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Community Needs Assessment of Native Americans and One Year Follow-up Evaluation

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Authors' Note

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The statements made are solely the responsibility of the authors.

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Abstract

Using participatory action research, Native American research technicians conducted screening interviews to identify tribal members with disabilities and community needs. Participants received a *Resource Guide* manual at the conclusion of the community needs assessment, and were encouraged to contact appropriate health care agencies for services. The results of needs assessment include the incidence of disability, major types of disabilities, limitations and needs, employment status, and consumer concerns and barriers for Native Americans with disabilities. Also one year follow-up evaluation is discussed regarding the improvement on knowledge about resources for people with disabilities

Community Needs Assessment of Native Americans and One Year Follow-up Evaluation

There is a disparity between needs and service provision for Native Americans (Marshall, 2001) and greater awareness of these issues by health related service providers and by Native Americans is clearly needed. Members of racial and ethnic minority groups may experience limited availability of, and access to, culturally sensitive treatments. A socioeconomic disparity also exists among Native Americans. According to U.S. Bureau of Census (2004), the income level for Native Americans was 73% of the U.S. average, and the poverty rate was twice as high. More than one-fourth of Native Americans live with significant disabilities (National Council on Disability [NCD], 2003). Strikingly greater prevalence rates of depression, anxiety, and substance use have been observed among Native Americans compared with other racial-ethnic groups of the population (Huang, Grant, Dawson, Stinson, Chou, Saha et al., 2006).

Several studies reported possible reasons for racial and ethnic minorities collectively experiencing a greater disability burden from mental illness than do whites. One explanation is that minorities may experience limited availability of, and access to, culturally sensitive treatments, rather than from their illnesses being inherently more severe or prevalent in the community (U.S. Department of Health and Human Service, 2001). Moreover, those striking health disparities may be due to poverty, socio-demographic, and cultural factors, inadequate resources, continued population growth, discrimination, traditional values, and historical contexts including devastating population losses through war and disease, appropriation of aboriginal lands by governments, and loss of traditional economies (Beals, Manson, Whitesell, Spicer, Novins, & Mitchell, 2005). Those social economic inequalities further place racial and ethnic minorities in greater exposure to racism and discrimination, violence, and poverty, all of which take a toll on mental health (U. S. Department of Health and Human Services, 2001).

Though research on Native Americans has been limited by the small size of this population and by its heterogeneity, existing studies suggest that youth and adults suffer a disproportionate burden of various disabilities (Huang, 2006; NCD, 2003). As one indication of distress, the suicide rate is 50% higher for the American Indian/Alaska Native population than the national rate (U. S. Department of Health and Human Services, 2001).

Even though federal funding has been directed to Native Americans through various programs, it has not been sufficiently addressed basic and very urgent needs of Native Americans (i.e., health care, education, public safety, housing, rural development) (Commission on Civil Rights, 2003). There have been several studies on the rehabilitation needs of Native Americans with western tribes and Native Americans as a whole (Feldstein, Venner, & May, 2006; National Council on Disability, 2003; Schacht, Gahungu, & Gallagher, 2002). Marshall, Johnson, Martin, Saravanabhavan, & Bedford (1992) used a community-based approach and the participatory action research model to identify incidence of disabilities and rehabilitation needs of Native American in Denver, Colorado. While some studies have been with western tribes, there has been scarce research on the health and disability needs of Native Americans with disabilities in eastern tribes.

To address the issue of lacking awareness about eastern tribes' health and service needs, this study on community needs assessment was conducted. It represents a collaborative effort among four eastern tribes, along with a Connecticut Bureau of Rehabilitation Services and the University of Connecticut. This five-year study of needs assessment, funded by the National Institute of Disability and Rehabilitation Research (NIDRR), presents data on 160 Native Americans with disabilities who completed

interviews from 2004-2008. This study identifies the prevalence of disability, the major types of disabilities, employment status, the needs and services received, and community responsiveness and barriers to Native Americans with disabilities. At least one year after completing the needs assessment survey, a service evaluation and follow-up survey was conducted to determine the impact of participation in the needs assessment study and improvement of service utilization in the community.

Method

This study used a community based approach and the participatory action research model to facilitate collaboration among four eastern tribes throughout the study. Beginning in 2004, tribal council members selected tribal members as research technicians who, after 3-day training, contacted individual tribal members with a goal of interviewing 30% of tribal members over 16 years of age. The training for research technicians consisted of a reading of the needs assessment survey and follow-up survey, question by question, answering concerns and modeling in response to the questions. Role-playing and observation during interviews were used as an evaluation tool to ensure that research technicians were adequately trained.

Research technicians conducted individual interviews in various locations, including tribal members' homes, tribal offices, and tribal events. Between 2004 and 2008, 35 trained tribal research technicians used *The Health and Disability Survey* as a screening device to identify tribal members with disabilities. The results of that study were reported elsewhere (Ni, C. F., Wilkins-Turner, Ellien, Harrington, & Liebert, 2008). From that study, 160 Tribal members with disabilities were identified and invited to participate in this presented study. The participants first completed a survey of *Community Needs*

Assessment of American Native Americans with Disabilities, and then received a 30-page community resource manual for the state where their tribes were. Participants were encouraged to take advantage of those resources and contact appropriate health care or social service agencies in their states of residence for services. The survey instrument *Community Needs Assessment of American Native Americans with Disabilities* was adapted with some modifications from the one used by Marshall and her colleagues (1992), which had high inter-rater reliability (97.9%). The inter-rater reliability for the instrument used in this study was 98.6% for research technicians trained in July 2004.

With the purpose of evaluating the improvement on knowledge of health services in the community, follow-up interviews were conducted with the participants one year after providing them the resource manual. These interviews took place mostly by telephone, with some in-person.

The study design included the following methodology:

1. Participatory action research to ensure tribal participation in the planning and implementation of community based research.
2. Culturally appropriate networks to maximize potential for recruitment of Native American research technicians.
3. Mandatory three-day research training workshop prior to conducting interviews to ensure consistency of interviewing procedures among the Native American research technicians.
4. Research team combining tribal and university based researchers met weekly throughout the study to discuss progress and to address research issues encountered by the research technicians.

5. Native American research technicians from the four participating tribes conducted individual interviews using surveys with tribal members with disabilities to collect the needs assessment information.
6. Participation was voluntary and convenient sampling was used. In the early stages of data collection, random sampling from tribal rolls was possible. Later, barriers to the access of tribal rolls arose and research technicians actively recruited tribal members to participate, resulting in predominantly convenient sampling throughout the study.

Results

Participants

Tribal members from four eastern tribes participated in the study. Date collection using disability screening survey ended in 2008 and 858 tribal members completed this screen as shown on Table 1. Of these, 174 tribal members (20 %) were identified as having disabilities and 160 (92%) participated in the current study with 39% being males and 61% females. The average age of the respondents was 49 with an age range of 17 to 86; 52% (83) were over 50, 40% (65) were between the ages of 25 to 50; and 8% (12) were 17 to 25 years of age. Almost all lived in small towns, suburbs or cities in the northeast states.

All follow-up interviews were between one and two years after participants completed the study. Of the 100 follow-up interviews attempted, 46 did not complete the survey; five declined to participate; ten could not be located due to moving out of the area and 35 others could not be reached due to answering machines and unreturned phone messages. The percent of each tribe's members in the sample is shown in Table 1. The largest tribe (tribe 4

on the table below) is 50% of the total sample; one tribe (tribe 1 on the table) is 24% and the third Tribe (tribe 3 on the table) is 26% of the total sample. The percent of each tribe's numbers in the sample ranged from 3% to 68% (see Table 1). Due to difficulties retaining research technicians and finding replacements in one tribe, only four (3%) participated in the current study even though tribal members with disabilities were identified using screening survey.

Table 1. Sample and Percent with Disabilities

Number of Tribal Members Responded to Disability Screening Survey (N=858)	Percent and Number of Tribal Members with Disabilities Identified	Percent of Identified Participants completing the Current Needs Assessment Study (n=160)	Percent of Each Tribe Completing the Study from Sample (n=160)	Percent of Participants completing Follow-up Interviews (n=54)
Tribe 1= 142	24% (34)	24% (34)	21% (34)	38% (13)
Tribe 2= 146	12% (18)	3% (4)	3% (4)	0
Tribe 3 = 66	21% (14)	22% (14)	9% (14)	100% (14)
Tribe 4= 504	21% (108)	21% (108)	68 % (108)	52% (27)

Incidence of Disability

As shown in Table 1, the percent of Tribal members with disabilities ranged from 12% to 23.8% for the four Tribes with 20% overall. Three (3) Tribes had 21% to 24% with disabilities

Major Health Conditions and Disabilities

The nine most prevalent disabilities, each with 22% to 48% of the sample (see Table 2), include hypertension, visual impairment, arthritis, mental health conditions, obesity, diabetes, orthopedic disorders, heart problems and asthma. Over a third (36%) had one or more mental health conditions when all types were combined, with anxiety (25%) and chronic depression (19%) the most prevalent. Of the 54 with mental health conditions, 16% had one condition, 10% had two, and 10% had three to six mental health conditions. Substance abuse, including alcohol, street drugs and sniffing glue, was reported as a problem for 13% (21) and 62% (13) of these had co-occurring mental conditions (four

had one co-occurring mental condition, four had two to three co-occurring disorders, and five had at least four co-occurring mental conditions).

Table 2: Major Types of Disabilities

Top 9 Disabilities	Percentage/Frequency (n = 160)
1. Hypertension	48% (77)
2. Visual Impairment	43% (67)
3. Arthritis	38% (61)
4. Mental Health condition (one or more)[1]	36% (54)
5. Obesity	36% (56)
6. Diabetes	28% (45)
7. Orthopedic Disorders	27% (42)
8. Heart Problems	24% (38)
9. Asthma	22% (35)

Limitations and Needs

Disabilities limited Tribal members in doing the following activities in order of highest frequency: working on a job, walking, seeing, lifting, reading, writing, remembering, learning, and sitting as shown in Table 3. Respondents reported the following needs related to their disability:

- 44% (69) used medications with 12% (19) needing new or improved medications;
- 41% (63) used glasses and 24% (38) needed new or improved glasses;
- 10% (16) used a cane or a crutch and two (2) needed new cane/crutches;
- 5% (7) used a wheelchair and 1% (2) needed a new wheelchair.

Table 3: Limitations in Daily Activities

[1] Anxiety 25.2% (40); Chronic Depression 19.4% (31); Bipolar Disorder 6.9% (11) Eating Disorder 4.4(7); Personality Disorder 4.5% (7); Schizophrenia 3.2% (5).

Daily Activity	Percentage/Frequency (n = 160)
Working on a job	48% (75)
Walking	41% (65)
Seeing	39% (61)
Lifting	38% (60)
Reading	37% (58)
Writing	26% (41)
Remembering	20% (31)
Learning	16% (25)
Sitting	16 % (25)

Employment

Of the 160 respondents, 56% (89) were working and 44% (69) were not employed.

Among the respondents who were working, 68% (59) were employed full-time and 32% part-time.

Of the 44% (69) not currently working for pay;

- 49% were unemployed because of limitations due to a disability.
- 86% had been unemployed for over a year:
    - 41% had been unemployed for more than 10 years;
    - 16% had been unemployed for 6 to 10 years;
    - 29% had been unemployed 1 to 5 years;
- 14% were unemployed for less than one year.

Of those not working, 43% (31) said they wanted a job, and of these 65% (20) had been looking for work (i.e. Internet, newspaper, temporary job service). Four (4) were currently using a rehabilitation agency to help find a job. Only 10% (15) had assistance getting a job, and 12% (17) needed or wanted assistance getting a job but three (3) did not feel well enough to use the service, three (3) said the services were not offered to them, two (2) did not know of the service and six (6) did not want to use the service.

As shown in Table 4, problems reported by participants related to finding and

keeping jobs included limitations due to a disability (25%), not having the right job skills (16%), not knowing what was available to them regarding jobs (14%) and lack of transportation to jobs (11%) and the belief that employers did not give them a fair chance due to race or ethnic background.

Of the 160 respondents, 34% (52) said their education did not adequately prepare them for work and 66% (101) said that their education did adequately prepare them for a job. Almost two-thirds (60%) responded that they would like to increase their education

Table 4. Problems Reported Related to Finding and Keeping Jobs

Self-report of Problems Related to Jobs	Percentage (Frequency) n = 160
Problems finding or keeping a job because of their disability (e.g. not able to bend, lift, walk or stand too long, lost work time related to my disability).	25% (37)
Did not have the job skills that were needed.	16% (22)
Did not know what was available to them regarding jobs. Did not know the best ways to look for jobs.	14% (20) 5% (7)
Lack of transportation prevented them getting a job. Could not find a job close to home.	11% (15) 9% (11)
Employers did not give them a fair chance. Problems finding work because of their race or ethnic background. Problem finding work because of age. Could not find a job because of gender.	11% (15) 9% (13) 5% (7) 1% (2)

Assistance and Support Received from Others, State or Local Agencies

Over 89% (138 members) had a family member they could count on to help them when needed. In addition, over the past year Tribal members received assistance from state, local or Tribal agencies:

- 45% (71) of the 157 respondents with disabilities had someone who coordinated services for them or put them in touch with someone who could help; 20% (32) wanted this service but did not get it, and 34% (54) did not need or want the service;

- 45% (69) received dental care and 51% (42) of the respondents wanted dental care but could not afford this or were not offered this service;
- 26% (41) received counseling of some kind; among those who did not receive counseling services 13% (15) needed the service;
- 17% (26) received pain management therapy; among those who did not receive pain management therapy 14% (18) needed the service;
- 15% (24) received help to get job training; 21% (27) needed or wanted assistance getting training but 11 were not offered this and six (6) did not know of the service.

Table 5 shows the sources of support where Tribal members were currently receiving assistance from providers, including private medical doctors (67%), Medicare or Medicaid (37%), Native American Health Services (29%) and Native American Service Agency (20%), Social Security (27%), State Division of Social Services (17%), their church (15%), mental health professionals (13%) and State VR (3%).

Table 5: Percentage of Interviewees Currently Receiving Services

Person or Program Providing Assistance	Percentage/Frequency (n = 160)
Private medical doctor	67% (105)
Medicare or Medicaid	37% (58)
Native American Health Service	29% (45)
Social Security Administration	27% (43)
Native American service agency	20% (31)
Your church	15% (23)
State Division of Social Services	17% (27)
Psychologist, social worker or mental health counselor.	13% (20)
State Vocational Rehabilitation (VR)	3% (4)

Consumer Concerns and Barriers to Tribal Members with Disabilities

Respondents with disabilities reported the following regarding their community experiences (see Table 6): 82% felt safe in their neighborhood; 78% were not isolated from friends and neighbors because of their disability; and 60% reported that their community is a good place for a person with a disability. About half (47-53%) said that churches are sensitive to needs of members with disabilities; that handicapped parking is adequate; that public services (library, police, etc.) are provided on an equal basis to people with and without disabilities; and that checkout stands and aisles in stores were safe and accessible for shoppers who had disabilities. Some disagreed with these statements, and 28% to 44% said they did not know or had no opinion on these matters. Over a fourth (28%) said accessible public transportation was not available; over one third (37%) said accessible public housing was not available to people with disabilities; almost half (48%) said affordable housing is not available to people with disabilities, and a third or more (33% to 40%) said they did not know if these things were available.

Table 6. Community Issues for Tribal members with Disabilities

Statement:	Yes	No	Don't Know No Opinion
You feel safe in your home and neighborhood.	82% (128)	11% (17)	6.7% (10)
Are you isolated from friends and neighbors because of your disability.	17% (26)	78% (121)	5% (8)
In general, your community is a good place for a person with a disability.	60% (93)	16% (25)	24% (37)
Churches are sensitive to the needs of members who have disabilities.	47% (73)	8% (12)	44% (69)
Handicapped parking is adequate and enforced.	53% (82)	19% (30)	28% (44)
Public services (library, police, etc.) are provided on an equal basis to people with and without disabilities.	47% (73)	17% (27)	35% (55)
Checkout stands and aisles in stores are	49% (76)	22% (34)	29% (45)

safe and accessible for shoppers who have disabilities.			
Affordable, accessible public transportation is available.	39% (61)	28% (44)	33% (51)
Accessible public housing units are available to people with disabilities.	24% (38)	37% (57)	40% (61)
Affordable housing is available to people with all types of disabilities.	19% (30)	48% (75)	33% (51)

Community concerns regarding service providers are shown in Table 7; 24% to 70% replied they did not know or had no opinion regarding these statements. Over half (62%) said health service providers treat them with dignity and respect; (54%) believe service providers are sensitive to their disability; and (51%) that they do not encounter discrimination; 14% to 25% disagreed with these statements, and the rest did not know or had no opinion.

As shown in Table 7, over half (54%) said that health service providers are sensitive to their disability, but only one- fourth (27%) said that health service providers are sensitive to their culture. About half (47%) said that social service agencies did not inform them about benefits and services available to them; one-fourth (27%) said that social services are not provided on an equal basis to those with and without disabilities and 28% felt that non-Native American service providers do not make appropriate referrals. Almost half (44%) said that non-Native American agencies do not understand the range of Native American services.

Over half (51%) said you can get help applying for welfare, food stamps and social services; over a third (40%) said adequate mental health care is available and (34%) claimed adequate substance abuse treatment is available, a small percent disagreed, and about half did not know if treatment was available. Less than one-fifth (17%) said that the state Vocational Rehabilitation agency is responsive to the needs of Native Americans

with disabilities, 12% said it was not responsive, and over 70% said they did not know or had no opinion whether state VR was responsive.

About a third (36%) said they knew their rights as a citizen with a disability, 34% did not know their rights, and 30% said they did not know if they knew their rights or had no opinion. Over half (51%) said they did not have a say in government disability programming and planning.

Table 7. Consumer Concerns: Service Providers and Disability Issues

Statement:	Yes	No	Don't Know No Opinion
Health service providers treat you with dignity and respect.	62% (97)	14% (22)	24% (37)
Health service providers are sensitive to your disability.	54% (84)	17% (26)	30% (46)
Health service providers are sensitive to your culture.	27% (42)	31% (49)	42% (65)
As a Native American, do you encounter discrimination from service providers.	25% (39)	51% (80)	24% (37)
Social services are provided on an equal basis to people with and without disabilities.	26% (41)	27% (42)	45% (72)
Non-Native American service providers understand the range of Native American services.	11% (17)	44% (68)	46% (71)
Non-Native American service providers make appropriate referrals.	24% (38)	28% (44)	47% (73)
Information and referral for disability services are available to Native Americans with disabilities.	35% (54)	16% (25)	49% (77)
You can get help applying for welfare, food stamps and social services.	51% (79)	10% (16)	37% (59)
Adequate mental health care is available to you.	40% (62)	13% (20)	45% (72)
Adequate substance abuse treatment is available.	34% (53)	10% (15)	56% (87)
The public Vocational Rehabilitation agency is responsive to needs of Native American people with disabilities.	17% (27)	12% (19)	70% (108)
Social agencies inform you about benefits and services available to you.	24% (37)	47% (74)	28% (45)
You know your rights as a citizen with a	36% (56)	34% (53)	30% (46)

disability.			
As a citizen with a disability do you feel you have a say in government (disability programming and planning).	22% (34)	51% (79)	27% (42)

Consumer concerns regarding Native American agencies and the Tribal community are shown in Table 8. Again a large percent, 17% to 51%, said they did not know or had no opinion on these statements. About a third (34%) said their disability interfered with their ability to take part in Tribal culture/social or ceremonial events, and 49% said it did not interfere. About a third (32%) agreed that Native American agencies consider the needs of people with disabilities and 20% disagreed with this statement. Over a third (33%) said that Native American service agencies are not barrier free and 18% said they were barrier free. Less than a third (28%) said that the Native American community understands the needs of its members with disabilities and over a third (34%) said the Native American community did not understand these needs.

Table 8. Native American Community: Response to People with Disabilities

Statement:	Yes	No	Don't Know No Opinion
Your disability interferes with your ability to take part in Tribal culture/social or ceremonial/spiritual events.	34% (53)	49% (77)	17% (26)
Native American agencies consider the needs of people with disabilities.	32% (50)	20% (31)	48% (75)
The Native American community understands the needs of its members with disabilities.	28% (44)	34% (53)	37% (58)
Tribal personal care attendants are available.	31% (48)	18% (28)	51% (79)
Native American service agencies are barrier-free.	18% (28)	33% (51)	48% (76)

Improvement one Recognizing Resources for Native Americans with Disabilities at One Year Follow-up Evaluation

At the conclusion of the needs assessment interviews, the research technicians gave each participant a *Resource Guide* manual with information on resources for individuals with disabilities as well as pamphlets and information specifically about a Native American Vocational Rehabilitation Program. As shown in Table 9, 32% of the follow-up respondents said they had used the *Resource Guide* manual they received last year and 37% said they had shared it with others.

Two-thirds (67%) of the follow-up respondents said they knew more about services and resources for individuals with disabilities than they did a year ago (see Table 9). As shown in Table 10, when respondents were asked which sources gave them useful information about services that can help individuals with disabilities; 51% said the tribal research technicians, who did the survey with them, were their source for that information. No other source of information came close to this response regarding useful information for people with disabilities; 19% said Indian Health Services gave useful information, 11% said Tribal Council members, 11% said relative, 9% friend, 8% said the Resource Guide manual, 6% said a Native American tribal service agency and 2% said a Native American Tribal Center, TV and newspapers gave useful information.

Table 9. Resource Guide Manual & Increase in Knowledge

Statement	YES
Have you used the Resource Guide manual that you received last year?	32% (18)
Did you share the Resource Guide manual with others?	37% (20)
Do you know more about services and resources for people with disabilities than you did a year ago?	67% (36)

Table 10. Resources That Gave Useful Information

Resources That Gave Useful Information About Services that can help you with your disability	% Yes (n = 54)
Tribal RTs (who did survey last year)	51% (27)

Indian Health Services	19% (10)
Tribal Council Member	11% (6)
Relative	11% (6)
Friend	9% (5)
Resource Guide	8% (4)
Native American/Tribal Service Agency	6% (3)
Native American Tribal Center	2% (1)
TV	2% (1)
Newspaper	2% (1)
Radio	0
School	0
Church/Religious Worker	0

Discussion

This study identified the prevalence of disability of Native Americans in four Eastern Tribes; 171 (20.4%) out of 858 tribal members were identified as having disabilities. Three tribes had disability rates of 21-24%, similar to the rate of 22% of Native Americans with disabilities in this country reported by the National Council on Disability (2003). The fourth tribe had only 12% with disabilities, much lower than the others and the NCD rate. While there are no known reasons for the low rate, one of the locations of the data collection may have influenced the responses. A large number from this tribe completed the health and disability screening instrument at a tribal election and public polling place which may have led to less trust and less truthful responses even though confidentiality measures were fully explained and carefully addressed. In addition, those who went to the tribal election might have less mobility concerns with better health condition than those who stayed home. The tribe with the lowest disability rate was also the one with the highest per capita income. These tribal members have access to better health care, including better preventive health care, which may reduce the number of certain types of disabilities and health conditions.

Women were over-represented in this sample (over two-thirds were women) and the

average age was 49 with close to half over 50. The six most prevalent types of disabilities included hypertension, visual impairment, arthritis, obesity, diabetes and one or more mental health condition, including anxiety, chronic depression, and other disorders. Substance abuse including alcohol and drugs was not one of the ten most prevalent disabilities, and may have been under-reported as it was lower in this population (13%) than reported by Marshall (1992) in a study of western tribes (24%); and as reported in other studies (Huang, Grant, Dawson, Simon, Chou, Saha (2006). Over half who reported substance abuse in this study had one or more mental health conditions, thus needing treatment for co-occurring disorders. Disabilities limited Tribal members from working on a job, walking, seeing, lifting, reading and other functions.

Regarding barriers in the community, about half of the participants said:

1. Affordable housing for people with disabilities is not available (48%).
2. They do not have a say in government disability programming and planning (51%).
3. Social service agencies are not informing respondents about benefits or services (47%);
4. Having a disability interferes with taking part in Tribal cultural/spiritual events (49%);

Other concerns expressed by about one-third of the respondents included:

- Not knowing one's rights as a citizen with a disability (34%);
- The Native American community does not understand the needs of its members with disabilities (34%);
- Health service providers are not sensitive to respondents' culture (31%)

Almost 90% had a family member or friend they could count on to help them when needed. Most were currently receiving services from providers, with over half receiving

services from a private doctor. Over half of the respondents wanted dental care but could not afford it or were not offered this service. There was limited use of mental health professionals or vocational rehabilitation.

Over half of the tribal members with disabilities were working and over half of these were working full-time. The rest were unemployed and close to half of these, or almost one-fifth of all respondents, said they wanted a job. Problems reported for finding and keeping a job included limitations due to their disability, not having the right job skills, not knowing about available job openings, lack of transportation and discrimination. This high unemployment or underemployment among tribal members with disabilities may be attributable in part to residential segregation, employment in occupations with high turnover rates, and labor market discrimination (Wilson, Tienda, & Wu, 1995).

Vocational rehabilitation (VR) service agencies can provide support to individuals with disabilities to achieve a goal of obtaining and maintaining gainful employment. However, a high percent of tribal members with disabilities responded that they did not know or had no opinion regarding VR services. This indicates a lack of knowledge and use of public health or social agencies. This is especially true regarding state VR service. Only three respondents were currently receiving VR services; only 16% said that the state VR agency was responsive to needs of Native American people with disabilities and 70% did not know if VR services were responsive or not. Earlier studies showed that VR provides minorities with different services and consistently spends less money on minorities (Feist-Price, 1995; Olney & Kennedy, 2002; U.S. General Accounting Office, 1993), and some rehabilitation difficulties with members from racial minority groups have been noted (Atkins & Wright, 1980; Feist-Price, 1995). The discrepancies of

employment outcomes among different racial groups may be also due to Eurocentric bias on the part of the VR counselor (Wheaton & Hertzfeld, 2002; Wilson, Harley, & Alston, 2001) or employers in the workplace (Capella, 2002; Olney & Kennedy, 2002). A recent study conducted as part of this research project (Ni, Wilkins-Turner, Liebert, Ellien, & Harrington, 2009) explored this question in one eastern state and found there were no significant differences between a matched non-racial minority group and an American Native American group regarding VR services, including acceptance for services, treatment (number of services received and cost of services) or outcomes. However, only a very small number of Native Americans had used the state VR service over a five-year period.

The distrust of state agencies was a major reason for the development of a tribal vocational rehabilitation program in one northeastern state in 2002 which originally offered services to all federally or state recognized Native Americans residing in that state and then expanded into another state. Yet tribal members in those states were also slow in going to this tribal program, perhaps due to lack of knowledge or stigma about disability. The fact that tribal members with disabilities were also minimally involved with mental health professionals could relate to the stigmatization felt by people with disabilities. The stigmatization may be manifested by bias, distrust, stereotyping, fear, embarrassment, anger, and/or avoidance. In a report by the U.S. Department of Health and Human Services (2001), the Surgeon General concluded that despite the existence of effective treatments for mental disorders, the fear of stigmatization often deters individuals from acknowledging their illness, seeking help, and remaining in treatment. Perceived need or stigma also shapes use of mental health services (Ojeda, McGuire, 2006). As racial

minority populations are projected to experience substantial growth in the coming years (US Census Bureau, 2000), more numbers of individuals will need mental health services. Consequently, low use of mental health care by racial minorities is concerning. Effective strategies to reach out to Native Americans are needed. Educational programs or health promotion programs may be needed to expand Native Americans' contact with mental health providers and other services.

Health education and knowledge of available resources for Native Americans is needed for those who have long-term health care needs, mental health problems and other disabilities. Those with mental illness need to know that research has identified a range of effective treatments. At the conclusion of our survey interviews, the Research Technicians gave each participant in the study a packet of information about available resources in general and specifically about the MPTN Vocational Rehabilitation Program. The support network among Research Technicians, service providers, and Tribal members was expanded via use of participatory action research, which may lead to improved VR outcomes. A follow-up study approximately one year after the needs assessment interview will determine if the information provided to Tribal members has increased use of available services. This community based study also provided a unique opportunity for tribal members who were hired as research technicians to learn firsthand about careers in health and disability research and to become resource persons for their respective Tribes.

VR knowledge translation was evident here, with two-thirds of the follow-up respondents saying they knew more about services and resources for people with disabilities than they did a year ago. Over half said that tribal research technicians gave

useful information about services for people with disabilities, while less than one-fifth said Native American Health Services provided useful information to people with disabilities –the next highest source that was useful. About a third said they used the *Resource Guide* manual for help, and over a third said they had shared the *Resource Guide* manual with others. In addition, the respondents became more aware of the operation of the tribal VR program.

As a result of this study, knowledge about VR and other services for individuals with disabilities increased as indicated by the follow-up survey data. In the follow-up study, no one said they were not offered VR services or that they had no knowledge of VR services. In addition, the tribal VR program and the research technicians reported about 20 tribal members went to the tribal VR program as a result of the dissemination of information by this study. Some were participants in the research study, some were referred by the research technicians and some received information about the tribal VR Program from the *Resource Guide* manual, the program's website or pamphlets that were disseminated by this study. The previous issue of not knowing VR programs providing free employment services for Native Americans with disabilities appears to have been successfully addressed by the study.

However, some in this follow-up study indicated that though they needed help getting a job, they did not want to go for employment services. Reasons for this were not explained by the respondents but may have included fear of losing disability benefits; difficulties working because of their disability, family obligations or other personal problems, or they may have preferred not to work due to a combination of factors that outweighed the benefits of employment. These factors include only low-paying jobs available, high cost of

transportation.

A major strength of this research was the capacity building component, with the involvement of tribal members throughout the research process, and especially with the collection of data. One outcome was an awareness of tribal members with disabilities that did not exist prior to this research project. This community-based study provided a unique opportunity for tribal members who were hired as research technicians to learn firsthand about careers in health and disability research and to become resource persons for their respective Tribes. The follow-up study shows that the research technicians were the most useful resource for information about services for people with disabilities, at least for those tribal members that participated in the research surveys.

Limitations of this study include convenient sampling and over-representation of women, self-report, and not matching the follow-up subgroup data with Survey B data to identify type of disabilities. The sub-group of follow-up respondents may not have been representative of the total group regarding type of disability. In addition, due to heterogeneity among Native American tribes, one should not make generalizations to Native Americans as a whole. The data interpretation needs to be cautious.

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