The Replication of a Model for Determining Community-Based Needs of American Indians with Disabilities through Consumer Involvement in Community Planning and Change: Minneapolis-St. Paul, Minnesota

EXECUTIVE SUMMARY
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A complete Final Report, which describes in detail the research process and results, is available from the American Indian Rehabilitation Research and Training Center. The Final Report includes analyses of the results by age and by sex.

RESEARCH PROCESS

During the spring and summer of 1991, 127 face-to-face interviews were conducted with American Indians who had disabilities in the Minneapolis-St. Paul metro area. The research was conducted through the American Indian Rehabilitation Research and Training Center (AIRRTC). Persons interviewed were to:

1. Be an American Indian with a physical, intellectual, or emotional disability.

2. Be between the ages of 14 and 70 (to include both transition age adolescents as well as the older worker).

3. Not have alcoholism as his or her sole disability.

4. Live in the Minneapolis and St. Paul metro area, and not on a reservation.

The AIRRTC has found that a critical component of carrying out community-based research involves developing strong support among Indian service providers and consumers (see, e.g., Marshall, Johnson, Martin, Saravanabhavan, & Bradford,1992; Marshall, Johnson, Martin, & Saravanabhavan, 1991). In addition to hiring an on-site research coordinator from the Indian community, linkages were established with the Minnesota Division of Rehabilitation Services. Consumers were involved from the beginning of the project, and contributed questions that were included in the interviews. Indeed, one purpose of this project was to involve Indian people with disabilities in the process of research--to ensure their involvement in research beyond that of being subjects. Indian people with disabilities were

involved in designing the project, in particular, through their contribution of the questions or "issue statements" which were included in the survey (see, e.g., Fawcett, Suarez de Balcazar, Johnson, Whang-Ramos, Seekins, & Bradford, 1987). American Indians with disabilities were also hired as interviewers.

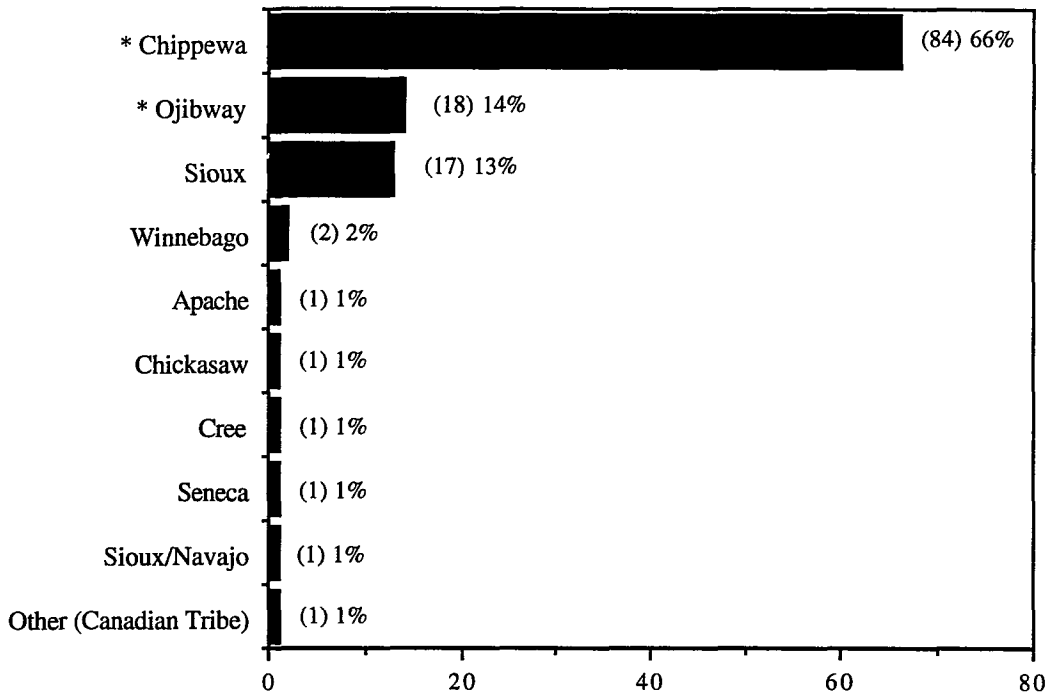
RESULTS

The majority of persons interviewed identified as either Chippewa or Ojibway (see Figure 1), with a mean age of 47 years. Slightly more than one-half [51% (n=65)] of the interviewees were male; 49% (n=62) were female. The average mean annual income of interviewees was $6,971. On average, interviewees reported having 2.14 disabling conditions each, primarily diabetes, arthritis, orthopedic disorders, and substance abuse (see Figure 2).

When describing their primary disability, many interviewees attributed the onset of their disability to an accident or traumatic injury. Typical statements included, "I got hit by a car and my head was smashed," "I got hit with a baseball bat," "I was in a car

Figure 1

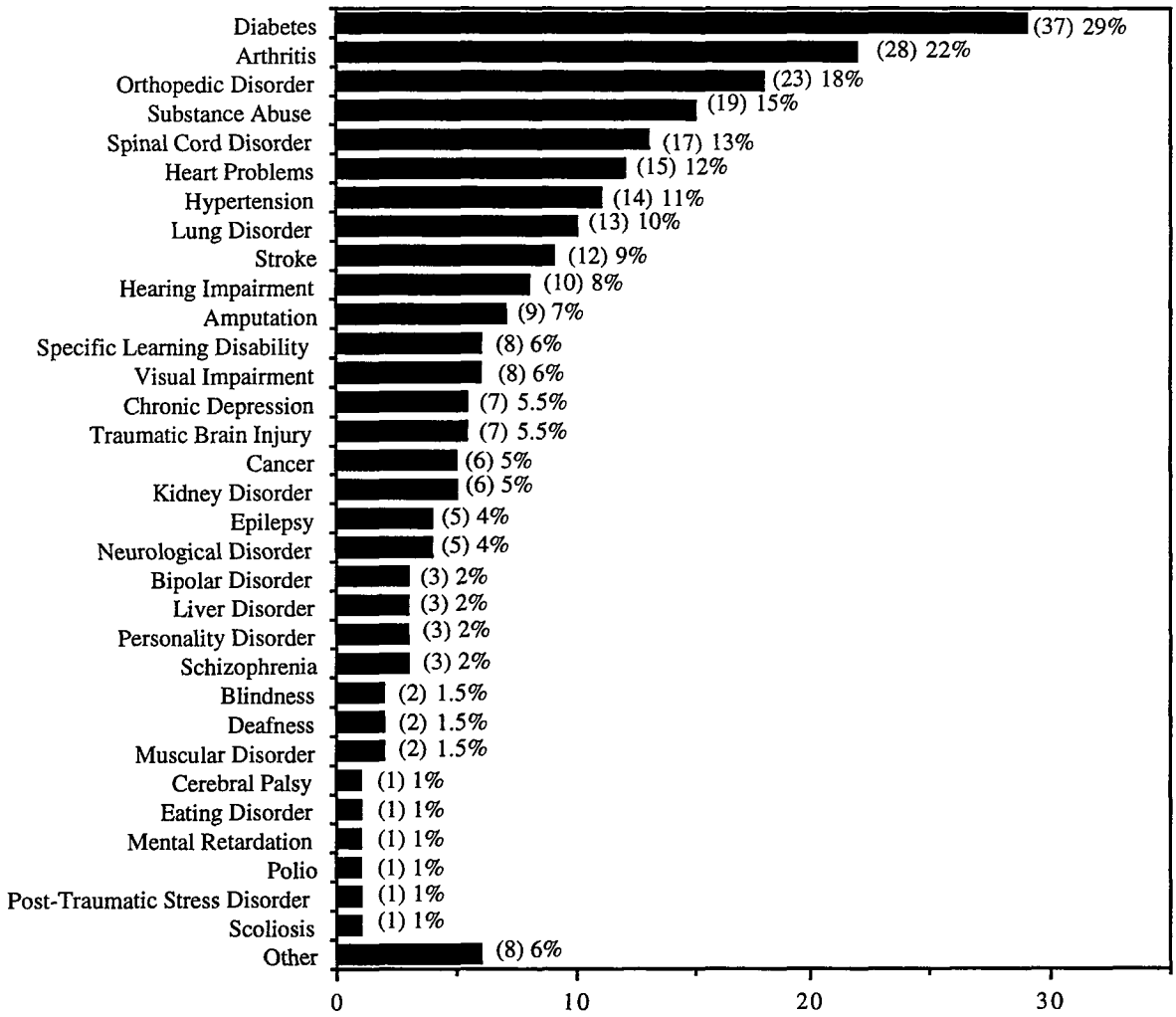
Tribal Affiliation



Note. Bar reflects percentage. Actual number in parenthesis. *Combined=(102) 80%; "Chippewa" and "Ojibway" are interchangeable terms referring to the same tribe. They are listed here separately to reflect the self-identification of individual interviewees.

Figure 2

Disabling Conditions Reported by Interviewees



Note. Bar reflects percentage. Actual number given in parenthesis.

accident and was hit by a truck," "I was in a car accident and I broke my neck," "I was in a car accident; it was hit and run. My knees and legs were smashed," "I was shot by a gun," and "I was accidently shot by a gun."

Interviewees frequently described how their primary disability resulted in multiple disabling conditions, as well as functional limitations. For example, "My back, hips, and shoulders are in constant pain which prevents me from sitting, standing, or walking for any length of time;" "My prosthesis (artificial foot) is

too heavy so I can't walk properly, and I have trouble standing;" "My depression ... prevents me from sleeping, eating, and going on with life;" "I drank alcohol until I damaged the nerves ... the part that affects my balance and my ability to walk;" "My diabetes bothers me most with my eyesight;" "Headaches, balance, chronic neck pain, double vision, and hearing impairment are caused by that brain injury ...;" and "I started with diabetes and finally had kidney failure...."

The majority of interviewees reported that their disability(ies) limited them in working on the job [72% (n=92)], lifting [67% (n=85)], and walking [67% (n=85)]. In terms of assistive devices, interviewees did not report needing expensive, state of the art, high-tech equipment. Instead, the majority reported needing very basic assistive devices such as glasses [57% (n=72)].

Information was obtained from interviewees regarding their health care and human service needs, access to formal and informal support systems, and barriers to accessing services and employment. For example, at the time of the interview, 50% (n=64) were utilizing Social Security Administration, while 10% (n=13) were utilizing the public vocational rehabilitation services. Typical barriers to accessing services included "service not offered," and "did not know of service." A lack of transportation was also given by many interviewees as the reason they were unable to access needed services (see Table 1).

Relative problem areas as identified through the interviewees' responses to "issue statements" included a lack of affordable housing, a lack of information from service agencies regarding the availability of benefits and services, a lack of self-advocacy among Indian people with disabilities, a lack of equal employment opportunity for people with disabilities, a lack of understanding in the Indian community regarding the needs of Indian people with disabilities, and the lack of a central information and referral service for Indian people with disabilities.

The majority of interviewees had obtained at least a high school diploma or GED. No one reported having a graduate degree; 6% reported having obtained a Bachelor's degree. The majority of interviewees reported that they would like to increase their education, even though they did not believe that their previous education had adequately prepared them to do so. The majority also stated that their education had inadequately prepared them for the "world of work." Twenty percent of those interviewed were working for pay. The average mean annual income for those employed was $12,867, almost twice the average for those not working. For working women, the average was $10,153; for working men, $16,033.

Table 1

Services Needed in Past Year but Not Received

Services	% of Interviewees Needing but Not Receiving[a]		Barriers[c]		
	n	%[a]	n	%[b]	Barrier
1. Coordination of Services	(32)	48%	(19)	59%	Service not offered
			(19)	59%	Did not know of service
			(10)	31%	Could not afford
2. Help Receiving Food	(25)	45%	(8)	32%	Service not offered
			(8)	32%	Did not know of service
			(7)	28%	Could not afford
3. Help Receiving Clothing	(45)	45%	(22)	49%	Did not know of service
			(20)	44%	Service not offered
			(13)	29%	No transportation
4. Help Receiving Housing	(33)	36%	(21)	64%	Service not offered
			(15)	45%	Did not know of service
			(7)	21%	No transportation
5. Help Receiving Benefits	(29)	40%	(19)	66%	Service not offered
			(7)	24%	Did not know of service
			(5)	17%	Did not want to use
6. Instruction in Activities of Daily Living	(21)	19%	(9)	43%	Service not offered
			(9)	43%	Did not know of service
			(4)	19%	No transportation
			(4)	19%	Not well enough to use
7. Vocational Training	(38)	37%	(21)	55%	Service not offered
			(18)	47%	No transportation
			(17)	45%	Did not know of service
8. Medical Care	(7)	39%	(3)	43%	Could not afford
			(2)	29%	Service not offered
			(2)	29%	Did not want to use
9. Dental Care	(34)	52%	(12)	35%	Could not afford
			(11)	32%	Did not want to use
			(9)	26%	Service not offered
10. Individual or Family Counseling	(24)	26%	(11)	46%	Service not offered
			(8)	33%	Did not know of service
			(8)	33%	Did not want to use
11. Alcohol Treatment	(13)	13%	(5)	38%	Service not offered
			(4)	31%	Did not want to use
12. Drug Treatment	(11)	10%	(6)	55%	Service not offered
			(4)	36%	Did not know of service
13. Legal Assistance	(18)	16%	(10)	56%	Service not offered
			(8)	44%	Did not want to use
			(6)	33%	Did not know of service

[a] Percentage based on number not receiving services. [b] Multiple-response item; percentage based on number not receiving services, and may be >100%. Top three barriers listed. [c] Barrier options: (a) the services were not offered to me, (b) I had no way of getting to the service, (c) the hours were not convenient, (d) I could not afford to use the service, (e) I wasn't feeling well enough to use the service, (f) did not know of service, and (g) I didn't want to use the service (explain).

The majority of interviewees cited their disability as having been a problem in terms of both finding and keeping a job. A lack of transportation was cited as a problem by over a third of the interviewees. Over a third also stated that their lack of skills, specifically their lack of education and training, was a problem. Over a third reported that employers did not give them a "fair chance." Various forms of discrimination were identified by interviewees as blocking their employment opportunities--discrimination due to ethnicity, age, sex, and disability.

CONCERNS FROM A PUBLIC MEETING

Interviewees and service providers were asked to comment on the results of this study at a public meeting held at the Minneapolis American Indian Center. Several consumers spoke of their experience in accessing services. Individuals expressed the desire to take responsibility for their health and well-being, but also expressed frustration after encountering insensitive health care professionals, and inadequate service delivery. For example, one man stated:

> *We go through four stages of life in this circle of life. One is an infant, into an adolescent, into adulthood, into an elder, and then back into Mother Earth. Along that scared hoop, the sacred ride, the road of life that we're supposed to walk on, that's where you're supposed to take care of yourself. I've experienced that I didn't do that myself. I was an alcoholic for 10 years on my reservation where I came from. I tried all these things, you know, so I have to suffer the consequences. So through that, I had a stroke, through that I was a borderline diabetic, so I'm fighting these things now within my own self.*

A young woman stated:

> *I am a diabetic and now I'm taking insulin because I'm six months pregnant and I can't control my blood sugar. Where I go to the doctor, you can take classes, and I asked why so many people that are Indian have diabetes ... I was told that, well, Indian people, most of them drink; they're poor, they don't eat the right kind of diet. It's mainly, to translate it, more or less, it's Indian people's own fault if they have diabetes. I didn't buy it. Needless to say, I never went back to another one of those classes because I didn't care to learn any more if that's what I was going to learn.*

In terms of vocational and education needs, one young man reported becoming "disabled as a result of a dislocated hip from a fight." Initially misdiagnosed as having a "pulled muscle," the man recalled:

They thought I was there [the hospital] for painkillers, so they sent me home, and about two weeks later, I drug myself back into the hospital. Before the injury I weighed about 195 pounds. And when I went back into the hospital, I weighed about 130 pounds ... I was in the hospital for about eight months, and I was told I was never going to walk again ... It took a long time for me to finally realize that there was some kind of plan for me to carry out. I decided I had better go to school. I went to vocational rehabilitation in Minneapolis, and they put me through school ... I went to Duluth, and ran into Sharon Johnson ... I think if it wasn't for her, I don't think I would have had any opportunity to put any of those skills to work ... The number one priority, I believe, for disabled people is to get that education, because it's tough to get a job without having any skills.

RECOMMENDATIONS

Findings from this study were so similar to that of an earlier study (Marshall, Johnson, Martin, & Saravanabhavan, 1991) that previous recommendations also apply, and include, in-home outreach, case-management services, vocational rehabilitation services which focus on the needs of an aging work force, increased employment opportunities, self-advocacy on the part of American Indians with disabilities, education regarding legal rights, education regarding the "health and wellness" aspects of disability, and increased numbers of American Indians working as professionals who serve people with disabilities. In addition, the following recommendations are made:

1. Non-Indian service providers and educators must assess their knowledge of Indian culture and traditions. Where their knowledge is deficient, or lacking altogether, they must take remedial action, for example, taking a university course on Indian culture; attending a conference on Indian education, health, or rehabilitation; or developing an in-service training program utilizing Indian consultants.

2. Service providers must be knowledgeable regarding the legal rights of American Indians with disabilities, including recent provisions under the Americans with Disabilities Act (ADA).

3. Service providers must be willing to advocate, along with the client, for the client's rights. In addition, service providers must be willing to listen to the client's self-advocacy. Service agencies must include American Indian consumers on their advisory boards, and follow their recommendations for service delivery.

4. Supervisors of health and human service professionals must ensure that performance evaluations include an assessment of the knowledge, skills, and attitudes required to competently serve clients of different cultures.

5. Service providers must be willing to reach out to Indian people in their communities, both to provide services, and to encourage them to continue their education in areas of health and human services.

6. Service agencies which receive Federal funds, and which serve American Indian populations, must demonstrate active recruitment of Indian service providers and active outreach efforts in Indian communities. This might include, for example, satellite offices located in Indian communities and staffed by Indian personnel. Non-federal funding sources such as the United Way, must also require recipients of their funding to demonstrate their recruitment and outreach efforts.

7. Universities which receive Federal funds to train professionals in rehabilitation counseling must demonstrate active recruitment of non-majority students.

8. Organizations which provide accreditation for university programs that train health and human service professionals, for example, the Council on Rehabilitation Education, must mandate that students receive required, core course work in providing services to non-majority populations.

9. Communities must work together to ensure that public transportation (now required by law to be accessible), is also convenient, with extensive routes linking inner cities to jobs.

10. Communities must work together to ensure that jobs pay enough to support oneself, one's family, and the added expenses that disability often brings.

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