

**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**

Final Report

**Follow-up Assessment (1995-1996) of the Impact of the
1991 AIRRTC Community-Based Needs Assessment**

2000

Robert M. Schacht, Ph.D.
Rebecca Vanderbilt, M.A.
Margaret White, Ph.D.

American Indian Rehabilitation Research and Training Center



**Arizona University Affiliated Program
Institute for Human Development
PO Box 5630
Flagstaff, Arizona 86011**

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American Indian Rehabilitation Research and Training Center
Arizona University Affiliated Program
Institute for Human Development
Northern Arizona University
PO Box 5630
Flagstaff, Arizona 86011
(520) 523-4791 Voice • (520) 523-9127 Fax • (520) 523-1695 TDD
Website: <http://www.nau.edu/~ihd/airrtc>

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This research project also investigated actions taken by the Minnesota Division of Rehabilitation Services (MDRS) in response to the recommendations listed in the 1991 needs assessment. MDRS took several steps to improve service delivery to American Indians with disabilities. For example, based on the AIRRTC recommendations from the 1991 study, MDRS created an American Indian Advisory Committee to develop training curriculums and to guide agency activities, and hired an additional five American Indians. MDRS staff also assisted with establishing improved public transportation that is accessible for individuals with disabilities.

Based on the focus group and survey information, this report provides several recommendations. For example, gains made based on recommendations from the 1991 study need to be made permanent. Transportation and human rights issues need to be addressed. Vocational rehabilitation counselors need support from their agency to obtain the best possible rehabilitation for their clients.

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

This project represents a follow-up study (Phase II) to the community-based needs assessment conducted in Minneapolis-St. Paul during 1991 (AIRRTC Project R-24) by Dr. Catherine Marshall, Charlene Day-Davila, and Denise Mackin (1992). The project design called for a follow-up to evaluate whether or not positive community change occurred in the areas identified as "consumer concerns," and whether the recommendations from the 1991 (Phase I) study had been addressed. The follow-up study was conducted in Minneapolis-St. Paul in 1995-1996.

Research Questions/Hypothesis

The principal research hypothesis for this project was that the information generated by the community-based needs assessment model used for Phase I resulted in improved rehabilitation service delivery to American Indians in Minneapolis-St. Paul. A subsidiary hypothesis was that participatory research of the kind used in this assessment model motivates action by members of the local community that results in improved service delivery.

The two sample populations invited to participate in the study were (a) American Indians who had disabilities who had lived with their disability in the Twin Cities metro area since 1991, and (b) agencies interested in serving them.

Thus, the intent of this follow-up study was to receive input from consumers and service providers regarding whether or not there had been positive community change on any of the issues initially identified by the community as high-priority problems. Attempts were made to associate these changes with specific activities conducted as part of the 1991 needs assessment.

The evaluation model used for this follow-up study was derived from "action research" as described by Patton (1990), "Action research explicitly and purposefully becomes part of the change process by engaging people in the program or organization in studying their own problems in order to solve those problems (pp. 157-158)."

The standard for judging this kind of research is "feelings about the process among research participants, [and] feasibility of the solution generated" (Patton, 1990, p. 161). In much action research, the process itself is the product, so a report for outside consumption may not always be necessary. Validation of the research depends in part on the practitioners (i.e., consumers) themselves, who take part in evaluating, interpreting, and reflecting on the data generated through the research process. This means opening the research process to a kind of validation through consensus. One way of gathering such a consensus is through the use of focus groups. Accordingly, focus groups were conducted in Minneapolis-St. Paul.

METHODOLOGY

The original proposal for the follow-up study for the first AIRRTC community-based needs assessment in Denver (O'Connell, 1987) called for conducting another survey (post-test) using the same questions as the original survey (pre-test), in which case the analysis would involve comparing aggregate responses to the same issue statements to test for significant differences in responses. However, when it came time to conduct the follow-up study in

Denver, there was a shift to a greater reliance on focus groups (Marshall, Aragon, Mitchell, Rose, & Saravanabhavan, 1994). A primary reason for the shift was that the planned post-test procedure would have been cost-prohibitive and the same results could be obtained through focus groups. The next follow-up study was scheduled for Minneapolis, and Schacht and Saravanabhavan (1993) decided to attempt an abbreviated form of the O'Connell post-test survey, combined with focus groups such as those used in the Denver follow-up study.

Procedure

The first step used by the AIRRTC in this community-based needs assessment follow-up began with a community meeting to plan the implementation of the project and select a local research coordinator. This was followed by a meeting with interested local parties to develop the survey instrument. At the completion of the follow-up, the results were presented and discussed at two focus group meetings in Minneapolis. The details of these procedures are described below.

Initial Planning Meeting

A meeting was convened on June 23, 1995, with a local project management team in the Twin Cities metropolitan area. The meeting was hosted by the Minneapolis office of the Rehabilitation Services Branch of the Department of Economic Security. Participants consisted of service providers and consumers who were involved in the 1991 community-based needs assessment (Phase I). During the morning session, the recommendations from the 1991 research were reviewed. A candidate for the position of local research coordinator (Charlene Day-Davila), who had been the on-site research coordinator in Phase I (the needs assessment), was interviewed and selected. Plans for implementation of the project were reviewed and discussed.

Instrumentation

During the afternoon session on June 23, the questionnaire used for the 1991 Minneapolis study, 23 pages long, was reviewed and questions that could be eliminated were identified (Marshall, Day-Davila, & Mackin, 1992). The questionnaire was reduced as much as possible, mainly by omitting open-ended questions. However, the entire Consumer Concerns section (4 pages) was retained in its 1991 form to facilitate comparison of results.

Target Population

There were two target populations for this study--service providers in the Twin Cities who worked with American Indians with disabilities and the American Indians with disabilities themselves. The role of the service providers was (a) to assist with project design and implementation, and (b) to assist with the evaluation of the project as a whole by providing information on how the results of Phase I of the project had been used in the community. The service providers were mainly those who had been involved in Phase I; they would have had the most direct access to information about the impact of the needs assessment. A letter was sent to these service providers, the first target population, on February 21, 1996, requesting their impressions of the role of the 1991 needs assessment in causing, stimulating, or influencing the course of change.

The role of the American Indians with disabilities was (a) to assist with project design and implementation, (b) to provide information, in a structured interview format, that would be used to analyze the impact of the Phase I needs assessment conducted in 1991, and (c) to assist with the evaluation of the project as a whole. The goal for this second target population was to interview 50 American Indians with disabilities who had lived in the Twin Cities from 1991 to 1996, and who had had a disability during that period. Half of these interviews

were intended to be with respondents who had participated in the 1991 study, and half could be new. If available, they were to be interviewed face to face, either using the modified questionnaire, or as part of a focus group (see below). Interviewees received a stipend for their time and effort. The interviewer also received a stipend for each interview.

Interviews

When the local research coordinator from Phase I of the project became available to fill the position in Phase II, she became interested in also conducting the interviews. Since she had been involved with the original interviews, it seemed that this would ease the process of contacting and recruiting previous respondents for this follow-up survey. Since she was already familiar with the survey instrument and procedures, this simplified the initial training process. Unfortunately, due to personal circumstances, she was unable to perform this job. This resulted in significant delays in the project. Two more interviewers were then recruited with the assistance of local service providers, including the Minneapolis American Indian Center. These interviewers were trained via conference call. The new interviewers attempted to contact all 1991 respondents; however, this proved to be very difficult. Additional respondents were interviewed. Since they were also American Indians with disabilities who had lived in the Twin Cities since 1991, they, like the 1991 respondents, had some knowledge of the same service delivery system.

Focus Group Interviews

Separate focus group interviews were conducted on July 23, 1996, at the Minneapolis American Indian Center, with (a) service providers to American Indians with disabilities, and (b) American Indians with disabilities in the community, following the procedures developed by Marshall and

Saravanabhavan (1992). These focus groups consisted of persons involved in the 1991 needs assessment, along with others who had become involved in community-based efforts to improve the quality of services to American Indians with disabilities in the target communities since the 1991 needs assessment. To stimulate and guide the focus group interviews, a preliminary analysis of the follow-up questionnaires was conducted.

Analytical Procedures

The impact of the 1991 community-based needs assessment (Marshall, Day-Davila, & Mackin, 1992) was measured in several ways: (1) A comparison of the consumer concerns in the 1991 study was made with the concerns in the follow-up assessment to identify changes in the relative importance and satisfaction of each item. (2) Service providers were requested to supply documentation on how they had used the results of the 1991 study in policy planning, grant applications, service delivery, and so forth--i.e., by examining the response to changes recommended by the 1991 community-based needs assessment. (3) The project team also looked for unanticipated responses on the part of the community to results of the 1991 needs assessment.

RESULTS

Results of the follow-up were obtained from three data sources: 1) A survey of consumers, 2) a survey (via letter) of service providers, and 3) focus group interviews with both service providers and consumers. The results from each of these three data sources are presented below.

Results from Questionnaires

Although the number of respondents (10) was disappointing and hardly forms a basis on which to draw conclusions, their responses are not without value, and in many ways do not differ from the 1991 results. The following quantitative summary of the questionnaires served as a basis to stimulate discussion of the focus groups.

Demographic Information

Previous Participation

Of those interviewed, 2 of 10 (20%) reported participating in the 1991 needs assessment. One interviewee did not provide information regarding participation in the 1991 survey and seven said they had not participated.

Age

The mean age of the interviewees in the follow-up study was 50.2 years, with a range of 26 - 66. The mean age of the interviewees in the 1991 study was 47.3 years, with a range of 14 - 70.

Sex

The interviewees in the follow-up study were divided evenly in terms of sex: five (50%) were male and five (50%) were female. This distribution was almost the same as the 1991 study, in which slightly more than half (51%; n=65) of the interviewees were male and 49% (n=62) were female (see Table 1).

Table 1				
Sex of Interviewees				
	1991		1996	
	n	%	n	%
Male	65	51%	5	50%
Female	62	49%	5	50%
Total	127	100%	10	100%

Length of Residence

Most of those interviewed in the follow-up survey had lived in the Minneapolis-St. Paul area for at least 10 years; however, one person had lived there for only 5 years. In the 1991 study, interviewees reported living in the Twin Cities metro area for an average of 24 years.

Tribal Affiliation

The most common tribal affiliations in the follow-up study were similar to those in the 1991 needs assessment (see Table 2). In the 1991 needs assessment, 63% (n=80) reported knowing their tribal roll/allottee number. All of those interviewed in the follow-up study knew their tribal roll/allottee number or the agency at which they were enrolled. The most frequent tribal affiliation was Red Lake (Chippewa) (40%; n=4), included within the category of Minnesota Chippewa in the table.

Table 2				
Tribal Affiliation				
	1991		1996	
	N	%	N	%
Minnesota Chippewa	102	80%	8	80%
Sioux	17	13%	1	10%
Other	7	7%	1	10%
	Winnebago, Apache, Chickasaw, Cree, Seneca, Sioux/Navajo, Canadian Tribe		Menominee	

Marital Status

Marital status in the follow-up study had a distribution similar to that of the 1991 needs assessment, except there was a higher percentage of widow(er)s (see Table 3) in the follow-up.

Income

The largest group of respondents in the follow-up study (40%; n=4) reported individual annual incomes of less than \$5,000 per year (see Table 4). Another 20% (n=2) said they earned \$5,000 to \$10,000 per year. In other words, 60% (n=6) earned less than \$10,000 per year.

As in the follow-up study, the largest group of interviewees in the 1991 study (46%; n=58) reported individual annual incomes of less than \$5,000 per year. Another 36% (n=45) reported that they earned \$5,000 to \$10,000 per year. In other words, 82% (n=103) earned less than \$10,000 per year.

Table 3				
Marital Status				
	1991		1996	
	n	%	n	%
Never Married	39	31%	4	40%
Divorced	39	31%	2	20%
Married	24	19%	1	10%
Widow(er)	16	13%	3	30%
Separated	6	4%	0	0%
Other	3	2%	0	0%

Table 4				
Annual Individual Income				
	1991		1996	
	n	%	n	%
\$0 - 4,999	58	46%	4	40%
\$5,000 - 9,999	45	36%	2	20%
\$10,000 - 14,999	8	6%	2	20%
\$15,000 - 19,999	5	4%	1	10%
\$20,000 and over	10	8%	1	10%

Language Usage

In the follow-up study, all interviewees (n=10) reported that they were able to speak English fluently, all reported being able to read English, and 90% (n=9) reported being able to write English. The dominant language used in the home was reported as English (90%; n=9) with 10% (n=1) reporting the use of their Native language. Ninety percent (n=9) reported that they preferred service providers to use English when helping them. Ten percent (n=1) reported preferring a combination of English and their Native language in such situations.

In the 1991 study, the vast majority (98%; n=125) of the interviewees reported being able to speak English fluently, 97% (n=124) reported being able to read English, and 97% reported being able to write English. The dominant language used in the home was reported as English (78%; n=99), followed by 17% (n=22) who reported that a combination of English and their Native language was most often spoken in the home. Eighty-seven percent (n=110) reported that they preferred service providers to use English when helping them. Ten percent (n=13) reported preferring a combination of English and their Native language in such situations.

Reservation Preference

Of those interviewed in the follow-up study, 90% (n=9) reported a reservation that they considered home. The majority (60%; n=6) of the interviewees reported visiting their reservation two or three times a year. The remainder of respondents (n=4) were evenly divided between visiting never, once a year, several times a year, and, as one respondent wrote, "not for 12-14 years."

In the 1991 study, 82% of interviewees (n=104) reported that they had a reservation which they considered home. More than a third (37%; n=38) reported visiting the reservation once a year, followed by almost a quarter (24%; n=25) who reported being able to visit the reservation two or three times a year.

Educational Information

Follow-up Study

Of those interviewed in the follow-up study, 70% (n=7) had obtained at least a high school diploma at the time of the survey (see Table 5). Of those who had not obtained a high school diploma (30%; n=3), two had completed 11th grade and one had finished 10th grade. Only 10% (n=1) reported attending a special education class during K-12. Additionally, only 40% (n=4) stated that they felt their education had adequately prepared them for the world of work.

Table 5				
Education Level				
	1991		1996	
	n	%	n	%
No HS diploma or GED	43	34%	3	30%
High School Diploma	31	24%	2	20%
GED	31	24%	4	40%
Some College (incl. A.A. or B.A.)	18	14%	1	10%
Other	4	3%	0	0%

1991 Needs Assessment

Sixty-three percent (n=80) of interviewees in the 1991 study reported having obtained at least a high school diploma at the time of the survey (see Table 5). For those who had not completed high school, or who had not obtained a GED (34%; n=43), the average highest grade completed was 9th. Fifteen percent

(n=19) of those in the 1991 study reported having been in special education or a resource room during at least part of their K-12 education. As in the follow-up study, less than half (44%; n=56) of the interviewees thought that their education had adequately prepared them for the world of work.

Comparison

If we pool respondents with a GED with those who have a high school diploma, and those in the "other" category with those who have some college education, then the distribution by educational level of the respondents in the follow-up study is not significantly different from the 1991 study (χ^2 [2 df]=.571; p =.752).

Disability Information

Reported Disabilities

The disabling conditions reported by interviewees in the follow-up study, the previous 1991 study, and a recent study by Steele (1996) are presented in Table 6, in descending order of most common conditions in the 1991 study. The Steele study was based on 134 Native Americans who contacted the Rehabilitation Services Branch--Indian Affairs staff in Minneapolis-St. Paul, from spring 1995 to 1996. The most common reported disability (60%; n=6) in the follow-up study was orthopedic disorder. Arthritis and diabetes were reported with equal frequencies (40%; n=4). Disabilities reported as "other" included partial paralysis (n=2), knee problems (n=2), car accident (n=1), "Addisons-Cushions" disease (n=1), and asthma (n=1). In the 1991 study, the most common reported disability (29%; n=37) was diabetes, with 22% reporting arthritis (n=28) and 18% reporting orthopedic disorder (n=23). Steele (1996) reported higher frequencies of substance abuse, mental or emotional problems, and specific learning disabilities than were found in either the 1991 needs assessment or the follow-up study.

Table 6
Reported Disabilities

DI-1: Describe your disability	1991		1996		Steele, 1996	
	n	%	n	%	n	%
Diabetes	37	29%	4	40%		
Arthritis	28	22%	4	40%		
Orthopedic Disorder	23	18%	6	60%	39	29%
Substance Abuse	19	15%	1	10%	42	31%
Spinal Cord Disorder	17	13%	2	20%		
Heart Problems	15	12%	0	0%	11	8%
Hypertension	14	11%	2	20%		
Lung Disorder	13	10%	3	30%		
Stroke	12	19%	2	20%		
Hearing Impairment	10	8%	1	10%	4	3%
Amputation	9	7%	0	0%		
Specific Learning Disability	8	6%	0	0%	17	13%
Visual Impairment	8	6%	0	0%	7	5%
Chronic Depression	7	5.5%	1	10%		
Traumatic Brain Injury	7	5.5%	1	10%	6	4%
Cancer	6	5%	2	20%		
Skin, tissue/tumor					12	8%
Kidney Disorder	6	5%	0	0%		
Epilepsy	5	4%	1	10%		
Neurological Impairment	5	4%	1	10%		
Bipolar Disorder	3	2%	0	0%		
Personality Disorder	3	2%	0	0%		
Schizophrenia	3	2%	0	0%		
Mental/Emotional					40	30%
Blindness	2	1.5%	0	0%		
Deaf	2	1.5%	0	0%		
Muscular Disease	2	1.5%	0	0%		
Mental Retardation	1	1%	0	0%		
Other (see text)	8	6%	7	70%		

Disability Limitations

Ninety percent of respondents in the follow-up study (n=9) reported that their disabilities limited them in walking and lifting. Additionally, a large number (70%; n=7) reported limitations in the use of their arms. Most interviewees in the 1991 study reported that their disabilities limited them in working on the job (72%; n=92), lifting (67%; n=85), and walking (67%; n=85). Other limitations for this group and the follow-up study group are presented in Table 7, in descending order of most common limitations in the 1991 study.

Services Information

Respondents were asked a series of questions about what services they had received during the past year from an agency and why they may not have received some of the services they needed or wanted. In the follow-up study, and in the 1991 study, the barriers to service most commonly indicated were "the services were not offered to me" or "did not know of service." In both studies, three services that were wanted or needed but were not received stand out from all the rest: (a) coordination of services; (b) help receiving benefits (i.e., getting or applying for cash or food benefits or programs like SSI or food stamps); and (c) help receiving housing (see Table 8).

In Table 8, the first percentage is based on the number of respondents not receiving a particular service. For example, when the 127 respondents in the 1991 survey were asked if they had received vocational training, 24 said "yes," leaving 103 who had not received it. Of those who had not received vocational training, 38 said that they needed it, so the first percentage ($\%_1$) = $38/103 = 37\%$. They were then asked what barriers stopped them from getting the service. This was a multiple-response item, so the percentages can add up to more than 100%.

Table 7
Disability Limitations

DI-2: Does your disability limit you in...	1991		1996	
	n	%	n	%
Working on a job (e.g., working full-time not missing work)	92	72%	5	50%
Walking	85	67%	9	90%
Lifting	85	67%	9	90%
Seeing	56	44%	5	50%
Remembering	56	44%	3	30%
Reading	50	39%	2	20%
Use of arms	43	34%	7	70%
Use of hands	42	33%	5	50%
Taking care of self (e.g., dressing, bathing, toileting, shopping, cooking, eating)	38	30%	3	30%
Writing	34	27%	3	30%
Sitting	29	23%	3	43%
Having a sexual relationship	26	20%	1	10%
Hearing	25	20%	0	0%
Getting along with people	24	19%	0	0%
Speaking	17	13%	4	40%
Other	18	15%	2	20%

Table 8
Services Needed in the Past Year, and Services Not Received

	Services needed		But not received		Barriers
	n ₁	% ₀₁	n ₂	% ₀₂	
Vocational Training					
1991 Study	38	37%	21 18 17	55% 47% 45%	Service not offered No transportation Did not know of service
1996 Study	1	14%	1	100%	Service not offered, did not know of service
Help Receiving Housing					
1991 Study	33	36%	21 15 7	64% 45% 21%	Service not offered Did not know of service No transportation
1996 Study	4	40%	3 1 1	75% 25% 25%	Service not offered "All" Did not know of service
Coordination of Services					
1991 Study	32	48%	19 19 10	59% 59% 31%	Service not offered Did not know of service Could not afford
1996 Study	3	60%	2 1 1	67% 33% 33%	Did not know of service Could not afford Hours were not convenient
Help Receiving Benefits					
1991 Study	29	40%	19 7 5	66% 24% 17%	Service not offered Did not know of service Did not want to use
1996 Study	4	50%	1 1 1 1	25% 25% 25% 25%	Turned down, able to work part-time Did not know of service Trouble getting medical assistance No barrier information provided
Instruction in the Activities of Daily Living					
1991 Study	21	19%	9 9 4 4	43% 43% 19% 19%	Service not offered Did not know of service No transportation Not well enough to use
1996 Study	2	29%	1 1	50% 50%	Service not offered, did not know of service, and could not afford (No barrier information provided)
Legal Assistance					
1991 Study	18	16%	10 8 6	56% 44% 33%	Service not offered Did not want to use Did not know of service
1996 Study	1	10%	1	100%	Did not know of service

Only the most frequent responses are shown for the 1991 survey. The second percentage ($\%_2$) is based on the number not receiving a specific service, so $\%_2 = n_2/n_1$.

The respondents were also asked which services they were *currently* receiving. The responses for both the 1991 and the follow-up study are shown in Table 9, in descending order of most common services received in 1991.

Table 9				
Services Currently Received				
	1991		1996	
	n	%	n	%
Social Security Administration	64	50%	2	20%
Medicare or Medicaid	51	40%	3	30%
Indian Health Agency	38	30%	5	50%
Your Church	32	25%	2	20%
Indian Service Agency	28	22%	0	0%
Native Medicine	25	20%	1	10%
State Division of Social Services	23	18%	1	10%
Indian Center	21	17%	3	30%
Sweat Lodge	21	17%	0	0%
Alcohol Counseling Program	16	13%	0	0%
Mental Health Program	15	12%	0	0%
State Division of VR	13	10%	2	20%
State Job Service Program	8	6%	0	0%
Other	5	4%	1	10%

Consumer Concerns

There were 38 items in this section of the questionnaire and each was rated on a scale of 0 to 4 according to its importance and the degree of customer satisfaction. Average importance and satisfaction scores on a 100-point scale were obtained by multiplying the 0 to 4 rating by 25, and then averaging the responses. The sample size varied because if an item was not considered important, the respondent did not need to assess his/her "satisfaction" with the item. A "relative problem" combines the importance and satisfaction ratings into a single index. Intuitively, something is a problem if it is important, but also unsatisfactory in some sense. Since "satisfaction" was rated on a scale of 0 to 4 and transformed to a scale of 0 to 100, "dissatisfaction" can then be measured by subtracting the satisfaction score from 100.

Consequently, for purposes of comparison, the relative problem index was calculated as the arithmetic mean of the average importance and "dissatisfaction" ratings, i.e., the square root of the average importance rating times the average dissatisfaction (dissatisfaction = 100 - satisfaction) rating. Table 10 compares the importance and satisfaction ratings of the top "relative problems" from the 1991 needs assessment with the results from the follow-up study for the same items. The problem index was not part of the original report; it was calculated for 1991 from the importance and satisfaction ratings obtained in 1991. All items with a problem index of 66.40 or more for 1991 are shown on Table 10 in descending order by the 1991 problem index. This cut-off level was chosen because the resulting list of concerns is the same as in Table 7, Consumer Concerns - Relative Problems - General Results (Marshall, Day-Davila, & Mackin, 1992). For comparison, those same items were rated for 1996 (see Table 10).

For 1996, the number one relative problem was "Health service providers treat you with dignity and respect, and are sensitive to your disability and your culture" (see Table 11). This was a new issue identified as a top relative problem

Table 10

Consumer Concerns

		Importance			Satisfaction			Problem Index**		
		1991	1996	D*	1991	1996	D*	1991	1996	D*
1.	Streets and sidewalks in areas of public housing are safe and accessible.	88%	75%	13%	47%	50%	(3%)	68.30	61	7
2.	Affordable housing is available to people with all types of disabilities.	90%	75%	15%	49%	36%	13%	67.75	69	-1
3.	Qualified job applicants with and without disabilities are given the same opportunities.	80%	78%	2%	43%	25%	18%	67.53	76	-8
4.	You feel safe in your home and neighborhood.	93%	90%	3%	51%	40%	11%	67.51	73	-5
5.	Social agencies inform you about benefits and services available to you.	84%	80%	4%	46%	33%	13%	67.35	73	-6
6.	Indians with disabilities advocate for their own needs at the local, state, and federal levels.	82%	73%	9%	45%	39%	6%	67.16	67	0
7.	The Indian community understands the needs of its members with disabilities.	86%	78%	8%	48%	36%	12%	66.87	71	-4
8.	There is a central resource for information and referral for disability services available to Indians with disabilities.	81%	80%	1%	45%	47%	(2%)	66.75	65	2
9.	You know your rights as a citizen with a disability.	92%	75%	17%	52%	50%	2%	66.45	61	5

* D = Difference between 1991 and 1996 ratings

** Problem 1991 Index equal to or greater than 66.40 (see text)

Table 11
New Issues Identified by 1996 Respondents

	Importance			Satisfaction			Problem Index		
	1991	1996	D**	1991	1996	D**	1991	1996	D**
1. Health service providers treat you with dignity and respect, and are sensitive to your disability and your culture.	87%	83%	4%	54%	*28%	26%	63	77	-14
2. Assistive devices (wheelchairs, braces, hearing aids, etc.) are available and affordable.	82%	80%	2%	51%	*28%	23%	63	76	-13
3. Affordable, accessible public transportation is available.	85%	85%	0%	55%	*33%	22%	62	75	-13
4. As an Indian, you do not encounter racial discrimination from service providers.	83%	75%	8%	55%	*33%	22%	61	71	-10

*Statistically significant at the $p = .05$ level

** D = Difference between 1991 and 1996 ratings

as compared to 1991. Other items increased as a relative problem. "Qualified job applicants with and without disabilities are given the same opportunities" moved up from third in the problem index rankings to second (tied with "Assistive devices [wheelchairs, braces, hearing aids, etc.] are available and affordable)." This change is due largely to an 18% decrease in consumer satisfaction, the largest change among the top relative problems identified in 1991. However, some items decreased as relative problems. For example, "streets and sidewalks in areas of public housing are safe and accessible" was first in 1991, but dropped out of the top five relative problems in 1996.

In total, four new relative problems (see Table 11) were identified in the 1996 follow-up that had not been included among the relative problems in the 1991 study. In each case, these four concerns showed a statistically significant decrease in satisfaction at the .05 level. The top relative problems in 1996, combining information from Tables 10 and 11, were: 1) Health service providers treat you with dignity and respect, and are sensitive to your disability and your culture, 2) Qualified job applicants with and without disabilities are given the same opportunities [tied with] Assistive devices (wheelchairs, braces, hearing aids, etc.) are available and affordable, 3) Affordable, accessible public transportation is available, and 4) You feel safe in your home and neighborhood; [tied with] Social agencies inform you about benefits and services available to you (see Tables 10 and 11).

To get a better idea about the *significance* of the observed differences between the 1991 survey and the follow-up survey, a t-test was used to analyze differences between the Importance and Satisfaction ratings reported in Tables 10 and 11. None of the changes in either Importance or Satisfaction as reported in Table 10 were statistically significant at the $p = .05$ level. Differences that were statistically significant at the $p = .05$ level are marked with an asterisk in Table 11. Notably, all of these differences show a decrease of at least 22% in the satisfaction ratings for each item. Use of the t-test establishes that the observed differences in

the Satisfaction ratings in Table 11 were statistically significant, but that none of the other differences in those two tables were large enough, or had a large enough sample, to be statistically significant.

Employment Information

At the time of the follow-up interviews, five (50%) of the respondents were working for pay. Two (40%) of these were working full-time and three (60%) were working part-time. Four of the respondents were satisfied with their jobs. Three of the respondents were looking for a job. Of those not working for pay, one reported being a full-time student, one was retired, one was unemployed because of disability, and the remaining two respondents did not provide an explanation.

A series of questions was asked about work experience (paid or unpaid) and whether respondents had ever had any problems finding or keeping a job because of certain circumstances, listed in Table 12 in descending order of importance. Respondents were given the option of stating that a specific issue was a major problem, a minor problem, or not a problem at all. The problem most often cited for finding or keeping a job, "major" and "minor," was the lack of jobs in their area (70%; n=7), followed by not having enough money to look for work (60%; n=6), and not having the right job skills (50%; n=5).

Table 12**Work Experience**

Considering your work experience (paid or unpaid) have you ever had any problems finding or keeping a job because (of)...	Major Problem	Minor Problem	Total Problems (% of 10)
...there are no jobs available where you live?	2	5	70%
...you don't have enough money to look for work	2	4	60%
...you don't have the right job skills that are needed	2	3	50%
...your disability?	2	2	40%
...your ethnic background?	2	2	40%
...you do not have transportation?	2	2	40%
...your home responsibilities?	0	3	30%
...you don't know the best ways to look for jobs?	0	3	30%
...you don't know how to best fill out application forms, write a resume, or interview for a job?	1	1	20%
...employers do not give you a fair chance?	1	1	20%
...of your age?	1	1	20%
...of your sex?	0	1	10%

Final Interview Questions

At the end of the 1996 interviews, respondents were asked questions regarding future contacts and requesting additional comments. Most (80%; n=8) stated that they would be able to attend a meeting where the results of this 1996 study would be presented. More than half (60%; n=6) reported that they would like to learn how to be an advocate for American Indians with disabilities. Half (50%; n=5) of the respondents agreed to have their names given to a VR

counselor to aid in receiving needed services. Additional comments included the need for more involvement with the community of people with disabilities, cultural sensitivity training for non-Native providers, problems with restricted services, lack of community awareness of available services, and agency confidentiality concerns.

Minnesota Rehabilitation Services Response to AIRRTC Recommendations

As stated in the Methodology section, one source of data used to evaluate the effectiveness of the community-based needs assessment methodology was to ask service providers in Minneapolis-St. Paul to supply documentation on how they had used the results and recommendations of the 1991 study in policy planning, grant applications, and service delivery. The Minnesota Department of Economic Security, Division of Rehabilitation Services (MDRS) "implemented a number of strategies in response to the recommendations of the 1991 study on the Needs of American Indians with Disabilities in Minneapolis and St. Paul" (Lunz, 1998, p. 22).

Results of the Demonstration Grant

The first major impact of the 1991 project was a demonstration grant submitted by the Minnesota Department of Rehabilitation Services to the U.S. Department of Education, Rehabilitation Services Administration (RSA), which was funded from 1995 to 1997. Lunz's 1998 publication is the final report for this grant. Recommendations and recommendation numbers cited here are taken directly from the 1991 study (Marshall, Day-Davila, & Mackin, 1992, pp. 92-93), with the responses cited from the Lunz report (1998, pp. 13-15).

Recommendation 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.

1998 Response: Rehabilitation Services established a Cultural Diversity Workgroup to look at the training needs of VR staff. Several training activities were initiated in the area of Indian culture and traditions, both through in-service training program and in collaboration with professional organizations. We also developed a Cooperative Agreement with the Red Lake Nation Division of Rehabilitation Services (a 130 funded program) to provide additional training in the area of cultural diversity for our staff. In exchange, we are providing training and technical assistance to their program in the areas of grant administration and VR program development.

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

1998 Response: All service providers conducting business with the Department of Economic Security, of which Rehabilitation Services is a part, must attend agency-sponsored training on the ADA and must be in compliance (or have an acceptable plan to achieve compliance) with the Act. The training includes cultural inclusiveness training. The agency also conducts on-site assessments to determine if the service provider is maintaining ADA compliance.

Recommendation 3: Service providers must be willing to advocate, along with the consumer, 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.

1998 Response: Self-advocacy training for American Indian service providers and consumers was included as part of the leadership development training discussed in the first recommendation. This training included information about the ADA and the Minnesota Human Rights Act (state law provides more protections than the ADA).

The project established an American Indian Advisory Committee to assist in the development of all training curriculums, and to provide direction for all agency activities. We have also added American Indian representation to our State Independent Living Council, and we are recruiting for American Indian representation on our State Rehabilitation Advisory Council.

Recommendation 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.

1998 Response: Each local VR office is required to develop an annual Resource Investment Plan, indicating how the team will invest their human and financial resources to achieve the agency's goals. One of the goals is to ensure that all individuals have equitable access to services. VR does not require that every employee possess all of the skills needed to serve American Indians with disabilities, but every team must

demonstrate that they have an adequate number of qualified people to meet the need.

Recommendation 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 the areas of health and human services.

1998 Response: Utilizing project and other agency funding, VR hired five American Indians (four Indian Affairs Representatives and one rehabilitation counselor) to provide outreach and services on the reservations and Indian communities in the Twin Cities. This supplemented the three staff we had previously hired. Three of the new employees are enrolled in rehabilitation counseling courses at Mankato State University (agency-sponsored training) to become qualified for promotion to rehabilitation counselor. Six of the eight employees continued their employment with VR.

Recommendation 6: Service agencies that receive federal funds and 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 United Way must also require recipients of their funding to demonstrate such recruitment and outreach efforts.

1998 Response: In addition to the grant-funded satellite office that was opened at the Minneapolis American Indian Center, VR opened satellite offices on the reservations in northwest Minnesota. This is in addition to the satellite offices previously opened serving the Indian reservations in northeast Minnesota. The emphasis has been to co-locate and share

resources with existing American Indian service providers to provide a more comprehensive approach to services.

Recommendation 7: Universities that receive federal funds to train professionals in rehabilitation counseling and other health and human services professions must demonstrate active recruitment of non-majority students.

1998 Response: Vocational Rehabilitation is collaborating closely with Mankato State University's Master's degree program in Rehabilitation Counseling to recruit more students with disabilities from minority backgrounds. As an incentive to consider employment with this agency after graduation, we provided paid internships for this targeted population. The paid internships have been discontinued due to budget restraints, but the agency continues to offer practicum and internship opportunities, and students are encouraged to consider employment with the agency.

Recommendation 8: Organizations that 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.

1998 Response: No action has been taken on this recommendation.

Recommendation 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.

1998 Response: Project staff assisted the Minneapolis American Indian Center to obtain a grant to purchase a van to provide door-to-door transportation for American Indians who cannot access public transportation. The Metropolitan Transit Authority is currently studying

ways to improve transportation to the suburbs, including light rail options. Rehabilitation Services has provided public testimony on the need for all current and planned public transportation to be fully accessible. Many buses in the inner city area are now equipped with lifts, and the South Minneapolis Indian community is served by an accessible neighborhood van service that runs between the housing projects, shopping mall and industrial parks. Project staff testified for the need for this van service to link the residential areas with the nearby industrial park.

Recommendation 10: Communities must work together to ensure that jobs pay enough to support the worker with a disability, her or his family, and the added expenses that disability often brings.

1998 Response: The project coordinated with the American Indian Chamber of Commerce, local Projects with Industry and the American Indian community to provide better job opportunities. Placement efforts were expanded beyond the traditional casino jobs into professional and technical jobs. The average hourly wage for American Indian consumers has increased from \$7.39 in 1994 to \$9.07 in 1997. Further growth in wages is anticipated as current consumers complete post-secondary training programs.

Results of Focus Group Interviews

Two community focus groups were held in Minneapolis at the conclusion of this project on July 23-24, 1996, to present the material found in the Results section of this report. These two focus groups were held at the Minneapolis American Indian Center. One focus group was attended by service providers, mostly staff members from the Minnesota DRS. A second focus group was held

with consumers. The second focus group was supplemented by a separate meeting with a consumer who could not attend the scheduled focus group. Except for the beginning of the focus group with the service providers, these sessions were recorded on audiotapes and transcribed for the purpose of analysis.

The results of the follow-up survey were presented during the focus group, and members of the community gave feedback to help clarify or contextualize some of the results with additional information. This process assisted researchers in measuring the impact of the 1991 community-based needs assessment. Using transcripts from the focus groups, the most relevant comments were extracted and related to the findings of the survey. Comments from both service providers and consumers are included; the consumers addressed mainly "Consumer Concerns" items. It is indicated whether a comment came from a consumer (C), or a service provider (SP), but it is important to remember that consumers and service providers met separately.

Educational Level

In discussing the differences between the 1991 needs assessment and the 1996 follow-up reported in Table 5, one of the service providers pointed out that the follow-up sample, with only 10 respondents, was probably not a reliable sample for comparison. Some of the service providers drew attention to Table 5, which showed differences in the educational level of the 1991 sample and the follow-up sample. These differences show that the follow-up sample lacked respondents with an AA or Bachelor's degree, whereas 14% of the 1991 sample had one of those degrees. Thus, it is possible that some of the differences in the consumer concerns were the result of different levels of education. Another participant remarked that there had been an increase in the drop-off [dropout] rate at the university:

SP: Drop-off rates [are high] at the University of Minnesota in the cultural diversity ... the Indian populations have not grown. And that's a big concern. The kids may be going to school, but they are not finishing. But that's across the country. So what does that mean, I don't know.

Disability Information

Responding to the information that a higher percentage of people reported orthopedic disorders in the follow-up study (60% versus 20%), one of the service providers commented on a paper that he had written. In his paper (Steele, 1996), the rate of orthopedic disabilities among 134 Native Americans was 29%, compared with 30% with mental or emotional disabilities and 31% with alcohol or drug impairments. These disability frequencies have been added to Table 6, showing seemingly significant differences (although no statistical comparisons were attempted to establish significant differences). In the Steele study, substance abuse, heart problems, and specific learning disabilities were observed in much higher frequencies than in the 1996 follow-up study. However, Steele's study has no diabetes category, and that was one of the most frequent disabilities reported in Table 6 (29% in 1991 and 40% in the 1996 follow-up survey). One of the male service providers made this comment:

SP: They had a thing on the news this morning, I don't know if you heard it, about diabetes in the American Indian community; it is the number one concern. Because it's such a large rate, and so many Indians having diabetes, they said one in four.

Services Needed but Not Received

Table 8, indicating services needed but not received, elicited a fair amount of discussion. The follow-up study highlighted the issues of help receiving housing, help receiving benefits, and coordination of services as areas where people most often needed but were not receiving services. This provoked the following responses:

SP: And therein are some of the problems for me, because when does the rehab counselor become the social worker?

RMS: But isn't it a matter of making referrals?

SP: But we do more than that here though. These guys aren't just making referrals. I see sometimes they have to explain how it works, and they have to in fact fill out the forms, they have to guide them through the system because if they don't do that, and you guys who do that, Cheryl and others, pipe up here, because you're the ones that have convinced me that they have to do some of this to get them going, these are kind of the prerequisites before we can get them into rehab. Correct me if I'm wrong. And so what happens is that it isn't just a referral. We do make the referral. We're technically, you're right, we're supposed to make a referral. But if we make a referral, and we only just make the referral, we lose the consumer.

For this focus group, the question of barriers to service had become an ambiguous area of responsibility, with providers caught between narrow interpretations of eligibility for vocational rehabilitation (e.g., initially making referrals only) and the need to help consumers within a larger social service context (e.g., walking them through the process).

Services Currently Received

Table 9, which indicates the services currently received by consumers, provided information for several purposes. The discussion pertaining to this table focused on the issue of where the consumers were actually going. In discussing the services, one service provider made the following remark:

SP: A lot of people confuse Indian Health Board with Indian Health Service, but they are funded through them. So, it's the place where most Indians go for clinical, and medical, and dental.

The discussion continued,

SP1: But then a lot of people will go back to the reservation to use their own clinics back there too ...

SP2: Do you guys go back to ... Indian Hospital when you need the clinic.

SP3: Years ago, we had and we still have Indian Health Service out there ... But I myself do not Three or four people have died because of ... [the] Indian Health Service, because people [doctors] are ... first year out of medical school, their first year, they are there for three years. And... my mother died there ... and that's because they did not keep a watch on ... and I know of two other people who have died when they've gone there, and all they did was give them aspirin, and tell them to come back tomorrow. And they died that night ... there was two or three of them. For that reason, I just don't trust them. It's not the Indian Health Service, it's the doctors that they put in there. And they ... it's for them. Like many of the Indian programs that are run by government society, are ... just no good for the Indian people. And that's my personal opinion They say they want our trust, but we can't trust them. We trust them, we get ... it's been like that for 400 years.

In the discussion, another local organization was identified:

RMS: One of the things I wanted to ask about, I talked with someone last night, I am trying to remember the name now. There's an organization in town called something like Disabled Indian Workers, or DIW. Does anyone know what I am talking about?

SP2: The Division of Indian Workers, the Division of the Greater Minneapolis Council of Churches. It's a fairly significant part of our social service army.... They have a teen parents program. They have a ... children's program. They have some kind of a job employment services.... It's been around for years ... it's fairly substantial ... and they service like 11,000 Native Americans.

SP1: It's a social service agency building. And they have a lot of services available. Funeral assistance, food, shelter, clothing, fair. They have a new employment program, mentorship program, youth program, and community meetings.

SP2: They have some counseling person, counseling kinds of stuff

Consumers also discussed the issue of services received. Dr. Schacht asked in what ways the services most important to consumers had gotten better or worse since 1991. Two consumers stated that their services were about the same, and another said things were a little better.

The following interaction suggested that consumers would like individual services to extend the varieties of help offered:

RMS: In what ways have the services most important to you gotten worse since 1991? Does anyone have a problem with this happening?

C: The Indian Health Board has gotten better, but their big downfall is that if you have to have a prescription and you need an antibiotic, you will have to shell out

Actions Addressing AIRRTC Recommendations

On a very positive note, there was approval in the focus groups regarding actions taken toward the active recruitment by the Minnesota vocational rehabilitation agency of Indian service providers and support of their further education (this relates to Recommendations 5 - 8):

SP: [Two service providers] have been awarded a scholarship commencing this fall at Mankato State University. That scholarship is all-inclusive--tuition fees, books, and supplies. The other thing we might add is that all the people enrolled in post-high school coursework are earning grades of B or better. And that is critical to note there. I think that alleviates some of the stereotypes that they can't perform in the classroom.

Student papers written by Steele (1996) and Cyson (1996) dealing with rehabilitation issues reinforce this assessment. There was another illuminating comment regarding the post-Phase I recruitment and training of Indian rehabilitation professionals in the Minnesota Department of Rehabilitation Services:

SP: This is probably the first administration in a long time where we not only talk about it, but we are actually doing something. We have it in place. We have had to bring in other staff.... We have had to increase demand on the staff to do more with less. And we certainly had to put more demands on the counselors.

Through this grant [see Lunz, 1998], services have expanded in the community and we have a long way to go, but at least we are going down the road straight for the first time in our history in the urban part of Minneapolis and St. Paul.

Other steps taken to address the 1991 recommendations were appreciated, but in certain respects there was a consensus that even more needed to be done to alleviate local barriers. For example, many of the recommendations targeted the knowledge of service providers in conjunction with the dissemination of

knowledge and services within local communities. Regarding ADA training, one person made the following comment:

SP: I think there is a breakdown in communication between the training and the information that gets to the reservations.... The reason I say that is because when you have the conferences, those people need to be sent that information specifically. There needs to be some type of people involved in the training that they know, or maybe are familiar with.

Here, it was felt to be essential that rehabilitation services support continue and find its way to consumers right where they live, specifically using persons with whom consumers feel comfortable to disseminate the information.

A lengthy discussion revolved around transportation issues (Recommendation 9), which came up for discussion under both Consumer Concerns and the review of AIRRTC 1991 recommendations. Dr. Schacht asked the consumers' group about the status of affordable, accessible public transportation, and received similar responses from several respondents:

C: It is worse. Less buses, less convenient times that they run. And definitely more expensive.

One individual reported the following:

C: I have a lot of trouble getting a ride. We have a program called Natural Mobility, and I have to call 6 weeks in advance to get a ride. Therefore, I miss a lot of appointments. I think they are working out the problems scheduling a ride. In transportation, able-bodied Indians don't seem to have too much trouble getting a ride, but us crippled people do not have the resources. Medicare will not pay for a service.

academic training; that is, Indian professionals were demonstrating an advantage in recruiting Indian consumers because of their cultural competence. One of the service providers had mentioned the high university dropout rate among American Indians. Although it is doubtful that this dropout rate can be directly linked to the decrease in respondents with higher degrees seen in the follow-up, the observation of high dropout rates underlines the need to support American Indian university students through the completion of their degree, especially in the area of rehabilitation services. Unfortunately, the academic financial support base is easily eroded. Lunz indicates that "the paid internships have been discontinued due to budget restraints" (1998, p. 15). It is discouraging to see such important advances slipping away.

Transportation, the issue addressed by Recommendation 9, which also resurfaced as a new consumer concern identified by respondents in 1996, continues to be a challenge for many American Indians with disabilities. For many locations, ease of access appears to be a problem that requires ongoing collaboration among service agencies.

A rehabilitation issue that arose in the discussion among service providers related to ambiguous areas of responsibility in recruiting, maintaining, and supplying services to vocational rehabilitation consumers. A service provider asked the question, "When does the rehab counselor become the social worker?" It appears that the counselor has two options. One is for the counselor always to make referrals to another agency prior to official eligibility. This option is frequently experienced by the consumers as "getting the run-around" or "passing the buck." The other option is for the counselor to document that the consumer is having specific problems that affect his or her ability to gain employment. In this case, the counselor may assume eligibility and help the consumer solve the problem, resulting in a successful job placement. Outreach efforts are more likely to work when counselors choose the second option.

In the interval between 1991 and the 1996 follow-up, there has been a *decrease* in consumer satisfaction about equality of opportunity for qualified job applicants with and without disabilities (Table 10, Concern 3). The reason for this decrease was not readily apparent and did not receive much attention from focus group participants. Vocational rehabilitation counselors may need to do a better job of advocating for their clients in the job placement process, to address any concerns that potential employers might have.

Earlier, a service provider was cited saying, "We are going down the road straight for the first time in our history in the urban part of Minneapolis and St. Paul." This statement was in reference to expanded community services. The expanded community services led to a higher workload for VR workers and demonstrated the need for non-majority professionals who could bring in even more consumers. This result can be seen as a very positive growth cycle brought about by the infusion of grant money for research, demonstration, and services in 1991 and 1995-1997 (Lunz, 1998).

However, there is a danger that after improvements become measurable following a period of study and focus, support for these programs may begin to fade. It is crucial to continue the momentum that has begun, to support the upward spiral of success rather than allowing services to discontinue. It was reported in *The Circle: News from a Native American Perspective* (Wagner, 1996) that the St. Paul Indian Health Clinic had to close due to lack of funds. A similar situation may be seen in a follow-up study for Texas Rehabilitation Services, where it was noted that "the gains made by TRC in improved services to American Indians from 1991 to 1995 are now in danger of being lost" (Schacht & Vanderbilt, 1997, p. 52).

Recommendations

As a result of the foregoing discussion, we feel that the following recommendations are warranted:

Recommendation 1: The momentum gained during the years 1991-1997 need to be consolidated and made permanent, so that these gains do not slip away and fade, as attention shifts to other priorities.

Recommendation 2: Advocacy for human rights and vigilance in hiring the best service providers need to be increased, while implementing stronger sanctions against discriminatory behavior.

Recommendation 3: Federal and state budget priorities should be re-examined to maintain academic financial support for future American Indian professional human service workers. We recommend that this be made a permanent part of outreach efforts.

Recommendation 4: More culturally appropriate ways are needed to better achieve community dissemination of information about disability services.

Recommendation 5: Transportation problems need to be addressed by continued financial support and increased planning for ease of access in collaboration with other urban agencies. Minnesota Department of Economic Security, Division of Rehabilitation Services can play an important advocacy role in this regard.

Recommendation 6: VR policies should provide incentives for VR counselors to take appropriate responsibility for new cases involving American Indians. For example, incentives for counselor outreach to American Indians with disabilities should be built into counselor evaluation criteria.

Recommendation 7: Counselors should advocate for their clients in the job placement process to ensure that they have the same opportunities as similarly qualified job applicants without disabilities.

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