and Internet use are shrinking in the U.S., differences persist. Wilhelm (1996), for example, reports on computer use among Latinos in the U.S. and notes that "civic networking" via the Internet "is evolving into an important public space" via networks such as LatinoNet and ChicanoNet. However, even after controlling for variables such as income and education, "Latinos still experience lower levels of computer access than do non-Latinos" (p. 23). In another report, Wilhelm (1995) notes that "overall, there are still 4.4 million households in the U.S. that go without a phone. Among Latinos, 13.3 percent of all households function without immediate access to a telephone" (p. 3).

Conclusions and recommendations

The larger literature on knowledge utilization indicates that, to be effective, dissemination and utilization cannot be "tag-on" activities. Rather, D&U concerns must be incorporated into the earliest planning stages of a research study (NCDDR, 1996). The D&U literature also indicates that, when potential users assess information about research outcomes, the credibility and perceived trustworthiness of the source is of paramount importance — and, as the literature on diversity suggests, trustworthiness relates to the capacity to be culturally responsive. The work of increasing the use of research outcomes among diverse consumer populations, then, lies not merely in selecting dissemination media or packaging information to be distributed via those media. The overarching task lies in becoming a "culturally competent" organization, one that knows, listens to, works with, and addresses the needs of its intended audiences; one that reflects the diversity of those audiences in its policies and personnel; and one that involves potential users throughout the research, development, and dissemination process.

The following are some suggestions for working toward cultural competence in terms of organizational structure and policies, research activities, and dissemination and utilization activities. Because little research exists that addresses the processes of dissemination and utilization for minority persons with disabilities, these recommendations must be considered tentative; they are based on a synthesis of understandings about knowledge utilization, on the one hand, and about racial, ethnic, and cultural diversity on the other.

Organizational recommendations

- Review and adapt organizational purposes and policies to include a commitment to cultural competence. Make this commitment pervasive and long term.

- Examine recruitment and hiring policies and procedures. Look for the cultural assumptions contained within them and consider the effects of those assumptions on the organization's staffing choices. Seek ways of diversifying staff. Avoid tokenism.

- Make sure all staff understand that cultural competence is the responsibilityof the entire organization, not only of minority staff members or "special" projects or committees.

- Seek ways of establishing an active, partnering presence within the community, whether "community" is defined by geography or interest.

- Build strong, ongoing relationships with a wide variety of intermediaries who have direct access to potential users. Approach these relationships as a partner rather than as a provider. Remember that intermediaries, like targeted users, will need to find the organization, its activities, and its outcomes both relevant and trustworthy.

Research recommendations

- Ground decisions about research purposes and hypotheses in a thorough knowledge of potential user audiences. Employ a variety of methods to learn about those audiences, including focus groups, surveys, community involvement, input from intermediaries, and ongoing input from potential users themselves.

- Examine the assumptions inherent in the goals, hypotheses, and methods of the intended research. Ask others to explore those assumptions, particularly people with experience and insight into potential user groups, and representatives from those groups.

- Explore a variety of research methodologies, seeking to identify approaches that are most likely to yield accurate, in-depth outcomes related to all target audiences. Consider a blend of qualitative and quantitative approaches.

- Define all variables fully; be cautious about hidden assumptions and/or comparisons with variables in other studies that may be differently or less fully defined.

- Use sampling techniques that provide for adequate representation among all targeted audiences, and address appropriate subpopulations, not merely broad racial or ethnic categories.

- Structure data collection activities to assure an appropriate rate of return from all targeted subpopulations. This likely will require a variety of data collection activities that extend beyond traditional mail or telephone surveys, particularly to reach low-income respondents. Take care to assure that interview and other questioning techniques are culturally appropriate. Assure language accessibility via both print and interpreters.

- In analyzing data, carefully consider within-group as well as between-group differences. Be cautious of making cultural assumptions in data analysis and conclusions.

- Seek input and feedback — eliciting both formal and informal "reality checks" — from representatives of target audiences in identifying data collection procedures, identifying or developing data collection instruments, analyzing data, and drawing conclusions.

Dissemination and utilization recommendations

- Begin thinking about the task of dissemination and utilization at the earliest stages of the research effort.

- In learning about potential user groups (see recommendation, above), seek to identify the information sources and media on which they most frequently rely. Consider not only traditional media, such as print and television, but community resources, leaders, and informal "gatekeepers."

- Use multiple dissemination strategies and media, targeted to specific subpopulations. Never rely on a single approach.

- In determining what information to disseminate, consider what the potential user will think is important. Labels, titles, and supporting data that are important to funding sources and other researchers often seem completely irrelevant to intermediaries, potential consumers, and their families.

- Assure that the information to be disseminated is accessible in language, syntax, format, and length; respectful of cultural customs and proprieties; and relevant to potential users' concerns.

- Draw as extensively as possible on D&U strategies that provide for personal contact between potential users and persons who can facilitate the use of research outcomes. Use intermediaries: service providers such as independent living centers or rehabilitation service agencies; community resources such as advocacy groups, churches, community centers, and the like; and informal community leaders and resources, including herbalists and healers who apply traditional cultural approaches. Remember that using intermediaries means the intermediaries themselves become a D&U audience.

- Seek input and feedback from representatives of target audiences throughout the D&U process.

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NOTICE

REPRODUCTION BASIS