

**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: Phase I

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For Opie, Connie, Harlo, and Anni

TABLE OF CONTENTS

LIST OF TABLES	iii
LIST OF FIGURES.....	iv
EPIGRAPH	vi
ACKNOWLEDGEMENTS	vii
SUMMARY	ix
INTRODUCTION.....	1
METHOD.....	4
Instrumentation.....	4
Pilot-testing the instrument	5
Procedure	5
Percentage of agreement	5
Interviewer characteristics	6
Interviewee characteristics and recruitment efforts	6
Conducting and verifying interviews.....	7
Conducting public meeting	7
RESULTS	10
General Information	10
Disability Information	18
Services Information (Formal Support Systems)	23
Consumer Concerns.....	30
Social Information (Informal Support Systems)	34
Quality of Life.....	35
Educational Information	38
Employment Information	39
Conclusions	42
Selected Results by Age Categories	44

Selected Results by Sex Categories	63
DISCUSSION	83
CONCLUSIONS AND RECOMMENDATIONS	88
Recommendations	92
REFERENCES	95
APPENDICES	
Appendix A Correspondence Regarding Initial Meeting	98
Appendix B Job Description of On-site Research Coordinator	100
Appendix C Correspondence/Agenda for First Working Group Meeting	103
Appendix D Correspondence/Agenda for Second Working Group Meeting	106
Appendix E List of Issue Statements in Order of Average Satisfaction .	109
Appendix F Pilot-test Interviewer Training Agenda	113
Appendix G Agenda for Interviewer Training	116
Appendix H Interviewer Job Description	119
Appendix I Interviewee Recruitment Flyer	121
Appendix J Interview Certification Form	123
Appendix K Public Meeting Agenda.....	125
Appendix L Flyer Announcing Public Meeting	127
Appendix M Native City News Article	129
Appendix N Reservation Map	131
Appendix O Minneapolis - St. Paul Urban Area Maps	133
Appendix P Interviewer Project Evaluation	136
Appendix Q Critiques of Final Report.....	141

LIST OF TABLES

Table 1	Use of Assistive Devices and Treatment.....	20
Table 2	Needed Assistive Devices and Treatment.....	21
Table 3	Services Received at Time of Interview	24
Table 4	Services Received in Past Year	26
Table 5	Services Needed in Past Year but Not Received.....	27
Table 6	Consumer Concerns - Relative Strengths - General Results	31
Table 7	Consumer Concerns - Relative Problems - General Results	32
Table 8	Consumer Concerns - Relative Strengths - Minneapolis	33
Table 9	Consumer Concerns - Relative Problems - Minneapolis	34
Table 10	Interviewees in Agreement with Quality of Life Statements.....	36
Table 11	Education Level.....	38
Table 12	Employment Information	39
Table 13	Problems Cited in Securing Employment	41
Table 14	Consumer Concerns - Relative Strengths - Age under 45	59
Table 15	Consumer Concerns - Relative Problems - Age under 45	60
Table 16	Consumer Concerns - Relative Strengths - Age 45 - 59	61
Table 17	Consumer Concerns - Relative Problems - Age 45 - 59	61
Table 18	Consumer Concerns - Relative Strengths - Age 60 - 70	62
Table 19	Consumer Concerns - Relative Problems - Age 60 - 70	63
Table 20	Consumer Concerns - Relative Strengths - Female	79
Table 21	Consumer Concerns - Relative Problems - Female	80
Table 22	Consumer Concerns - Relative Strengths - Male	81
Table 23	Consumer Concerns - Relative Problems - Male	82

LIST OF FIGURES

Figure 1	Sex of Interviewees	12
Figure 2	Tribal Affiliation.....	13
Figure 3	Marital Status	14
Figure 4	Annual Individual Income.....	15
Figure 5	Most Frequently Used Transportation	17
Figure 6	Disabling Conditions Reported by Interviewees	18
Figure 7	Functional Limitations	22
Figure 8	Health Status.....	23
Figure 9	Primary Referral Source.....	29
Figure 10	Income Ranges of those Employed	40
Figure 11	Age of Interviewees.....	44
Figure 12	Sex of Interviewees by Age.....	45
Figure 13	Marital Status of Interviewees by Age	46
Figure 14	Affiliation to Tribe and Community by Age	47
Figure 15	Average Years Lived in Minneapolis Metro Area by Age	47
Figure 16	Preferred Language for Service by Age	48
Figure 17	Primary Transportation Modalities by Age.....	49
Figure 18	Primary Disabling Conditions by Age	50
Figure 19	Primary Needed Assistive Devices by Age	51
Figure 20	Health and Life Satisfaction Ratings by Age.....	52
Figure 21	Primary Functional Limitations by Age	53
Figure 22	Primary Service Needs by Age.....	54
Figure 23	Educational Degrees by Age	55
Figure 24	Adequacy of Education by Age.....	56
Figure 25	Full-time vs. Part-time Employment by Age.....	57
Figure 26	Primary Problems in Finding or Keeping Employment by Age	58

Figure 27	Ages of Interviewees by Sex	64
Figure 28	Martial Status of Interviewees by Sex	65
Figure 29	Affiliation to Tribe and Community by Sex.....	66
Figure 30	Average Years Lived in Minneapolis Metro Area by Sex	66
Figure 31	Preferred Language for Services by Sex	67
Figure 32	Primary Transportation Modalities by Sex	68
Figure 33	Primary Disabling Conditions by Sex	69
Figure 34	Primary Needed Assistive Devices by Sex.....	70
Figure 35	Health and Life Satisfaction Ratings by Sex	71
Figure 36	Primary Functional Limitations by Sex.....	72
Figure 37	Primary Service Needs by Sex	73
Figure 38	Educational Degrees by Sex	74
Figure 39	Adequacy of Education by Sex	75
Figure 40	Full-time vs. Part-time Employment by Sex	76
Figure 41	Primary Problems in Finding or Keeping Employment by Sex	78

The child said, "My name is Mary in the English way, but in the language of our people, I am called A-wa-sa-si."

"And what is it you wish, my child?" asked Oona.

"I should like," said the child, "to hear the stories of our people."

Oona felt a joy in her spirit and a light on her face. She knew that the Ojibway ways would forever be known in future years.

Ignatia Broker, 1983
Night Flying Woman

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SUMMARY

During the spring and summer of 1991, 127 face-to-face interviews were conducted with American Indians who had disabilities, and who lived 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 majority of persons interviewed identified as either Chippewa or Ojibway, with a mean age of 47 years. On average, interviewees reported having 2.14 disabling conditions each, primarily diabetes, arthritis, orthopedic disorders, and substance abuse. The majority of interviewees reported that their disability(ies) limited them in working on the job, lifting, and walking. 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.

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 the Social Security Administration, while only 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, or employment.

In terms of the research process, the AIRRTC has found that a critical component of carrying out community-based research involves developing strong support among

Indian service providers and consumers. For example, in addition to hiring an on-site research coordinator, linkages were established with the Minnesota Division of Rehabilitation (MDR) Services. Consumers were also 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. They were also hired as interviewers.

Interviewees and service providers were asked to comment on the results at a public meeting held in Minneapolis, and to provide written critiques of a draft of the final report. 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.

**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 continuation of the efforts of the American Indian Rehabilitation Research and Training Center (AIRRTC) to identify the concerns of American Indians with disabilities at the community level and in an urban setting (Marshall, Johnson, Martin, Saravanabhavan, & Bradford, 1992; Marshall, Johnson, Martin, & Saravanabhavan, 1991). Perhaps most importantly, this project represents a continuation of research that includes consumer involvement in the planning of the research process, in the development of the research instrumentation, and in the recommendations for community change (Fawcett, Suarez de Balcazar, Johnson, Whang-Ramos, Seekins, & Bradford, 1987; Muñoz, Snowden, & Kelly, 1979; Whyte, 1991). The specific research questions addressed through this project include:

1. Can the Concerns Report Method, as modified by the AIRRTC in its study involving American Indians with disabilities in Denver, Colorado, be successfully utilized by another urban Indian community to assess the needs of its members who have disabilities?
2. Does the information generated by the Concerns Report Method again result in improved rehabilitation service delivery to American Indians in the targeted urban community?

As indicated by the research questions, this study will be conducted in two phases. Phase I, which involved the identification of the target community, the identification of “consumer concerns,” the survey of consumers, and the analysis of the results has been completed. Phase II will consist of a follow-up study to assess whether or not positive community change has occurred in the areas identified as “consumer concerns.”

This project took place in an area of the country predominantly inhabited by a tribal group not represented in the previous urban study referred to above (Marshall, Johnson, Martin, Saravanabhavan, & Bradford, 1992; Marshall, Johnson, Martin, & Saravanabhavan, 1991). The research site was selected in order to investigate the utility of the Concerns Report Method with a different population, and in order to respond to a request by a local service provider to investigate the needs of urban Indian people with disabilities in Minneapolis, Minnesota. Located in Region V, the Northern Plains, the metro area of Minneapolis-St. Paul is home to approximately 20,000 American Indian people according to Francis Fairbanks, Director, Minneapolis American Indian Center. Approximately 25-30 tribes are represented in Minneapolis--among them are the Chippewa or Ojibway, the Winnebago, the Oneida, and the Sioux (Personal communication, February 24, 1989).

A critical component of carrying out community-based research involves developing a support base of service providers and consumers. A detailed account of the initial contacts made in Minnesota is given in order to demonstrate the development of support for the project. The Principal Investigator traveled to Minneapolis on November 6, 1990 to propose to the Minneapolis Indian community that this research be conducted. Arrangements for a meeting at which the research was to be proposed were made through Mr. Michael Wiebe, Director of Planning for the Minneapolis American Indian Center (MAIC). Mr. Wiebe provided a list of American Indian service providers and consumers in the Minneapolis area whom he felt would be interested in attending the meeting (see example letter, Appendix A). The meeting was held on November 7, 1990, and began with an overview of the purpose of the meeting, followed by a slide presentation of the results of the study completed in Denver, Colorado. Copies of the final report of the previous study were available for participants to review, as well as copies of the survey instrument and the manual used to train interviewers.

Discussion centered around whether or not the Indian community in the Minneapolis area would find a similar study useful. Consultant Barbara Bradford explained the process involved with the Concerns Report Method. A question was raised by one participant as to whether the research was needed; he stated that "Indian people are satisfied with the services in Minneapolis." However, other participants were supportive of the proposed research. Another issue was raised in terms of defining the Minneapolis metro-area. Participants indicated that they felt St. Paul should be included in the study, that is, that the research should encompass the "Twin Cities." The meeting concluded with a tentative plan to meet again in January; it was the opinion of service providers in attendance that it was best to wait until after the holidays to meet again. Interestingly, a consumer in attendance voiced the opinion that he would like to meet sooner, before the holidays!

As it was not possible for her to attend the meeting at the MAIC, a separate meeting was scheduled for November 7 with Doreen Day, Executive Director, Indian Family Services (IFS). Again, the slide presentation was given, with materials from the completed Denver study available for review. Consultant Barbara Bradford explained the process involved with the Concerns Report Method. IFS, located in Minneapolis, is identified with providing social services to American Indians with disabilities. However, due to recent funding cuts, the services which it can provide to this population are quite limited. Ms. Day expressed her enthusiastic support for the project, and agreed to be a sponsor of the research.

A meeting, arranged by rehabilitation counselor Sharon Johnson, was held on November 8 with James House, Director, Vocational Rehabilitation, Minnesota Division of Rehabilitation Services, and Mary Shortall, Director, Client Support Services, Minnesota Division of Rehabilitation Services. The purpose of the meeting was to provide the administration of the state vocational rehabilitation agency with information regarding the proposed research, to solicit support for the research, and to obtain approval for the

involvement of Sharon Johnson in the research. Ms. Johnson is affiliated with the Chippewa tribe, and in her role as a rehabilitation counselor, conducts extensive outreach to Indian people in Northern Minnesota (see Marshall, Johnson, & Lonetree, in press). Support and sponsorship for the project were obtained from the Division of Rehabilitation Services, including approval for Ms. Johnson's active participation.

In order to further investigate the possibility of including St. Paul in the study, a meeting with Mr. Prosper Waukon, Executive Director, St. Paul American Indian Center was held on November 9. Mr. Waukon suggested that the results from the study would be of greatest use to him if the data from the Twin Cities, were, in fact, analyzed separately according to residence in either Minneapolis or St. Paul. An individual meeting was also held on November 9 with Dr. Sue Ann Kroeger, Director of the Office for Students with Disabilities, University of Minnesota. Through her role at the university, Dr. Kroeger stated that she would like to assist by informing Indian students, in particular those who have disabilities, of the project.

Method

After gaining community support for the research, a first step in carrying out the project involved the hiring of an on-site research coordinator (see Appendix B). Charlene Day-Davila (Ojibway) accepted the position on December 17, 1990. Initially, the on-site research coordinator assisted the Principal Investigator in identifying potential sponsoring agencies, consumers, and interviewers. After the research design and instrumentation were finalized, the on-site research coordinator was expected to coordinate and conduct research activities as independently as possible.

Instrumentation

In order to secure input from consumers, the first working group meeting of consumers was held on January 17, 1991 at the Phillips Community Center in Minneapolis (see Appendix C). The meeting was conducted by the on-site research coordinator, Charlene Day-Davila, with assistance from consultant Barbara Bradford. Concerns

identified by consumers were written in the form of "issue statements" (Fawcett, Suarez de Balcazar, Johnson, Whang-Ramos, Seekins, & Bradford, 1987). The issue statements identified by consumers were included in a draft instrument that was reviewed at a second meeting of consumers held on January 24, 1991 at Indian Family Services in Minneapolis. Potential demographic items were drawn from the interview instrument used in a previous study (Marshall, Johnson, Martin, Saravanabhavan, & Bradford, 1992; Marshall, Johnson, Martin, & Saravanabhavan, 1991). Service providers were invited to attend the January 24 meeting, and asked to add or delete demographic items based on their agency's information needs (see Appendix D).

After the second working group meeting, the on-site research coordinator met individually with several consumers in order to secure a wide range of input, especially from Indian people with disabilities who lived in St. Paul, and who had not been able to attend the working group meetings in Minneapolis. A final draft of the instrument contained 38 issue statements identified by consumers in the Twin Cities (see Appendix E).

Pilot-testing the instrument. The survey instrument was finalized on February 27, 1991 with assistance from the on-site research coordinator. On February 28 and 29, interviewer training for the pilot-test was conducted in Flagstaff, Arizona with the on-site coordinator and a potential interviewer (see Appendix F). The pilot-test was conducted from March 14, 1991 through April 11, 1991. Ten persons were interviewed, with no substantial changes to the instrument being recommended. [A copy of the Consumer Interview is available from the AIRRTC upon request.]

Procedure

Seven persons were recruited to participate in a three-day interviewer training conducted in Minneapolis on April 29, 1991 through May 1, 1991 at the Pillsbury United Neighborhood Waite House (see Appendix G). [A copy of the Interviewer Manual is available from the AIRRTC upon request.] Interviewer trainees were recruited through the

posting of the job description at Indian service agencies (see Appendix H), and through the assistance of the Minnesota Division of Rehabilitation Services.

Percentage of agreement. In order to be hired as an interviewer, each interviewer trainee was required by the end of the training to demonstrate competency and reliability in using the instrument by achieving a percentage of agreement score of at least 80% (Borg & Gall, 1983). During the afternoon of the last day of the interviewer training, the on-site coordinator interviewed consultant Barbara Bradford using selected portions of the Consumer Interview. The interview was observed by the interviewee trainees who recorded the responses to the interview. Immediately following the interview, items were checked for accuracy. Where responses were recorded incorrectly, retraining and retesting occurred. Percentage of agreement scores for each interviewer were obtained by dividing the number of responses (both qualitative and quantitative) recorded correctly by the total number of possible correct responses ($n = 76$). Percentage of agreement for those trainees hired as interviewers ($n = 5$) ranged from 88% to 96%, with the mean percentage being 92%. The majority of errors were in the qualitative data; for example, the recording of a verbal response was counted incorrect if key words from the interviewee's account were missing.

Interviewer characteristics. The six interviewers (including the on-site research coordinator who also conducted interviews) consisted of three females and three males, with an average age of 39. They ranged in age from 23 - 54. The majority reported having a disability, with three persons having received services through the Minnesota Division of Rehabilitation Services. All had a minimum education of a high school diploma or GED, with the majority having had previous experience in the delivery of human services. Five of the six interviewers were American Indian, with the following tribal affiliations: Chippewa/Ojibway (3), Oglala/Lakota (1), and Omaha (1). The non-Indian interviewer was also employed by an Indian service agency, and was known by many of the prospective interviewees.

Interviewee characteristics and recruitment efforts. Four primary criteria for interviewees were established in conjunction with local service providers and consumers. Interviewees 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.

No documentation of the above criteria was required of interviewees. For example, persons were identified as being an American Indian based solely on their self-report.

Sponsoring agencies were asked to assist the AIRRTC in recruiting potential interviewees. For example, all American Indians on current caseloads in the Twin Cities metro area who had been found eligible for services by the Minnesota Division of Rehabilitation Services (n= 120) were sent a letter from rehabilitation counselor Sharon Johnson requesting their participation (24 were returned as undeliverable for a balance of 96 delivered). An announcement of the survey was printed in the newsletter of Indian Family Services, and distributed in the newsletter of the Minneapolis American Indian Center, "The Circle," as an insert. Flyers announcing the study and recruiting interviewees were distributed to all sponsoring agencies, as well as interested individuals who had participated in working group meetings (see Appendix I).

Conducting and verifying interviews. Maggie Spears, case manager, Indian Family Services, was available to interviewers in the event they encountered a clinical emergency (e.g., evidence of elder abuse) when conducting an in-home interview, and the on-site coordinator was not immediately available. Indian Family Services also provided office space for the on-site coordinator. All interviews were assigned to interviewers by the on-site coordinator. Interviewers were paid \$25.00 for each interview completed. Of this \$25.00, \$5.00 were allocated for travel costs. Where this was found to be inadequate,

interviewers were reimbursed, upon request, at .24 per mile traveled. Interviewers were also reimbursed, upon request, for incidental expenses incurred in conducting the interviews. Approximately 10% (n = 12) of interviewees were randomly selected to undergo a verification process which involved being telephoned by a project staff person from the AIRRTC (see Appendix J). The majority [92% (n = 11)] of these interviewees reported that the interviewer was courteous throughout the interview; all reported that the interview was relevant to their concerns.

Conducting public meeting. As a major component of the Concerns Report Method, results of the survey are presented to the target community prior to the publication of a final project report. The purpose of this meeting, therefore, is not only to share the results of the survey, but to also elicit from consumers any additional concerns they may have, and any recommendations for community change which participants at the meeting would like to see included in the final report.

After the interviews were completed, and the data were analyzed, a public meeting was held on September 19 in Minneapolis at the Minneapolis American Indian Center (see Appendix K). All persons interviewed were mailed a flyer (see Appendix L) and a letter inviting them to attend the meeting. The flyer also was reproduced as an announcement in the September issue of "The Circle." Notice of the meeting was reported in a Twin Cities weekly newspaper, "Native City News," through an interview with Mr. Al Wensman (see Appendix M).

Several consumers spoke of their experiences in accessing services at the meeting. Due to space limitations, it is not possible to include all of the experiences which were shared; the following excerpts were selected as representative of the tone and content of the majority of comments. 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 scared ride, the road of life that we're supposed to walk on, that's where you're suppose 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, your 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.

Similarly, 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 educational needs, one man recalled:

I discovered that there was something wrong with me, and it wasn't because I didn't try hard enough, and it wasn't because I didn't look for a job. It was because when I'd get on a job, I would have an eye/hand coordination problem, and I could not do the job. I usually get laid off or put in a very menial task. The last job I got, they knew I couldn't do the job, so they had me sweeping the floor over and over and over again in the same spot; I quit because it was degrading . . . And so I guess my problem is: (1) coordination of services. I would like to know what's available to me as a person, now that I know that I have a disability, and (2) I would recommend that state disability, their bureaucratic system, would work a little bit better.

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 weighted 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.

And, finally, from a man who stated "first of all, we're human beings":

I woke up in ICU last year with a heart attack, and when I was waking up (I hadn't had a drink in 10 years, not one drink), and my heart was barely going, the first thing the staff person asked me was, "How much were you drinking last night?" That was asked of me because I was an American Indian . . . It never quits — the racism I'm talking about, the misunderstandings, the lack of communication. The fact that some people say, "I don't understand what you're talking about." But, I think somehow, people will be able to explain their problems, and somehow redress them, and somehow get some things done for themselves, hopefully. Until then, this is still a brand new start, and I hope this start is the start for someone in this room. Maybe for a lot of people . . .

Results

Interviews were conducted from May 7, 1991 through July 26, 1991. A total of 128 individuals were interviewed; one interview was not included in the data analysis due to the age of the interviewee. Therefore, the results of 127 interviews are presented below in the following order: General Information, Disability Information, Services Information (Formal Support Systems), Consumer Concerns, Social Information (Informal Support Systems), Educational Information, Employment Information, and Conclusions. The results include analyses of both quantitative and qualitative data. In reporting quantitative data, the actual number (n) reflected by a percentage is given in parenthesis in order to facilitate an accurate interpretation of the given percentage; as a general descriptor, the term "majority" is used to refer to a proportion equal to or greater than 51%.

General Information

A majority [61% (n = 77)] of the interviews were conducted in the interviewees' homes; the remaining interviews took place in a variety of locations, for example, the office

of Indian Family Services [8% (n = 10)], a restaurant [6% (n = 8)], a hospital or clinic [5.5% (n = 7)], or an interviewer's home [5.5% (n = 7)]. Interviewees were given the option to be interviewed in English or in their native language. Ninety-eight percent (98%), or 125 of the interviewees, were interviewed in English. Two interviews were conducted in Sioux. On average, interviews took 82 minutes to complete, or approximately 1 hour and 20 minutes. Ninety-eight percent [98% (n = 125)] were persons with a disability. The remaining two individuals were a parent, and a son or daughter of a person with a disability.

The majority [83% (n = 106)] of interviewees lived in Minneapolis, followed by 9% (n = 11) who lived in St. Paul. The remaining interviewees [8% (n = 10)] lived in the surrounding metro areas of Crystal (n = 3), Inver Grove Heights (n = 2), Blaine (n = 1), Bloomington (n = 1), Brookland Center (n = 1), Edina (n = 1), and St. Louis Park (n = 1). The majority [89% (n = 113)] of interviewees lived in Hennepin County, followed by 9% (n = 11) in Ramsey County, 2% (n = 2) in Dakota County, and 1% (n = 1) in Anoka County.

Slightly more than one-half [51% (n = 65)] of the interviewees were male; 49% (n = 62) were female (see Figure 1). The mean age of interviewees was 47.3 years, with a range of 14 - 70. The majority [80% (n = 102)] of interviewees identified as either Chippewa or Ojibway, followed by 13% (n = 17) who identified as Sioux. Additional tribal affiliations are listed in Figure 2.

Figure 1

Sex of Interviewees

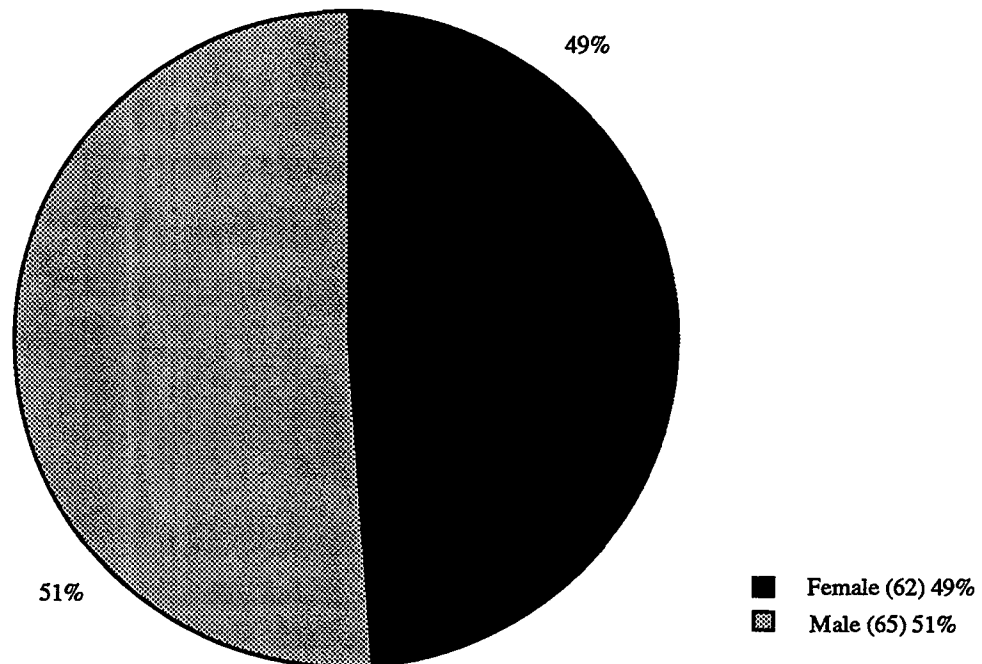
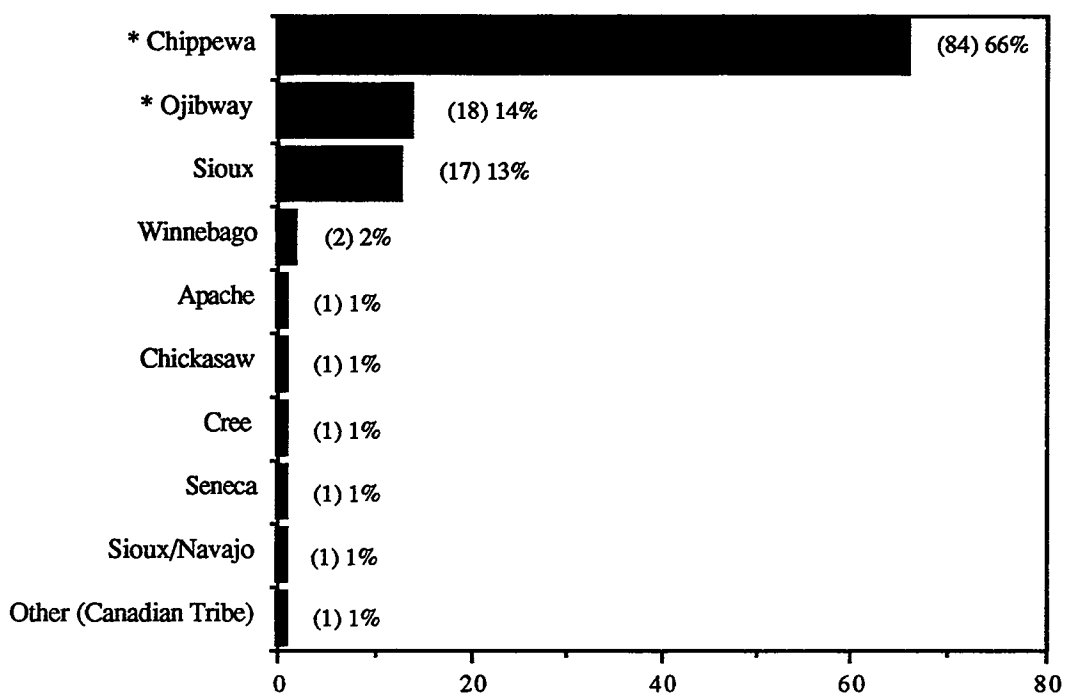


Figure 2

Tribal Affiliation

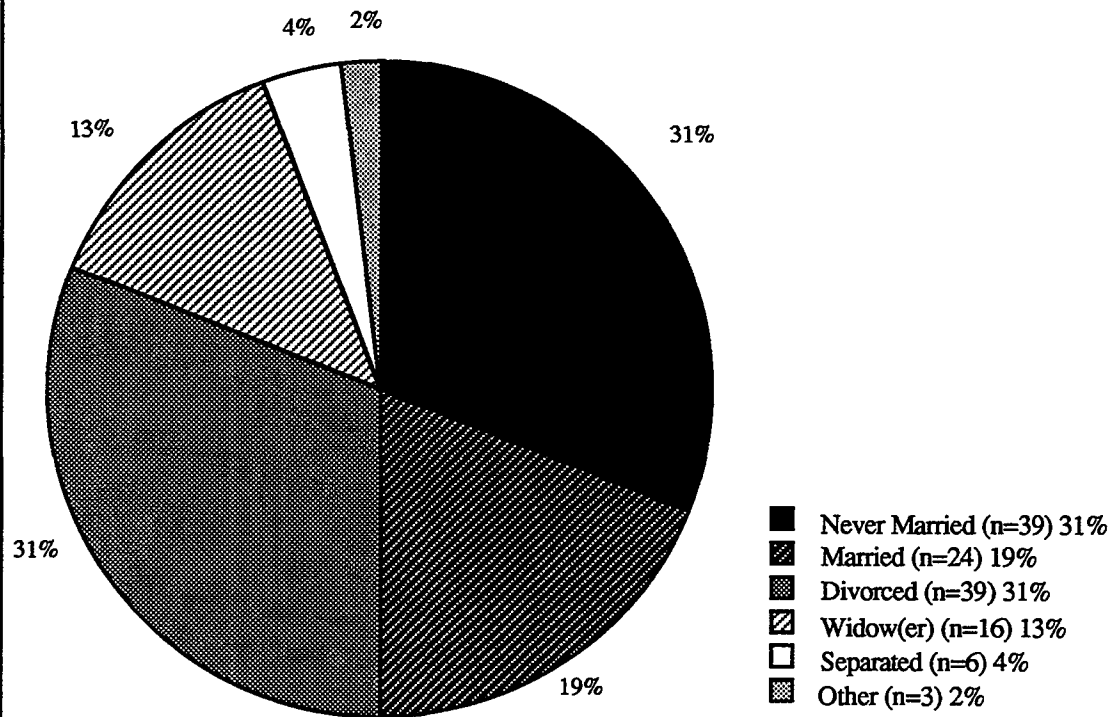


Note. Bar reflects percentage. Actual number in parenthesis. *Combined = (102) 80%; “Chippewa” and “Ojibway” are interchangeable terms referring to the same tribe. They are listed here separately to reflect the self-identification of individual interviewees.

As many interviewees reported having never been married as were divorced (see Figure 3). Sixty-three percent [63% (n = 80)] reported knowing their tribal roll or allottee number. Everyone interviewed (100%) reported having a social security number. Seventy-seven percent [77% (n = 98)] reported being a registered voter in their tribe; 69% (n = 87) reported being a registered voter in their county. Twenty-two percent [22% (n = 28)] were veterans; of these individuals, 43% (n = 12) served in Korea, 25% (n = 7) served in World War II, and 25% (n = 7) served in Vietnam. Three persons served during two periods of war.

Figure 3

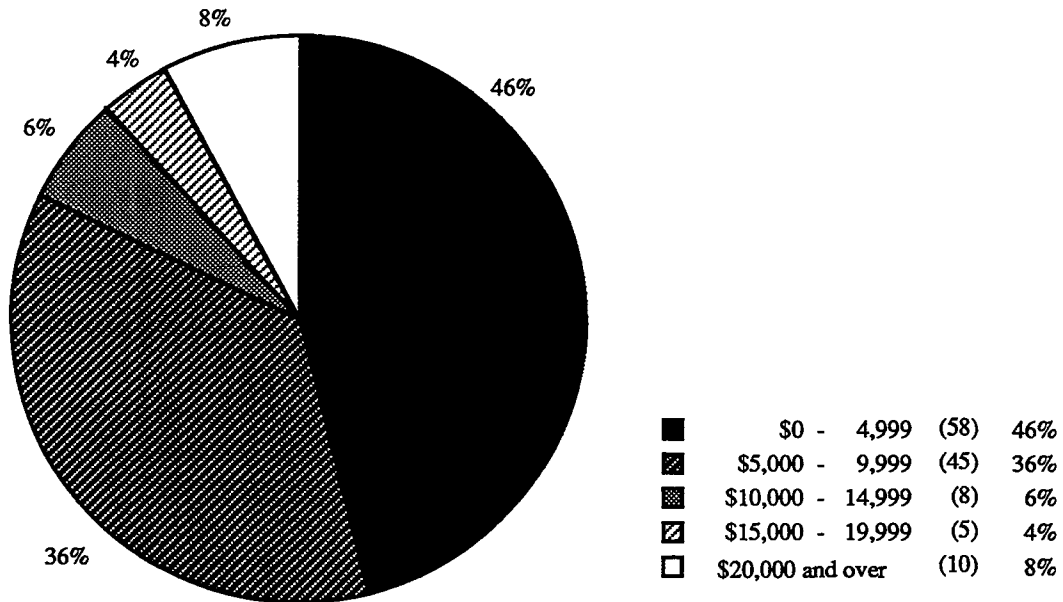
Marital Status



The mean calculated individual (not family) annual income, including all sources, for the persons interviewed was \$6,971. The lowest income reported was \$600 annually; the highest income was \$49,000. The plurality, or most of the interviewees, reported an annual individual income of less than \$5000 (see Figure 4).

Figure 4

Annual Individual Income (n=126)



Interviewees reported living in the Twin Cities metro-area for an average of 24 years. Typical reasons given for living in the Twin Cities included employment opportunities [25% (n = 32)], family ties [21% (n = 27)], and the availability of health services [13% (n = 16)]. The majority [54% (n = 68)] reported that they plan to always live in the Twin Cities. Of these individuals, just over a quarter [26% (n = 14)] indicated that they planned to stay in the Twin Cities because it was their home, frequently simply stating, "This is my home." Of those who did not intend to stay [26% (n = 33)], almost half [45% (n = 15)] reported tentative plans to move back to the reservation. A typical statement was "I want to move back to the reservation someday." Twenty percent [20% (n = 26)] reported that they did not know whether or not they would stay in the Twin Cities.

The majority of interviewees reported having been born on or near a Minnesota reservation (see Appendix N), specifically, White Earth [15% (n = 19)], Cass Lake [9% (n

= 12)], Cloquet (Fond du Lac) [8% (n = 10)], Red Lake [6% (n = 8)], Leech Lake [2% (n = 3)], and Nett Lake [2% (n = 3)]. Five persons each [8% (n = 10)] reported having been born in Minneapolis and in St. Paul. A large majority of interviewees [82% (n = 104)] reported that they had a “home reservation.” Of these individuals, over a third [37% (n = 38)] reported that they were able to visit the reservation once a year, followed by almost a quarter [24% (n = 25)] who reported that they were able to visit two or three times a year. Interviewees (n = 104) identified their home reservations as White Earth [30% (n = 31)], Leech Lake [18% (n = 19)], Nett Lake [8% (n = 8)], Red Lake [7% (n = 7)], Mille Lacs [4% (n = 4)], and Standing Rock [4% (n = 4)]. In response to the question, “Would you live on the reservation if the services you needed were there?,” the majority [71% (n = 80)] of interviewees responded “yes.”

The vast majority [98% (n = 125)] of interviewees reported that they speak English fluently; 97% (n = 124) reported being able to read English, and 97% reported being able to write English. Thirty-six percent [36% (n = 46)] reported that they could speak a Native language fluently; of these, 70% (n = 32) speak either Chippewa or Ojibway, while 15% (n = 7) speak a form of Sioux, for example, Lakota. One person reported speaking Cree. Thirty-one percent [31% (n = 36)] reported being able to read a Native language; of these individuals, 83% (n = 30) read Chippewa or Ojibway, and 14% (n = 5) read a form of Sioux. One person reported reading Cree. Eighteen percent [18% (n = 21)] reported being able to write a Native language; of these individuals, 76% (n = 16) write Chippewa or Ojibway, and 14% (n = 3) write a form of Sioux. One person reported writing Cree.

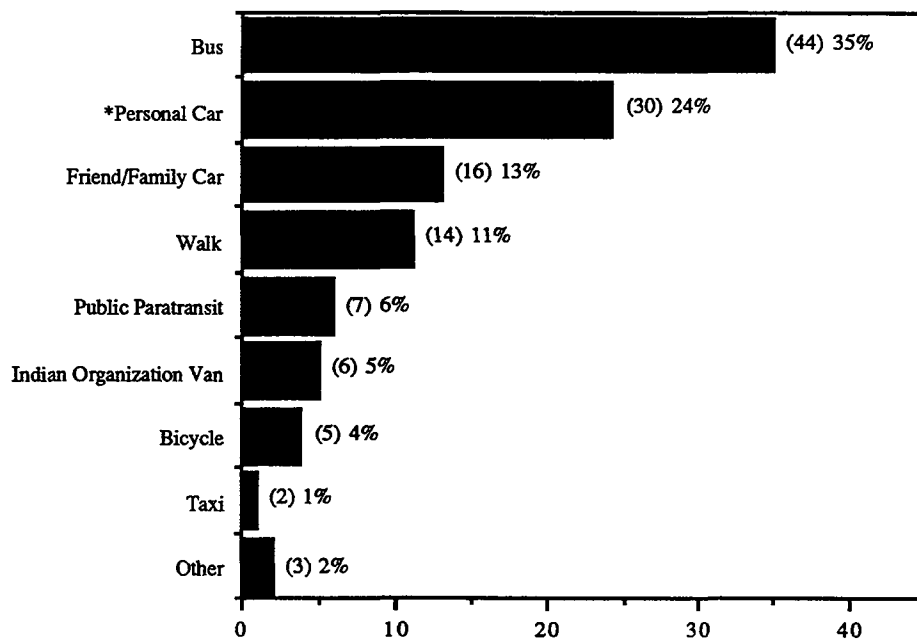
The majority [78% (n = 99)] of interviewees reported that English was the language spoken most often in their home, followed by 17% (n = 22) who reported that a combination of English and their native language was most often spoken. Five percent [5% (n = 6)] reported that their native language was most often spoken in their home. Eighty-seven percent [87% (n = 110)] reported that they preferred health and human service workers to use English when providing services. Ten percent [10% (n = 13)]

reported preferring a combination of English and Native language in such situations; one person reported preferring that health and human service workers use a Native language.

In terms of transportation and access to services, just over a third [35% (n = 44)] reported owning a car; however, 43% (n = 54) reported having a driver's license. To the question, "What means of transportation do you use the most?", a plurality responded that they used the public bus (see Figure 5). Of those interviewees using an "Indian Organization Van," the majority [83% (n = 5)] reported using a van from Indian Family Services. Interviewees who reported using "Other" forms of transportation included two persons who use primarily a wheelchair, and one person who uses a personal van.

Figure 5

Most Frequently Used Transportation



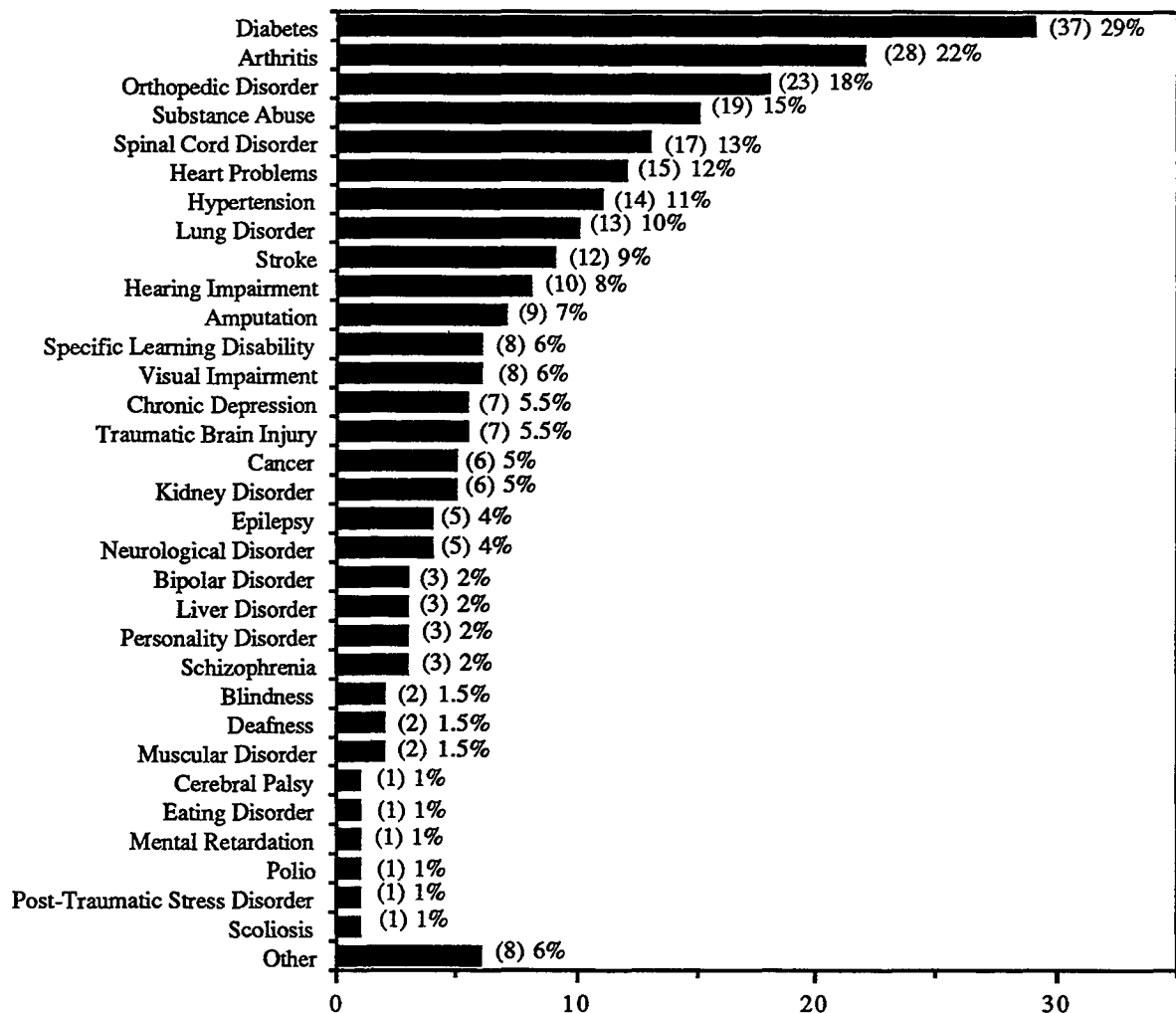
Note. *43% of those interviewed (n = 54) reported having a driver's license.

Disability Information

The disabling conditions reported by interviewees are presented in Figure 6. Due to space limitations, it was not possible to list all specific disabilities. In some cases, broad categories are listed; "Spinal Cord Disorder," for example, is a broad category that includes all disabling conditions resulting from trauma to the spinal cord or spinal column.

Figure 6

Disabling Conditions Reported by Interviewees



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

On average, interviewees reported having 2.14 disabling conditions each. Disabling conditions reported under “Other” included, for example, chronic back pain, circulatory problems, thyroid problems, internal bleeding, and “loss of memory.” Those persons reporting “substance abuse” as a disabling condition (n = 19), also reported having, on average, an additional 1.47 disorders. For example, 21% (n = 4) reported having arthritis; the same number [21% (n = 4)] reported having an orthopedic disorder. Additional disabling conditions for this group included, amputation [16% (n = 3)], chronic depression [16% (n = 3)], diabetes [11% (n = 2)], and traumatic brain injury [11% (n = 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 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 accidentally 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 . . .”

In terms of assistive devices and treatment, a large majority of interviewees reported using both glasses and medication (see Table 1). Interviewees who used medication (n = 101) were asked, “What kind of of medication(s) do you use and for what reasons?” The

plurality [26% (n = 26)] of these interviewees reported using insulin or pills for diabetes, followed by 18% (n = 18) who used some form of pain medication. The use of pain medication was frequently mentioned in association with arthritis. Of those persons who used medication, 46% (n = 46) reported experiencing side-effects. These included drowsiness [22% (n = 10)], dizziness [20% (n = 9)], and stomach problems, including nausea and diarrhea [17% (n = 8)]. Other problems included impotency, hair loss, elevated blood pressure, headaches, sweating, swelling, dry mouth, insomnia, vision problems, weight gain, kidney problems, and unspecified neurological and emotional problems.

Table 1

Use of Assistive Devices and Treatment

Assistive Devices/Treatment	n	Use Currently %
Glasses	(103)	81%
^a Medication	(101)	80%
Native Medicine Way	(29)	23%
Cane/Crutch	(28)	22%
Wheelchair	(28)	22%
Prosthesis/Brace	(21)	17%
Walker	(7)	6%
Hearing Aid	(6)	5%
Lip Reading	(3)	2%
Sign Language	(2)	1.5%
Braille	(1)	1%
Other	(5)	4%

^a 46% (n=46) reported experiencing side-effects.

Of those persons using a wheelchair for mobility (n = 28), the majority [57% (n = 16)] reported using a manual chair. A quarter [25% (n = 7)] reported using an electric chair; 2 persons (7%) reported having both a manual chair and an electric chair. Additional assistive devices or treatments that were used by interviewees and classified in Table 1 under “Other” included, for example, homeopathic medicine, oxygen, exercise therapy using a bicycle, and physical therapy.

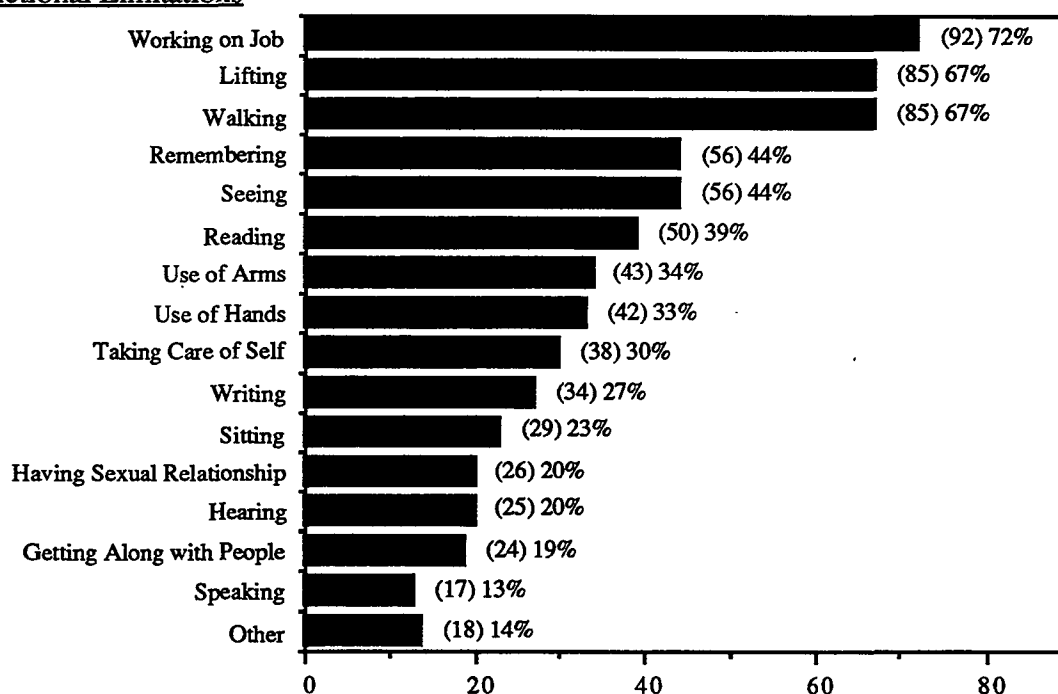
A majority of interviewees reported needing or needing improved glasses, but not medication (see Table 2). “Other” assistive devices or treatments that were needed by interviewees included a seeing eye dog, a bicycle, and physical therapy.

Table 2		
<u>Needed Assistive Devices and Treatment</u>		
Assistive Devices/Treatment	Need/Need Improved n	%
Glasses	(72)	57%
Medication	(36)	28%
Wheelchair	(21)	17%
Cane/Crutch	(18)	14%
Native Medicine Way	(13)	10%
Prosthesis/Brace	(12)	9%
Hearing Aid	(8)	6%
Lip Reading	(1)	1%
Sign Language	(1)	1%
Braille	-0-	-0-
Walker	(1)	1%
Other	(4)	3%

In terms of functional limitations, the majority of interviewees reported that their disability(ies) limited them in working on the job, lifting, and walking (see Figure 7). “Other” limitations reported included, for example, “running” (3 persons), “driving” (2 persons), and concentrating (2 persons). Additional limitations included problems with balance, breathing, dancing, sleeping, and “becoming more social.”

Figure 7

Functional Limitations



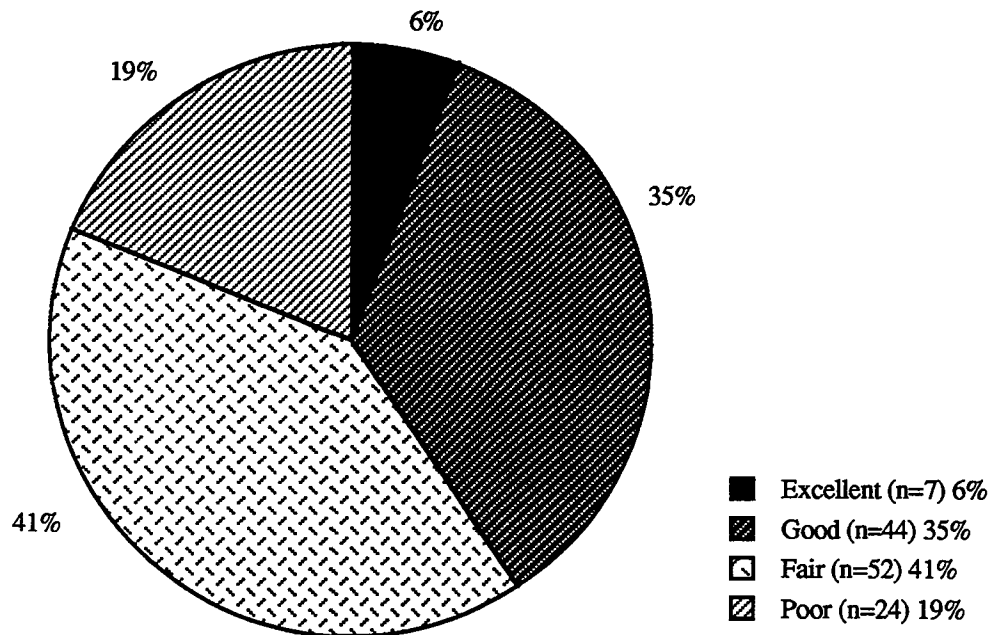
Note. Bar reflects percentage. Actual number given in parenthesis.

Ten percent [10% (n = 13)] of the interviewees reported that they had had their primary disability since birth; for the remainder, the average age of onset was age 35. A plurality of interviewees reported their health status as “fair” (see Figure 8). In response to the question, “How would you describe your satisfaction with life in general at this time?,” a plurality [38% (n = 48)] reported “good,” followed closely by 35% (n = 44) who

reported “fair.” Seventeen percent [17% (n = 22)] reported their satisfaction with life to be poor, while the remaining 10% (n = 13) rated their satisfaction with life as “excellent.”

Figure 8

Health Status



Services Information (Formal Support Systems)

At the time of the interview, one-half of the interviewees were receiving assistance through the Social Security Administration (see Table 3). The majority of services, across all categories, were provided in the city of Minneapolis, with the exceptions of “Sweat Lodge” and “Native Medicine.” While interviewees indicated that these services were available in both Minneapolis and St. Paul, the majority of interviewees who reported receiving them indicated that they obtained the services outside of the Twin Cities, and frequently outside of the state.

Table 3

Services Received at Time of Interview

Person or Program Providing Assistance	Interviewees Receiving Service	
	n	%
Social Security Administration	(64)	50%
Private Medical Doctor	(54)	43%
Medicare/Medicaid	(51)	40%
Indian Health Agency	(38)	30%
Your Church	(32)	25%
Indian Service Agency	(28)	22%
Native Medicine	(25)	20%
State Division of Social Services	(23)	18%
Indian Center	(21)	17%
Sweat Lodge	(21)	17%
Psychologist	(19)	15%
Alcohol Counseling Program	(16)	13%
Mental Health Program	(15)	12%
State Division of Vocational Rehabilitation	(13)	10%
Veterans Affairs Administration	(13)	10%
Senior Citizen Program	(9)	7%
Job Service Program	(8)	6%
School	(8)	6%
State Division of Developmental Disabilities	(2)	2%
Other	(5)	4%

Many of the programs or agencies listed in Table 3 are presented in general terms such as "Indian Health Agency." In such cases, interviewees were asked to specify which agency or service they utilized. For example, interviewees who received services from an Indian health agency typically reported obtaining those services through the Minneapolis Indian Health Board [82% (n = 31)]. Of those persons who received services from an Indian service agency, the majority [61% (n = 17)] specified Indian Family Services. Services obtained through the State Division of Social Services typically included Food Stamps and General Assistance (welfare). Of those persons who received services from an Indian Center, a third [33% (n = 7)] reported receiving services from the Minneapolis American Indian Center; 14% (n = 3) reported receiving services from the St. Paul American Indian Center.

Over a third of the interviewees [38% (n = 6)] who received services from an alcohol counseling program specified that they attended Alcoholics Anonymous (AA) meetings. Interviewees utilizing a mental health program most often referred to Hennepin County Mental Health [20% (n = 3)] and the Minneapolis Indian Health Board [13% (n = 2)]. Of those persons who received services from a senior citizen's program, the plurality [33% (n = 3)] referred to the Minneapolis American Indian Center congregate dining program. Persons or programs identified in the "Other" category included a retirement pension, an adoption agency, family, and friends.

Interviewees were also asked to report on the type of services they had received during the year prior to the survey, and to rate the degree to which each service was helpful. Ratings included "Made my problems much worse," "Not helpful," "OK/so-so," "Helpful," and "Made my problems much better" (see Table 4). In addition, interviewees were asked to identify services which they had needed in the year prior to the interview, but had not received, and to identify what barriers had kept them from receiving the service(s) (see Table 5). For example, 61 persons, or 48% of the population surveyed (see Table 4), reported having received dental care. The remaining 66 persons, or 52% of the population

surveyed, did not receive dental care. Of these latter individuals, 34, or 52% of those who did not receive dental care, reported needing the service. A plurality [35% (n = 12)] of those needing, but not receiving dental care, stated that they “could not afford” dental care.

Table 4

Services Received in Past Year

Service	Interviewees Receiving Services		Reporting Services as Helpful ^a	
	n	%	n	%
1. Coordination of Services	(60)	47%	(37)	62%
2. Help Receiving Food	(71)	60%	(49)	69%
3. Help Receiving Clothing	(27)	21%	(19)	70%
4. Help Receiving Housing	(35)	28%	(20)	57%
5. Help Receiving Benefits	(54)	43%	(32)	59%
6. Instruction in Activities of Daily Living	(17)	13%	(11)	65%
7. Vocational Training	(24)	19%	(12)	50%
8. Medical Care	(109)	86%	(86)	79%
9. Dental Care	(61)	48%	(39)	64%
10. Individual or Family Counseling	(35)	28%	(24)	69%
11. Alcohol Treatment	(25)	20%	(17)	68%
12. Drug Treatment	(13)	10%	(7)	54%
13. Legal Assistance	(16)	13%	(11)	69%

^a Includes rating of “Helpful” and “Made my problems much better.”

Persons who reported that they did not want to use a service for reasons other than those specific barriers listed on the “Consumer Interview” were asked to explain why they would choose not to use an available service. For example, five persons reported that they did not want to use help in receiving cash or food benefits (see Table 5). Reasons given included: “I didn't think I was eligible,” “I didn't think I could get services,” and “They discriminated due to my race.” Almost a third of those who needed, but did not receive dental care (n = 11) stated that they did not want to use the service. Reasons given included: the fear that the individual would be held “financially hostage,” “teeth aren't that bad,” “can't have novacane and other anesthetics,” concern with accessibility issues and racism, and simply being “afraid.” A third of the interviewees who needed individual or family counseling (n = 8) choose not to use such services. Reasons given included: “not sure,” “I fell off the wagon and started drinking,” and “I'm afraid of the white people.” Reasons given for choosing not to use alcohol treatment (n = 4) included the statement that such programs are “classist;” one individual stated, “I don't want it on my record.” Almost half of those persons needing but not receiving legal assistance (n = 8) choose not to use the service. Reasons given included: “I was afraid of police blaming me,” “discrimination because I'm Indian,” and “police wouldn't come out.”

The majority of interviewees reported that a “friend” provided them with the most useful information about available services (see Figure 9). Of those persons citing “Indian Health Agency,” the majority [86% (n = 12)] specified the Indian Health Board as being the agency which provided them with the most useful information about services. The two persons citing “Indian Service Agency” both specified Indian Family Services. Of the two persons citing “Indian Center,” only one specified a particular agency--the St. Paul American Indian Center.

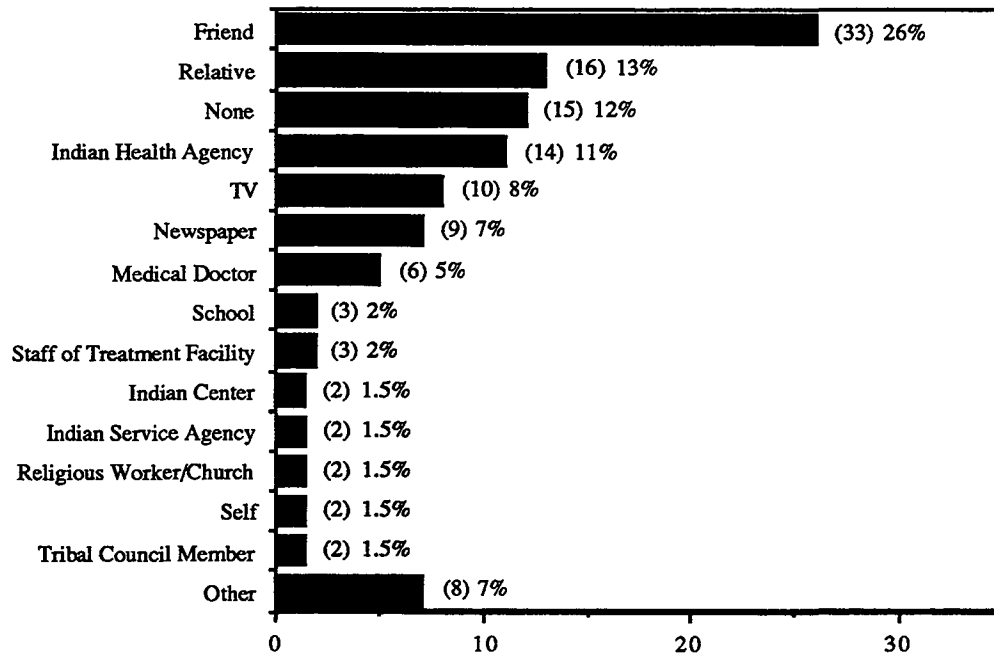
Table 5
Services Needed in Past Year but Not Received

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

Figure 9

Primary Referral Source



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

In response to the question, “What services would you like to have available to you that you don’t get now,” interviewees identified a wide variety of needs. The plurality [18% (n = 23)] involved some aspect of transportation, for example, “a more readily available van service.” However, most frequently, interviewees simply stated that they needed “transportation.” Transportation needs were followed by desires to access services that involved Indian culture [9% (n = 11)]. For example, interviewees stated, “I would like to see a cancer support group for Native American people.” They stated that they needed “services in Indian traditions and use of plants for medicine;” “a place where disabled and elderly can meet, and make and sell their tribal arts and crafts;” to “see an Indian healer or medicine psychiatrist;” to have “spiritual help with alcoholism;” and to have “culturally relevant [assessment] materials” available to determine speech disorders.

In response to the question, “Are there any other things you are doing now to help with your disability,” the plurality [31% (n = 40)] reported engaging in some form of exercise, including walking. This was followed by diet, including vitamins [9% (n = 12)]. Several persons reported utilizing meditation (n = 8), physical therapy (n = 7), staying “busy” (n = 6), staying sober (n = 5), reading (n = 4), resting (n = 4), praying (n = 3), and talking with friends (n = 2).

The majority [69% (n = 88)] of interviewees reported that they had at least one relative who had a disability or long-term illness; many mentioned several relatives. For example, among these 88 interviewees, over a third [38% (n = 33)] reported having a relative with diabetes.

Consumer Concerns

A major focus of the “Consumer Interview” consisted of 38 consumer-identified “issue statements,” also referred to as “consumer concerns.” These 38 issue statements are listed in Appendix E in ascending order by mean percentage of satisfaction. Only those issue statements for which interviewees gave both a rating of “Satisfaction” and a rating of “Importance” were included in the analysis of mean percentages. Additionally, interviewee ratings which reflected little or no variability throughout the 38 items were judged invalid, and not included in the data analysis. The number of issue statements considered valid and used in the data analysis is also given in Appendix E.

According to Fawcett, et al. (1987), the “strengths” of a community, as identified by consumers, appear as items with high “Importance” ratings and high “Satisfaction” ratings. Conversely, “problems” appear as items with high “Importance” ratings and low “Satisfaction” ratings. The ratings of individual interviewees have been averaged through a computerized mathematical formula (Suarez de Balcazar, Bradford, & Fawcett, 1989), and analyzed by consultant Barbara Bradford, Barrier Breakers, South St. Paul Minnesota. Any issue that is more than one standard deviation from the mean in either category is considered a “top strength” or a “top problem.” The relative strengths of the Twin Cities

metro area are listed in Table 6. The relative problems of the Twin Cities metro area are listed in Table 7. While mean percentages are given for both "Importance" and "Satisfaction," the issue statements are ranked in descending order by relative strength and relative concern (problems). For example, as regards relative strengths, the metro area scored "highest" in terms of adequate parking for persons with disabilities; it scored

Table 6

Consumer Concerns - Relative Strengths - General Results (n = 93)

Item #	Survey Question	Average Importance	Average Satisfaction
17	Handicapped parking is adequate and enforced.	81%	62%
*28	You know your rights as a citizen with a disability.	92%	52%
24	Checkout stands and aisles in stores are safe and accessible for shoppers who have disabilities.	86%	56%
4	You are not isolated from your friends and neighbors because of your disability.	78%	61%
*37	You feel safe in your home and neighborhood.	93%	51%
14	Health service providers treat you with dignity and respect, and are sensitive to your disability and your culture.	87%	54%
15	Affordable, accessible public transportation is available.	85%	55%
23	You have control over choosing and managing your personal care attendants and housekeepers.	81%	58%
19	Accessible public housing units are available to people with disabilities.	86%	53%
7	As an Indian, you do <u>not</u> encounter racial discrimination from service providers.	83%	55%

Note. * Items also appear as relative problems.

“lowest” (but again as a strength of the community) in terms of the lack of discrimination from service providers. Similarly, as regards relative problems, the metro area scored “highest” in terms of safety and access in public housing areas. Issue statements identified as relative problems should be interpreted in the negative; for example, “You do not feel safe in your home and neighborhood.” It is possible for issue statements to be listed as both relative strengths and as relative problems where the issues were not clearly differentiated.

Table 7

Consumer Concerns - Relative Problems - General Results (n = 93)

Item #	Survey Question	Average Importance	Average Satisfaction
29	Streets and sidewalks in areas of public housing are safe and accessible.	88%	47%
*37	You feel safe in your home and neighborhood.	93%	51%
18	Affordable housing is available to people with all types of disabilities.	90%	49%
20	Social agencies inform you about benefits and services available to you.	84%	46%
9	Indians with disabilities advocate for their own needs at the local, state, and federal levels.	82%	45%
33	Qualified job applicants with and without disabilities are given the same opportunities.	80%	43%
*28	You know your rights as a citizen with a disability.	92%	52%
3	The Indian community understands the needs of its members with disabilities.	86%	48%
11	There is a central resource for information and referral for disability services available to Indians with disabilities.	81%	45%

Note. * Items also appear as relative strengths.

The majority of interviewees lived in the city of Minneapolis. Their concerns were included in the analyses presented in Tables 6 and 7; however, their concerns were also analyzed separately. The relative strengths of Minneapolis are listed in Table 8. The relative problems of Minneapolis are listed in Table 9.

Table 8

Consumer Concerns - Relative Strengths - Minneapolis (n = 79)

Item #	Survey Question	Average Importance	Average Satisfaction
17	Handicapped parking is adequate and enforced.	84%	64%
4	You are not isolated from your friends and neighbors because of your disability.	80%	62%
34	You can get help in applying for welfare, food stamps, and social services.	85%	56%
31	Adequate mental health care is available to you.	82%	58%
*28	You know your rights as a citizen with a disability.	93%	51%
24	Checkout stands and aisles in stores are safe and accessible for shoppers who have disabilities.	86%	55%
15	Affordable, accessible public transportation is available.	86%	55%
14	Health service providers treat you with dignity and respect, and are sensitive to your disability and your culture.	87%	53%
7	As an Indian, you do <u>not</u> encounter racial discrimination from service providers.	85%	54%
23	You have control over choosing and managing your personal care attendants and housekeepers.	80%	58%

Note. *This item also reported as a relative problem.

Table 9

Consumer Concerns - Relative Problems - Minneapolis (n = 79)

Item #	Survey Question	Average Importance	Average Satisfaction
37	You feel safe in your home and neighborhood.	93%	48%
29	Streets and sidewalks in areas of public housing are safe and accessible.	89%	45%
13	Sidewalk snow removal is adequate.	83%	44%
*28	You know your rights as a citizen with a disability.	93%	51%
18	Affordable housing is available to people with all types of disabilities.	90%	49%
9	Indians with disabilities advocate for their own needs at the local, state, and federal levels.	82%	44%
6	As a citizen with a disability, you have a say in city, county, and state government disability programming planning.	75%	40%
11	There is a central resource for information and referral for disability services available to Indians with disabilities.	83%	46%
33	Qualified job applicants with and without disabilities are given the same opportunities.	81%	45%
36	Local media provide adequate information about disabilities, programs, and services available.	80%	44%

Note. *This item also reported as a relative strength.

Social Information (Informal Support Systems)

In response to the question, "Is there someone you can count on to give you help when you need it?," the majority [81% (n = 103)] of interviewees responded "yes." Of these, 85% (n = 88) reported that they were provided with emotional support, 65% (n = 67) reported that they were provided with "help around the house," 64% (n = 66) reported

that they were assisted with transportation, and 62% (n = 64) reported that they were provided with financial support. Interviewees typically [52% (n = 66)] mentioned a family member such as a spouse (13 persons), a parent (13 persons), a daughter/son (11 persons), a brother (8 persons), or a sister (4 persons) as being the person they could count on. An additional 18% (n = 23) mentioned a friend, followed by 6% (n = 7) who mentioned a “significant other” such as a “boyfriend.” Four percent [4% (n = 5)] reported that the person they could count on to give them help when they needed it was a service provider.

The majority [62% (n = 79)] of interviewees reported that they did not live alone. On average, interviewees reported living with 3.19 persons. For example, 42% (n = 33) lived with their children, 30% (n = 24) lived with a friend or “significant other,” 28% (n = 22) lived with a spouse, 23% (n = 18) lived with grandchildren, 10% (n=8) lived with their parents, 8% (n = 6) lived with a brother, 6% (n = 5) lived with a niece or nephew, 4% (n = 3) lived with an aunt or uncle, and 1% (n = 1) lived with a sister.

One-half of the interviewees [50% (n = 64)] reported having had daily face-to-face or telephone contact with an immediate family member in the year prior to the interview. Seventeen percent [17% (n = 21)] reported having such contact “once or twice a week,” followed by 12% (n = 15) who reported having contact “once or twice a month.” In terms of extended family, 24% (n = 31) reported having contact “once or twice a month,” followed by 23% (n = 29) who reported having contact daily. Twenty percent [20% (n = 25)] reported having contact “once or twice a week.” In response to the question, “Do you see your relatives and friends as often as you want to?,” the majority [54% (n = 67)] of interviewees responded “yes.”

Quality of life. The majority [63% (n = 80)] of interviewees reported living in an apartment. A quarter [25% (n = 32)] reported living in a house; of these individuals, the majority [59% (n = 19)] reported owning their home, while 38% (n = 12) reported renting.

No one reported being homeless; however, one person reported living in “a room,” while 6% (n = 7) reported living in a treatment setting such as a halfway house or group home.

Interviewees were asked to rate the extent to which they agreed or disagreed with nine statements in regard to their living environment. Responses to the ratings “agree” and “agree a lot” were added together and are presented in Table 10.

Table 10

Interviewees in Agreement with Quality of Life Statements

Statement	Agree/Agree a lot	
	n	%
1. The people who live with me care about what happens to me.	(98)	77%
2. I like the number of people who live with me.	(88)	69%
3. The people I live with make me feel comfortable.	(86)	68%
4. I am happy where I live.	(81)	64%
5. If I could, I would live somewhere else.	(80)	63%
6. It is convenient to get my clothes washed, go shopping, etc.	(80)	63%
7. The people in the neighborhood are nice to me.	(79)	62%
8. I feel safe from danger.	(67)	53%
9. It is difficult to get services when I need to.	(61)	48%

In response to the question, “Is your income enough to live on?,” the majority [53% (n = 67)] stated “no.” However, many of the comments of interviewees who reported having insufficient incomes, were similar to those who reported that their incomes were enough on which to live. For example, those who reported an insufficient income stated, “Just barely enough to get by;” “I have to go without, and I can’t go home if I

wanted to;” “We get by . . . , but don’t have the funds for other things like dental, etc.,” and “SSI isn’t that much . . . I have no insurance, medical or dental now.” Those reporting a sufficient income typically stated, “I have enough money to pay for my bills;” “My income is enough to pay for my expenses right now . . . , but if my rent or something else changes, it would be different;” “It is enough to live on, but I want more for my family;” and “My rent is low which allows me a few extra dollars, but I have to budget very carefully to get by.” Thus while some who reported an insufficient income must live with family, or depend on financial support from relatives, and some who reported a sufficient income, indeed, had no complaints, a great many in both categories were living independently, but made comments to the effect that they had little financial resources beyond what was available for food and rent.

Almost all of the interviewees [90% (n = 114)] reported being covered by some type of medical insurance or assistance. All of these individuals reported having more than one type of coverage. Specifically, 83% (n = 95) reported having two types of coverage, 16% (n = 18) reported having three types of coverage, and 1% (n = 1) reported having four types of coverage. For example, 38% (n = 43) were covered through the local Medical Assistance program, 31% (n = 35) were covered by Medicare; 18% (n = 20) were covered by Medicaid, 5% (n = 6) were covered through the Veteran’s Administration (VA), and 2% (n = 2) were covered through the Indian Health Service. Private insurance was carried by 12% (n = 15).

The 10% (n = 13) who reported not having medical insurance or assistance gave a variety of reasons for their lack of coverage, most of which involved being “ineligible,” either for state assistance, veteran’s assistance through the VA, or private insurance. Two persons reported that they “haven’t applied.”

In response to the question, “What do you do for relaxation or fun?,” the majority [57% (n = 73)] of interviewees reported that they watched television, followed by reading [28% (n = 35)]. A quarter [25% (n = 32)] of the interviewees identified some form of

exercise, including walking. Socialization activities were also frequently mentioned, for example, “visiting,” in particular with friends and relatives [22% (n = 28)]. Playing bingo was also mentioned [20% (n = 26)], as were outdoor activities, primarily fishing, camping, and hunting [17% (n = 21)].

Educational Information

The majority [63% (n = 80)] of interviewees had obtained at least a high school diploma or GED at the time of the survey (see Table 11); no one reported having obtained a graduate degree.

Table 11		
<u>Education Level</u>		
Level	n	%
High School Diploma	(31)	24%
GED	(31)	24%
AA Degree	(10)	8%
Bachelor’s Degree	(8)	6%
Other	(4)	3%

For those interviewees who did not complete high school, or who had not obtained a GED [34% (n = 43)], the average highest grade completed was 9th grade. Fifteen percent [15% (n = 19)] reported having been in a special education class or resource room during at least part of their K - 12 education. Of these, the majority [68% (n = 13)] began participating in special education by the 5th or higher grades. Just over a quarter [26% (n = 5)] of the interviewees who participated in special education reported receiving assistance in all or several subjects. Interviewees reported receiving assistance in two or three subjects such as reading (8 persons), math (6 persons), and English (4 persons).

Less than half of the interviewees felt that their education adequately prepared them for the world of work [44% (n = 56)], or for continuing their education beyond high school [45% (n = 57)]. However, in response to the question, "Would you like to increase your education," 65% (n = 83) responded "yes." At the time of the survey, an additional 3% (n = 3) reported being currently involved in increasing their education.

Employment Information

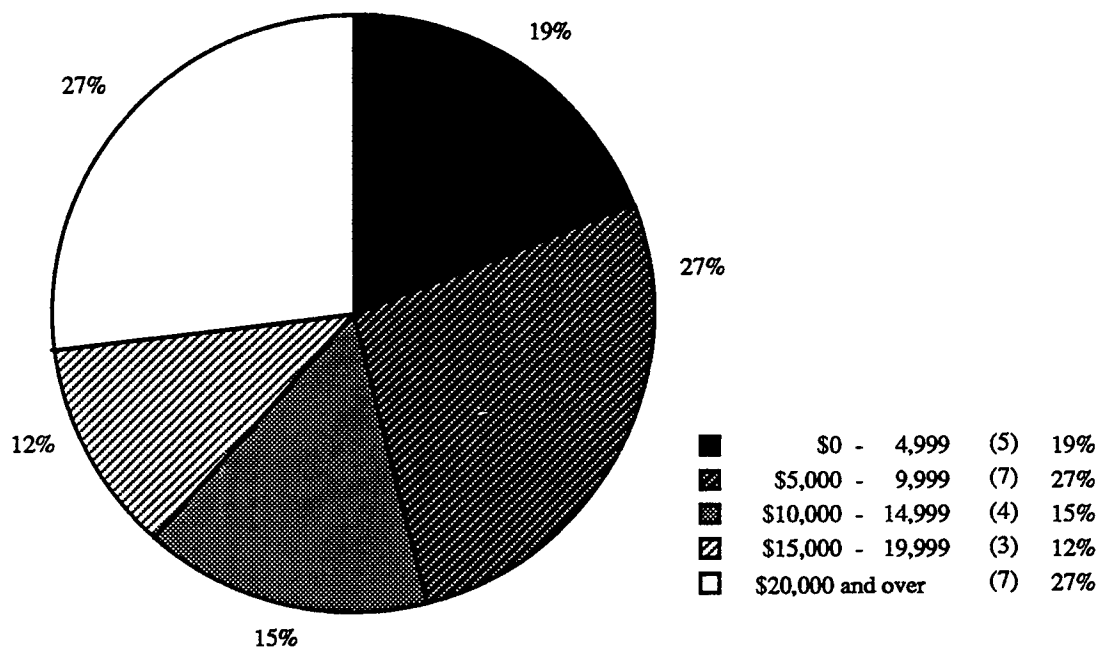
A fifth [20% (n = 26)] of those interviewed were working for pay; exactly half [50% (n = 13)] were working full-time with the remaining half working part-time (see Table 12).

Table 12		
<u>Employment Information</u>		
Status	n	%
Unemployed due to disability	(70)	55%
Retired on disability	(19)	15%
Full-time work for pay	(13)	10%
Part-time work for pay	(13)	10%
Retired	(8)	6%
Full-time student	(2)	2%
Part-time student	(1)	1%
Status Unknown	(1)	1%

The average mean income for those employed was \$12,867. Less than 20% (n = 5) of those working reported individual incomes of less than \$5,000 annually (see Figure 10); all persons in this income range worked part-time. The average mean income for those

Figure 10

Income Ranges of those Employed (n = 26)



employed full-time was \$18,792; the average mean income for those employed part-time was \$6,942.

The majority [73% (n = 19)] of those working reported being satisfied with their job. Twenty percent [20% (n = 26)] of the interviewees reported that they were looking for work at the time of the survey; of these individuals, 23% (n = 6) were already working. One person reported having been looking for work for more than five years; an additional person reported having been looking for more than 10 years. Excluding these two outlying responses, the average time reported by interviewees to have been spent looking for work was eight months. Of those interviewees who reported that they were looking for work, the majority [58% (n = 15)] utilized the newspaper, followed by 15% (n = 4) who utilized the state job service agency, 15% (n = 4) who utilized their friends and other connections, and 8% (n = 2) who utilized the public vocational rehabilitation agency.

In terms of both finding and keeping a job, the majority of interviewees reported having experienced problems due to their disability, for example, “I missed work because of my arthritis, joints painful” (see Table 13). Over a third reported having experienced

Table 13		
<u>Problems Cited in Securing Employment</u>		
Problems Cited	n	%
Because of disability	(66)	52%
Lack of transportation	(48)	38%
Employers do not give fair chance	(46)	36%
Lack of skills required for job	(46)	36%
Lack of money	(43)	34%
Lack of job availability	(39)	31%
Because of ethnic background	(34)	27%
Lack of job-finding skills	(27)	21%
Because of age	(25)	20%
Lack of skills in completing application forms, etc.	(23)	18%
Because of home responsibilities	(19)	15%
Because of your sex	(13)	10%
Lack of skill in English	(9)	7%
<u>Note.</u> Multiple response item.		

problems due to a lack of transportation (e.g., “Electronics factories are far out of the way in the suburbs . . . you need a vehicle;” and “Buses stop running or do not go as far as I need to go to access a job.”). Over a third also reported having experienced problems due to the lack of a fair chance, a lack of job skills, and a lack of money (e.g., “No money for

uniforms or buses”). Responses regarding the lack of a “fair chance” and “ethnic background” were similar; both resulted in comments such as: “Outright discrimination, lack of accessibility in buildings . . .,” “I feel a lot of racial discrimination when I walk into the room,” “Because they discriminate, they automatically think I’m an alcoholic,” “White people would rather hire white people,” “Because I’m disabled, Indian and a woman,” and “Every once in a while, I have my suspicions . . .” Of those citing “lack of skills,” 54% (n = 25) specifically mentioned their lack of education or vocational training as a problem (e.g. “I am not skilled in anything. No schooling or training”). Of those citing “lack of job availability,” 49% (n = 19) specifically mentioned the lack of employment opportunity they had experienced on or near a reservation. Persons who reported problems due to their age, referenced both being “too young” [36% (n = 9)] and “too old” [20% (n = 5)]. Persons who reported problems due to their sex, referenced both discrimination against women [46% (n = 6)], and against men [23% (n = 3)]. Persons who reported having a lack of skill in English gave a variety of explanations including: “My grammar just isn’t good, and even on my present job I get criticized,” “I speak Lakota,” and “My speech is hard to understand because of cerebral palsy.”

Conclusions

Responses to the question, “How do you think members of your tribe view people with disabilities,” were categorized as “positive,” “negative,” or “neutral,” from the interviewee’s perspective. The majority [52% (n = 66)] of responses were categorized as “positive,” and included, for example, statements such as “They treat us with respect . . . and we let them know how we need help,” “They view them with tolerance and dignity,” and “I think they treat them well.” “Neutral” statements accounted for 27% (n = 34) of the responses, for example, “I have no idea,” and “That’s hard to say; there are so many people with disabilities.” “Negative” statements accounted for 17% (n = 22) of the responses, for example, “I think that they don’t view them very fairly because they

probably don't understand disabilities very well," and "I think they feel sorry for them, or look down on them."

The majority [97% (n = 123)] of interviewees reported that they would be able to attend the public meeting where the results of the survey would be presented. Forty percent [40% (n = 51)] stated that they knew of someone they could refer to participate in the survey.

Comments contributed by the interviewees at the conclusion of the interview included, for example:

"Be nice if this study would be used to make some changes . . . There are a great number of Native Americans that are not looked on as being disabled, but they have psychological problems caused by being displaced people. Before we can educate people we have to deal with these problems."

"Hope to see this study go somewhere . . . not end up on someone's bookshelf."

"Non-Indian social agencies don't know how to deal with Indians with disabilities. The Indians feel a lot of distrust towards non-Indian service providers."

"We need accessible and affordable housing for American Indians with and without disabilities instead of flooding them into high rises and overcrowded apartment complexes. We need more outreach workers from the various Indian organizations, at least Indian representation from the existing agencies in the urban communities."

"I feel very dissatisfied about my neighborhood . . . Where I live there are many problems. Nobody wants to help us. When I called the police to help me . . . the police threatened to throw my whole family in jail . . ."

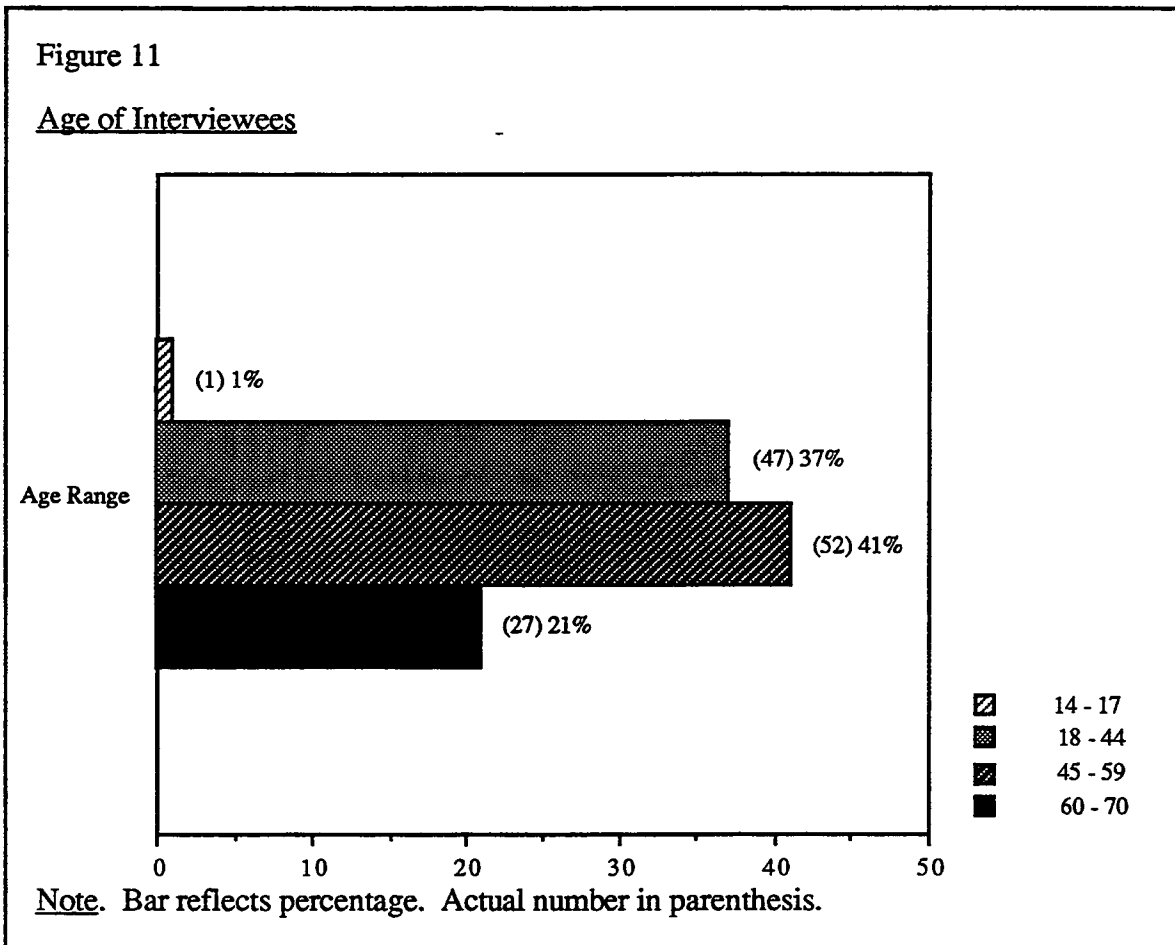
"Native Americans need to be taken more serious as a nation, and respected by Caucasians, and treated with better health care. The ignorance among Caucasian health care workers needs to be addressed legally and legislated."

"I'd like to find a coordinator who will do cottage industries for Native Americans who are disabled to supplement their income. Get Indian barbers to cut disabled Indians' hair who can't go to the barber shops."

Selected Results by Age Categories

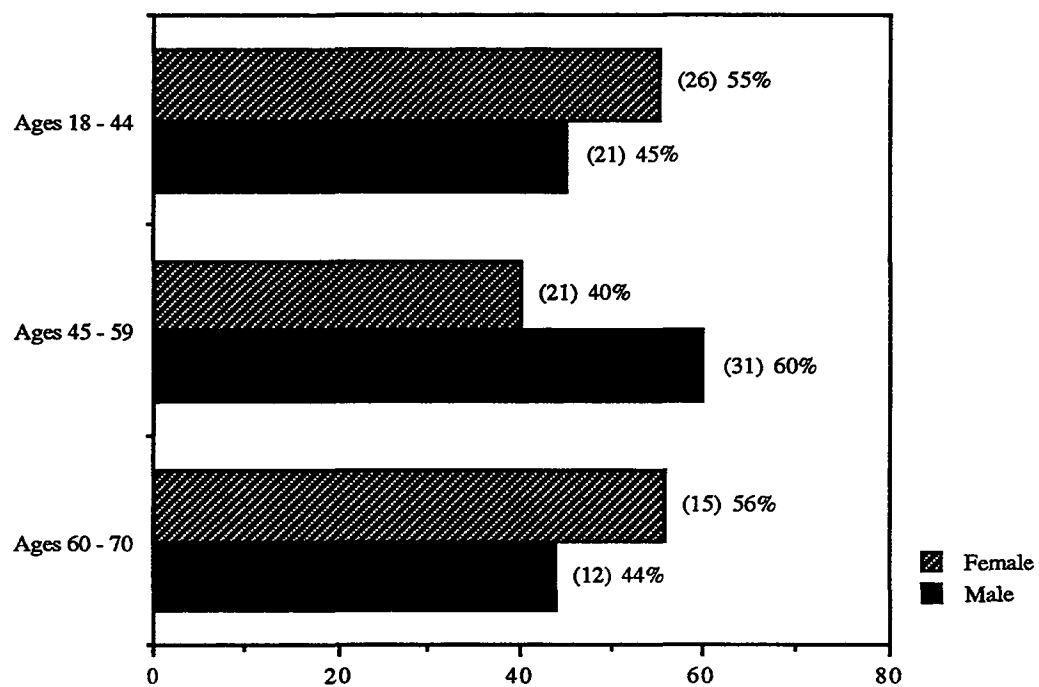
At the request of service providers, and in an attempt to identify any age-specific needs, data were analyzed according to three age categories: ages 18 - 44, 45 - 59, and 60 - 70. Selected results are presented below.

A plurality of interviewees were between the ages of 45 to 59, followed closely by those ranging in age between 18 and 44 (see Figure 11). While males represented a slight



majority in terms of the total population surveyed, they did not represent a majority in the younger or older populations (See Figure 12). In terms of marital status, the majority of the younger population reported “never married;” the largest percentage of those divorced occurred in “ages 45 - 59;” (see Figure 13). The older population reported the strongest

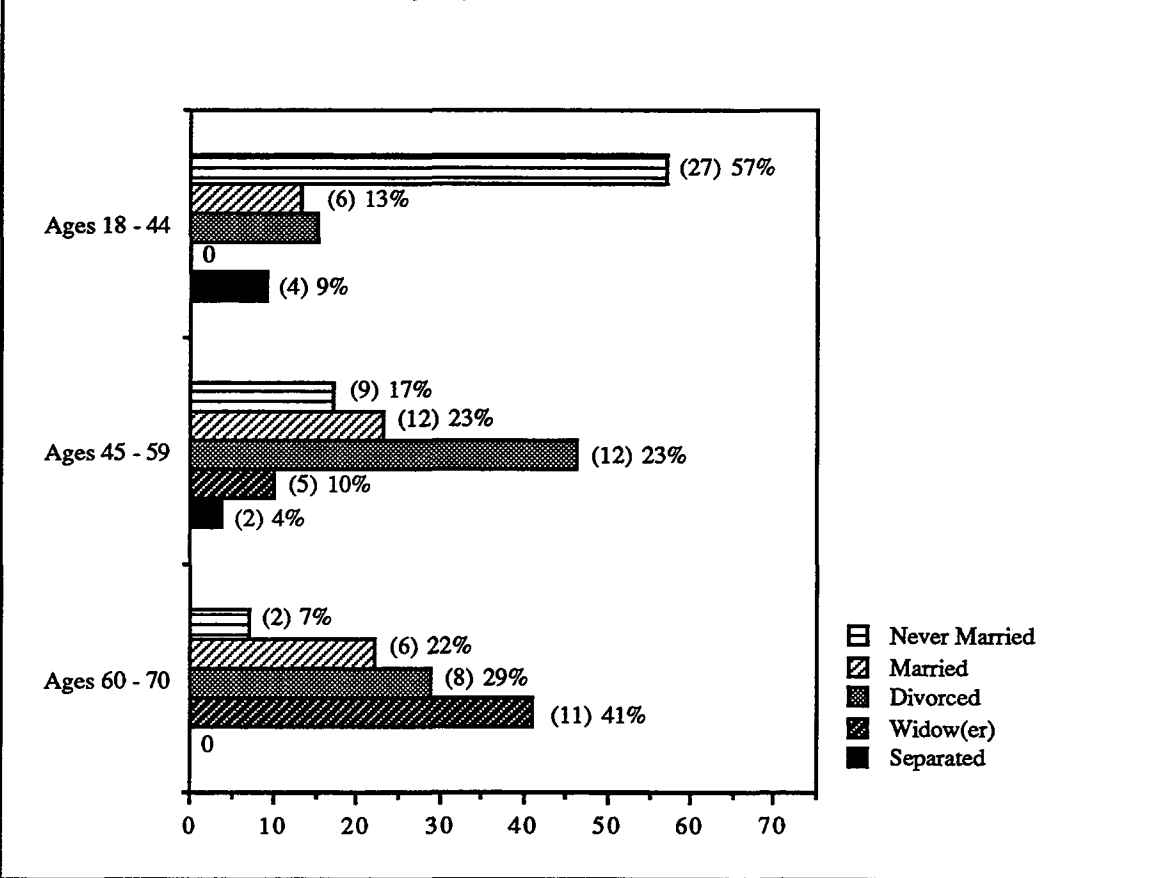
Figure 12
Sex of Interviewees by Age



Note. One person (male), age 14, not included.

Figure 13

Marital Status of Interviewees by Age



affiliation to a tribe, as defined by the percentage who knew their tribal roll number, and who were registered to vote in their tribe (see Figure 14); yet they had also lived the longest in the urban environment (see Figure 15). Across all age categories, the majority of persons reported that they preferred human service workers to use English when assisting them (see Figure 16). Transportation use varied by age category; both the younger population and the older population primarily depended upon the public bus system. A plurality of respondents ages 45 - 59 utilized a personal car (see Figure 17).

Figure 14

Affiliation to Tribe and Community by Age

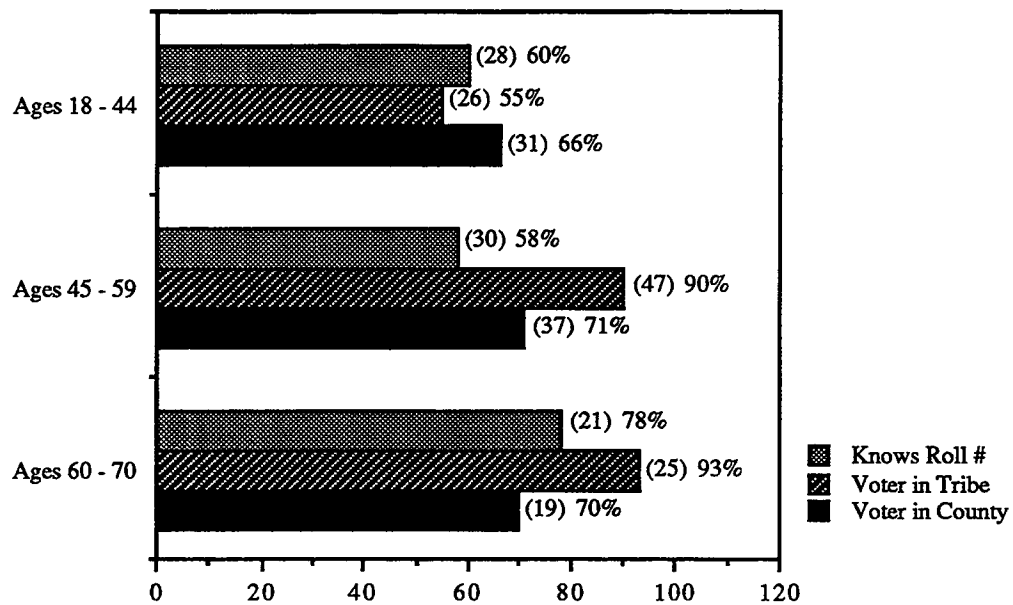


Figure 15

Average Years Lived in Metro Area by Age

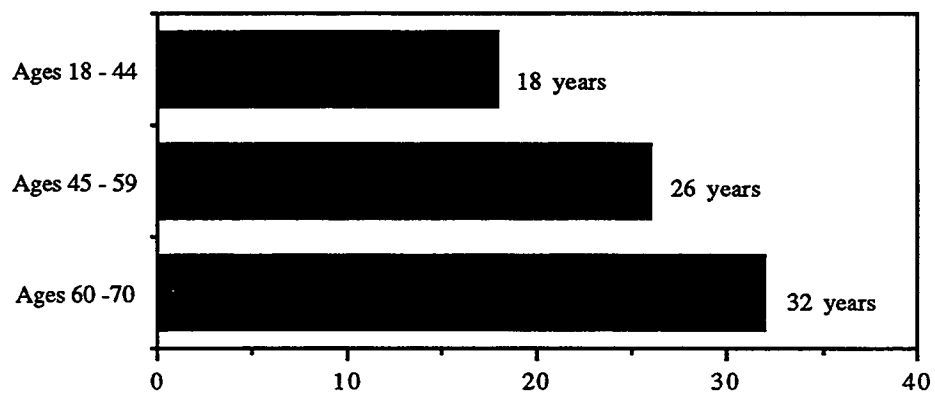


Figure 16

Preferred Language for Services by Age

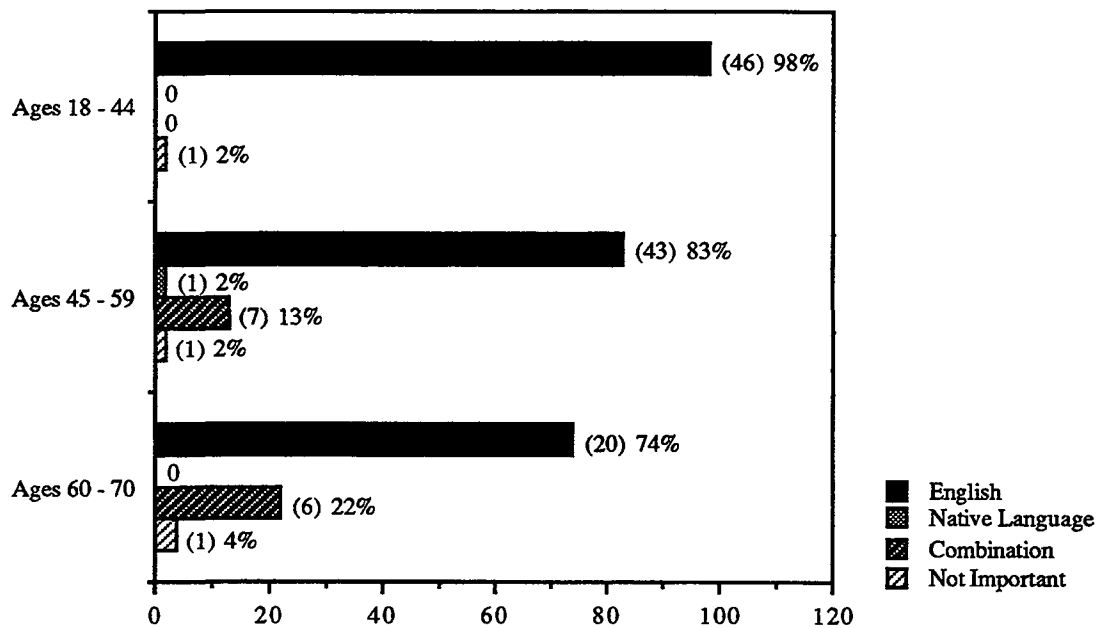
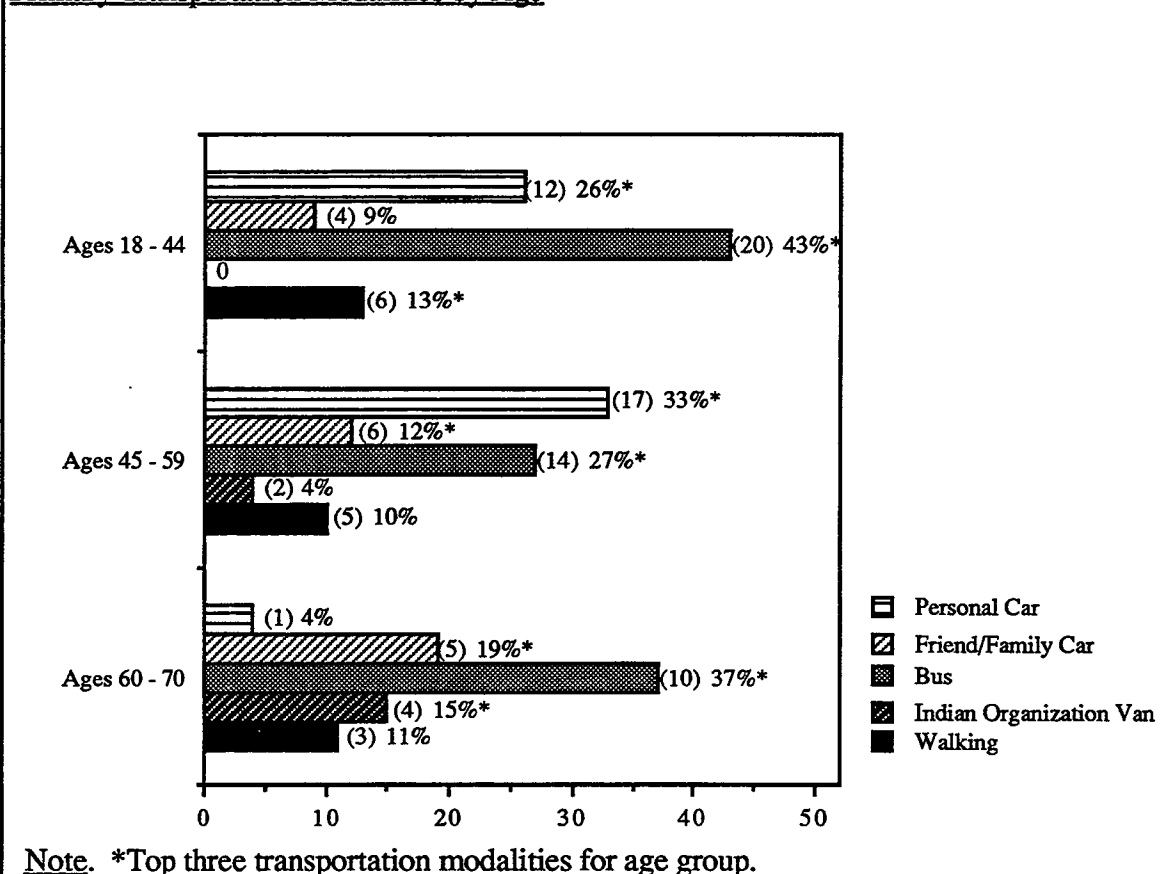


Figure 17

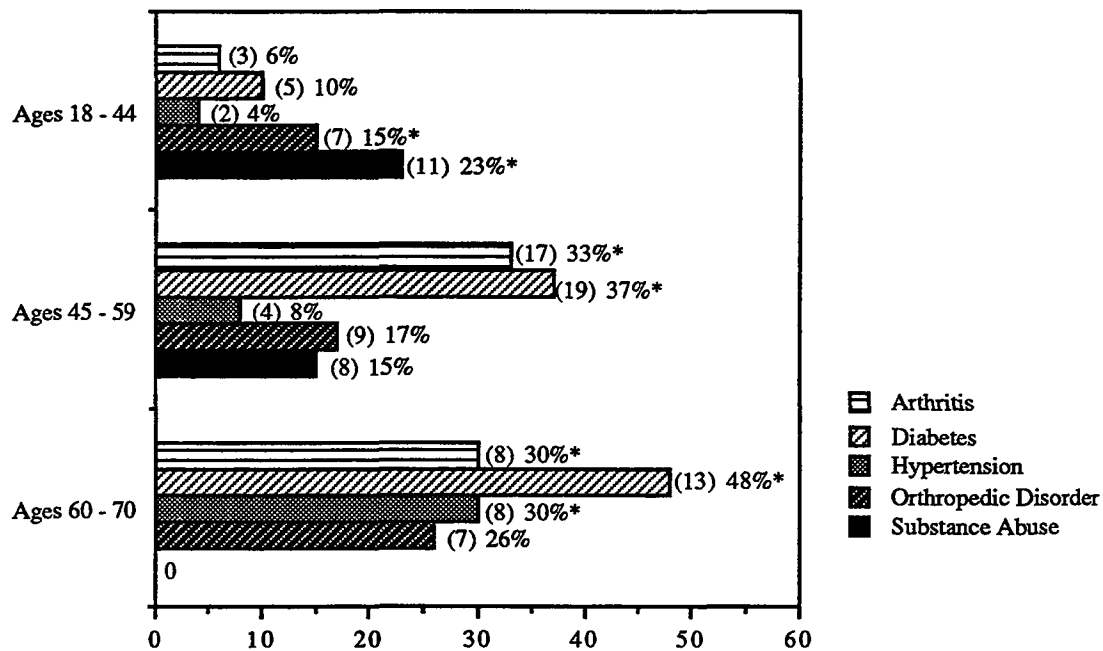
Primary Transportation Modalities by Age



Disabling conditions also varied by age; substance abuse, for example, which was the disability most frequently reported by the younger population, did not appear in those disabilities reported by the older population (see Figure 18). Almost one-half of those ages 60 - 70 reported dealing with diabetes; by comparison, 10% of the younger population reported having this disability. In terms of onset of disability, for those interviewees ages 18 - 44, 19% (n = 9) reported having had a disability since birth; for the remainder, the average age of onset was 23. For interviewees ages 45 - 49, 6% (n = 3) reported having had a disability since birth; for the remainder, the average age of onset was 39. For interviewees ages 60 - 70, no one reported having had a disability since birth; the average age of onset was 45.

Figure 18

Primary Disabling Conditions by Age

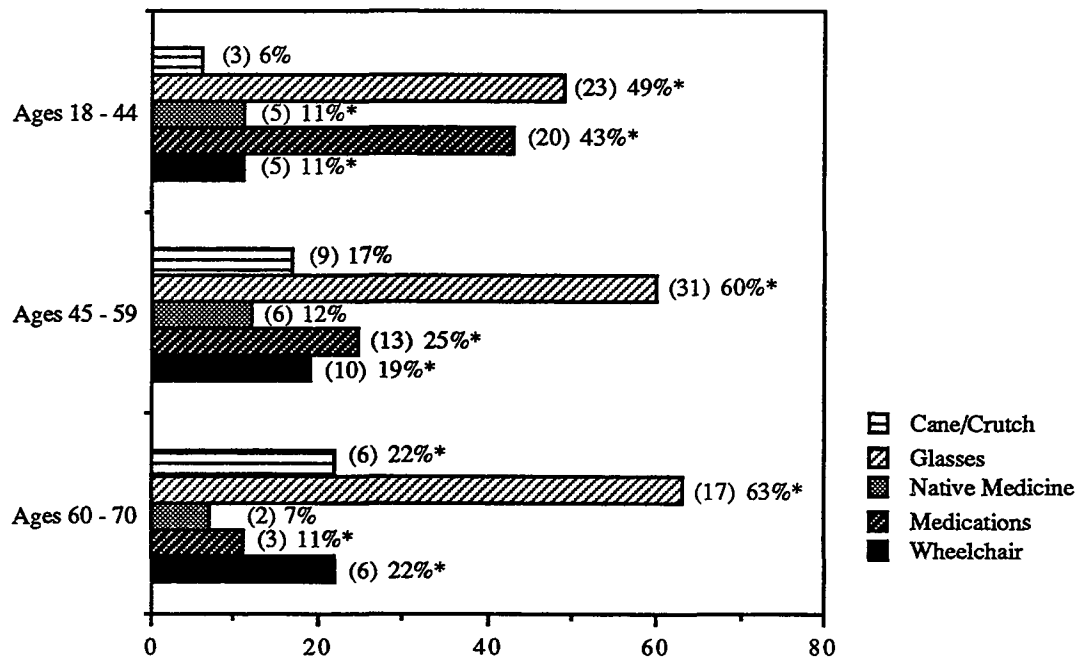


Note. *Top two disabling conditions for age group; rank order can not be inferred beyond these two conditions.

While type of disabilities varied across age categories, glasses were needed by the largest number of interviewees regardless of age (see Figure 19). In terms of health and life satisfaction, only in the younger population did the majority rate their health as excellent or good, while only in the older population did the majority rate their satisfaction with life as excellent or good (see Figure 20). "Lifting" and "Working on Job" were identified as functional limitations by the majority of interviewees across all age categories (see Figure 21); however "Walking" was the most frequently reported functional limitation by the older population. Primary service needs varied across age categories. Pluralities of those ages 18 - 44 reported needing vocational training, of those ages 45 - 59 reported needing

Figure 19

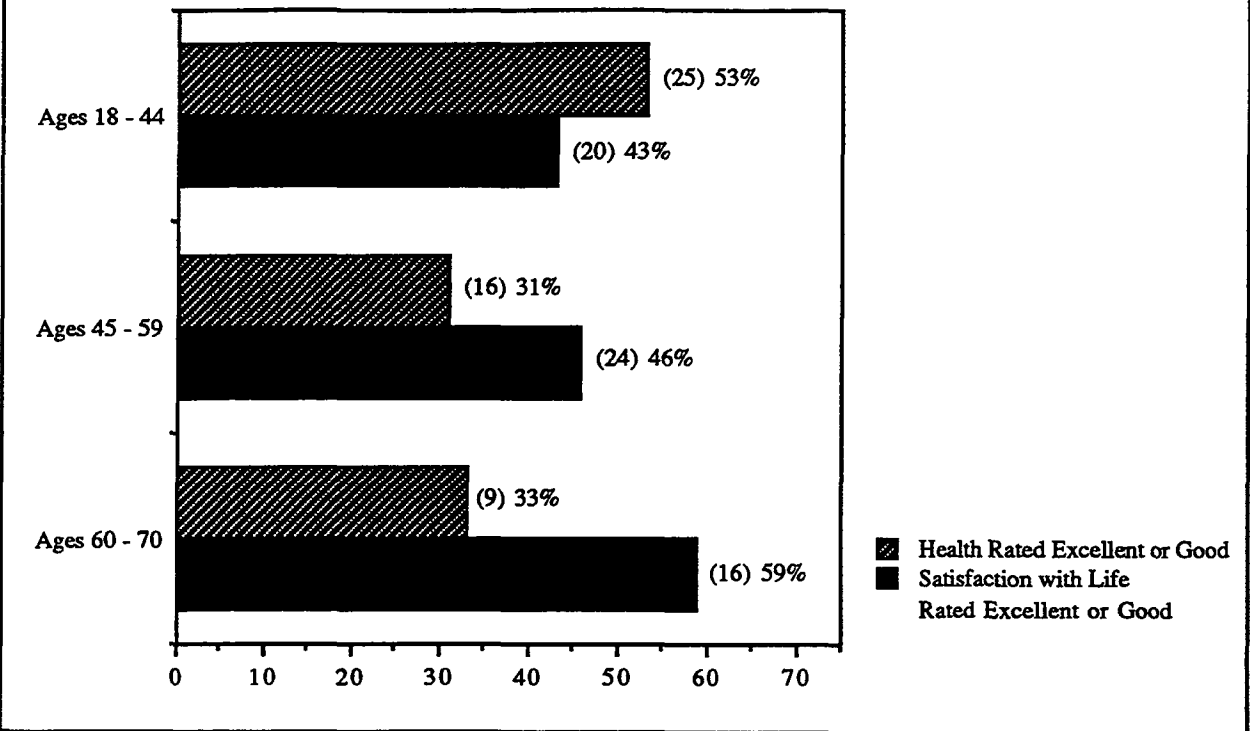
Primary Needed Assistive Devices by Age



Note. *Top three needed assistive devices for age group; rank order can not be inferred beyond these three devices.

Figure 20

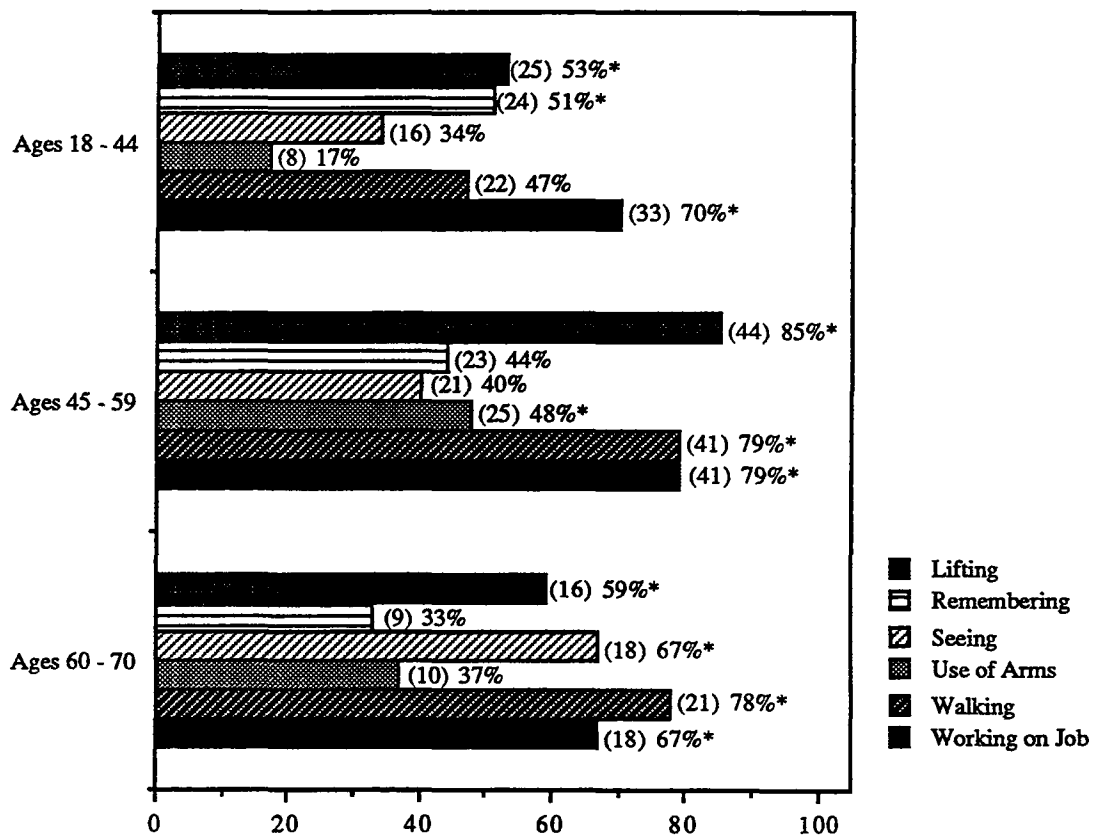
Health and Life Satisfaction Ratings by Age



clothing, and of those ages 60 - 70 reported needing housing (see Figure 22). In both younger population and with those ages 45-59, the majority of interviewees had received at least a high school diploma or GED (see Figure 23). Over 40% of the older population had received at least a high school diploma or GED. The proportion of those ages 18 - 44 who had received a bachelor's degree was more than double that of other age categories. For those who did not complete high school or obtain a GED, the highest average grade completed for ages 18 - 44 was 10th grade, for ages 45 - 59, 8th grade, and for ages 60 - 70, 9th grade.

Figure 21

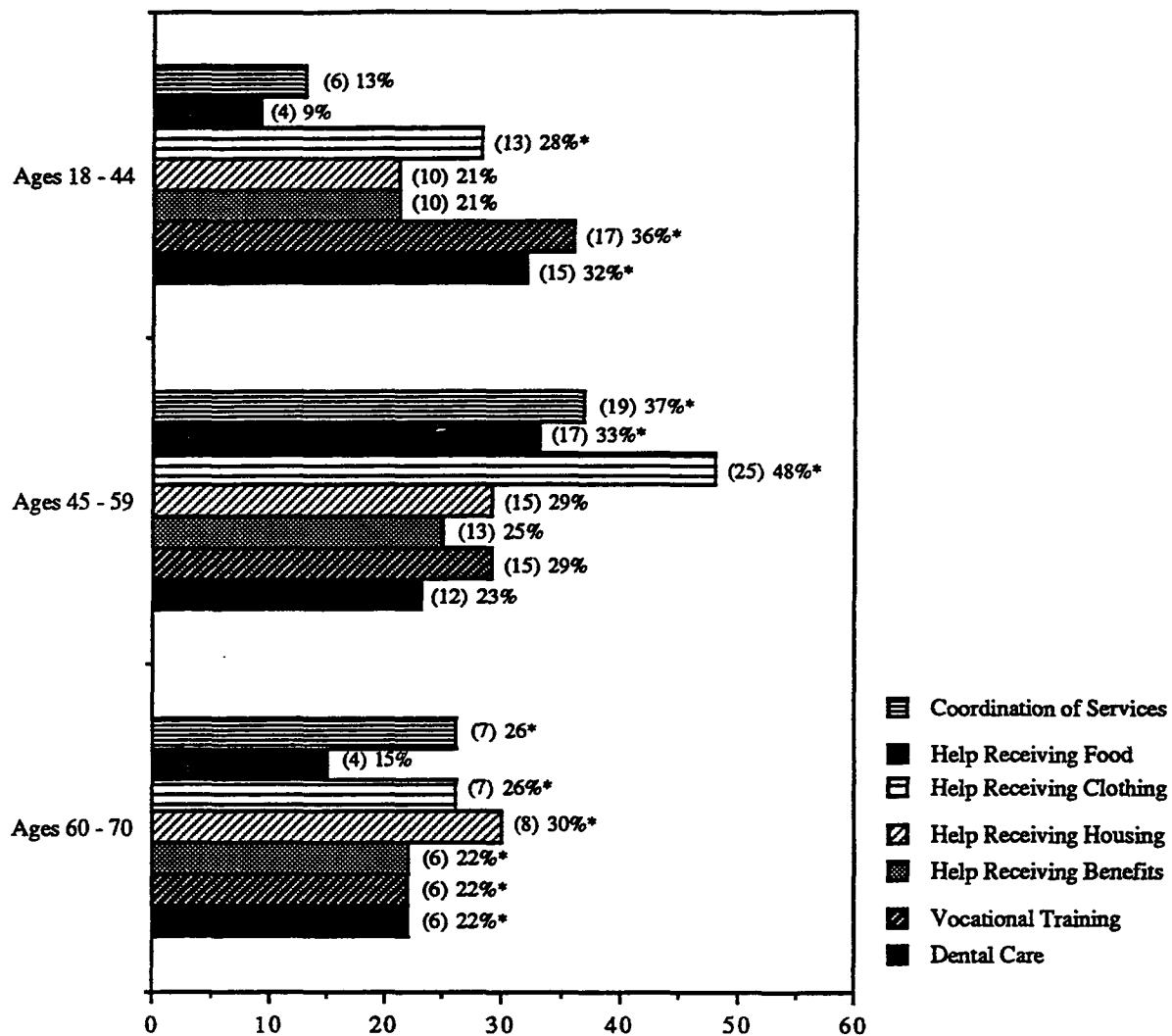
Primary Functional Limitations by Age



Note. *Top three functional limitations for age group; rank order can not be inferred beyond these three limitations.

Figure 22

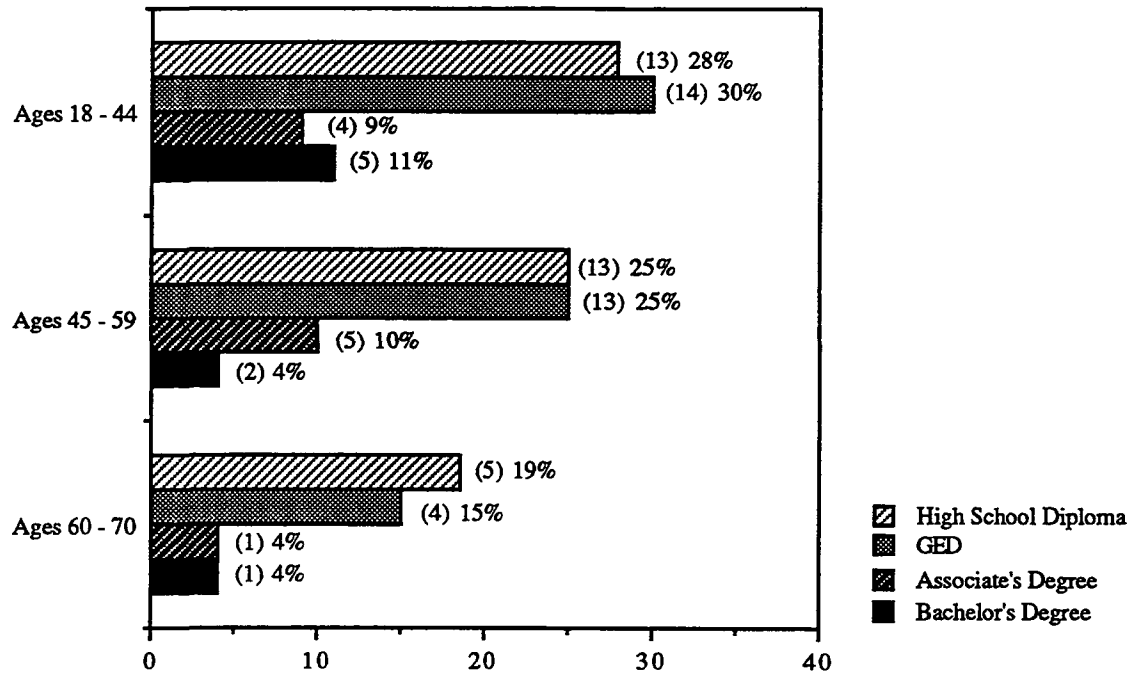
Primary Service Needs by Age



Note. *Top three service needs for age group; rank order can not be inferred beyond these three needs.

Figure 23

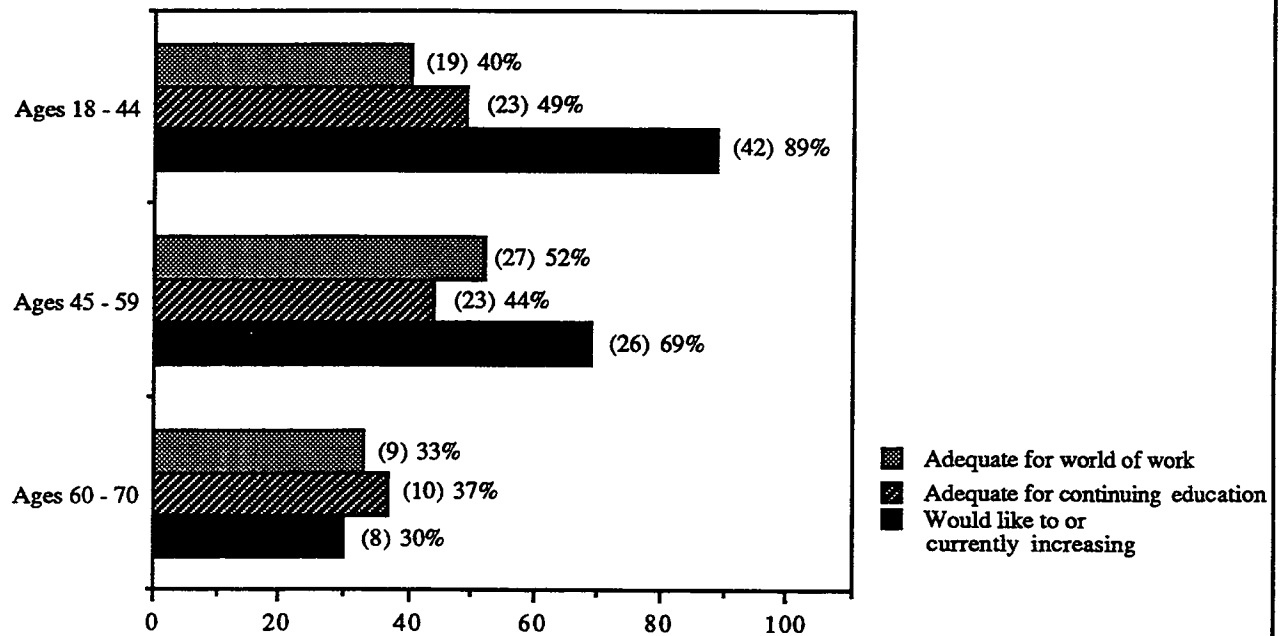
Educational Degrees by Ages



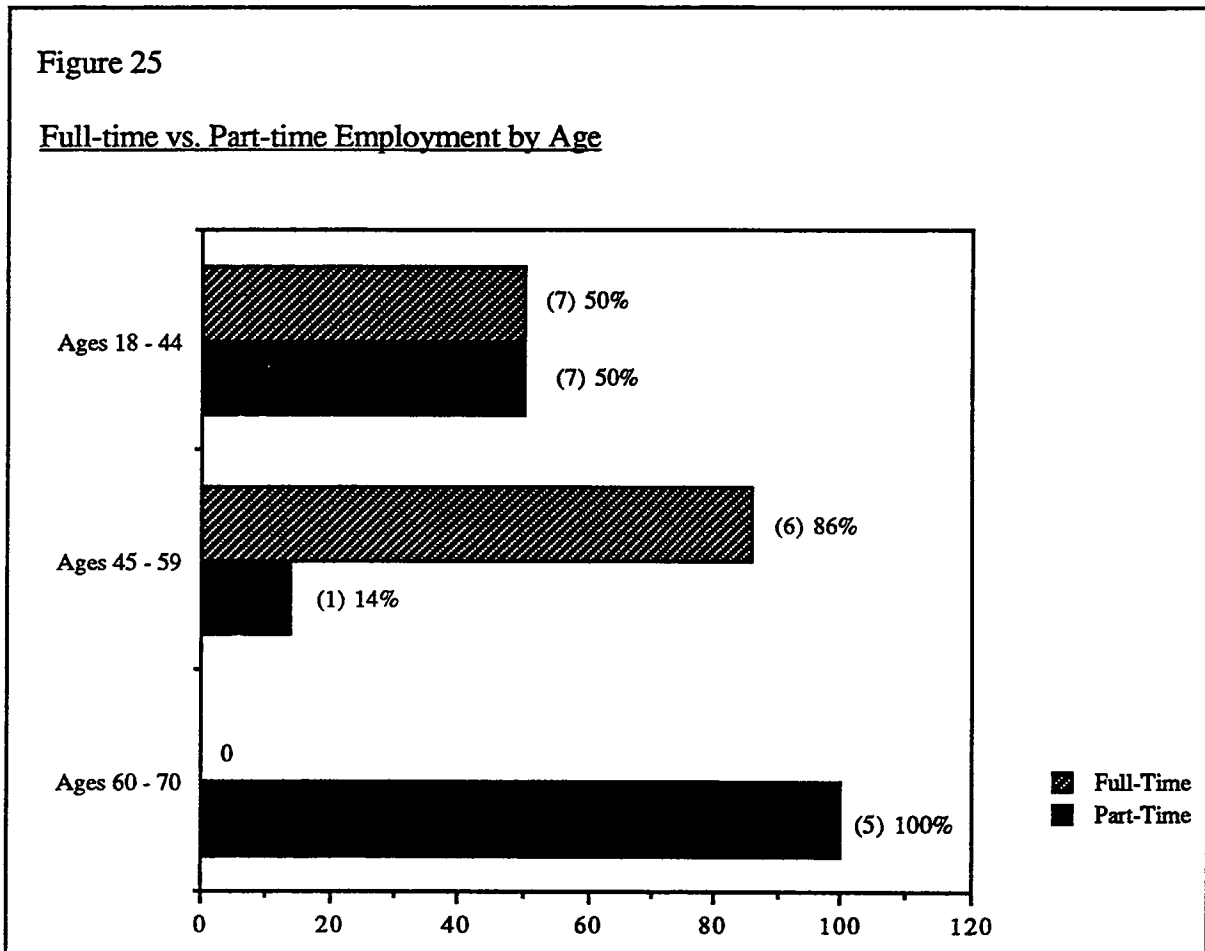
In no age category did the majority of interviewees believe that their education adequately prepared them for education beyond high school (see Figure 24). However, the majority of those under age 60 would like to increase their current educational level (see Figure 24).

Figure 24

Adequacy of Education by Age



Only in ages 45 - 59 were the majority of interviewees working full-time (see Figure 25). However, in terms of the proportion of those working to those not working in each category, 30% (n = 14) of those ages 18 - 44 were working, 13% (n = 7) of those ages 45 - 59 were working, and 19% (n = 5) of those 60 -70 were working. While interviewees across all age categories identified their disability as a problem in finding or

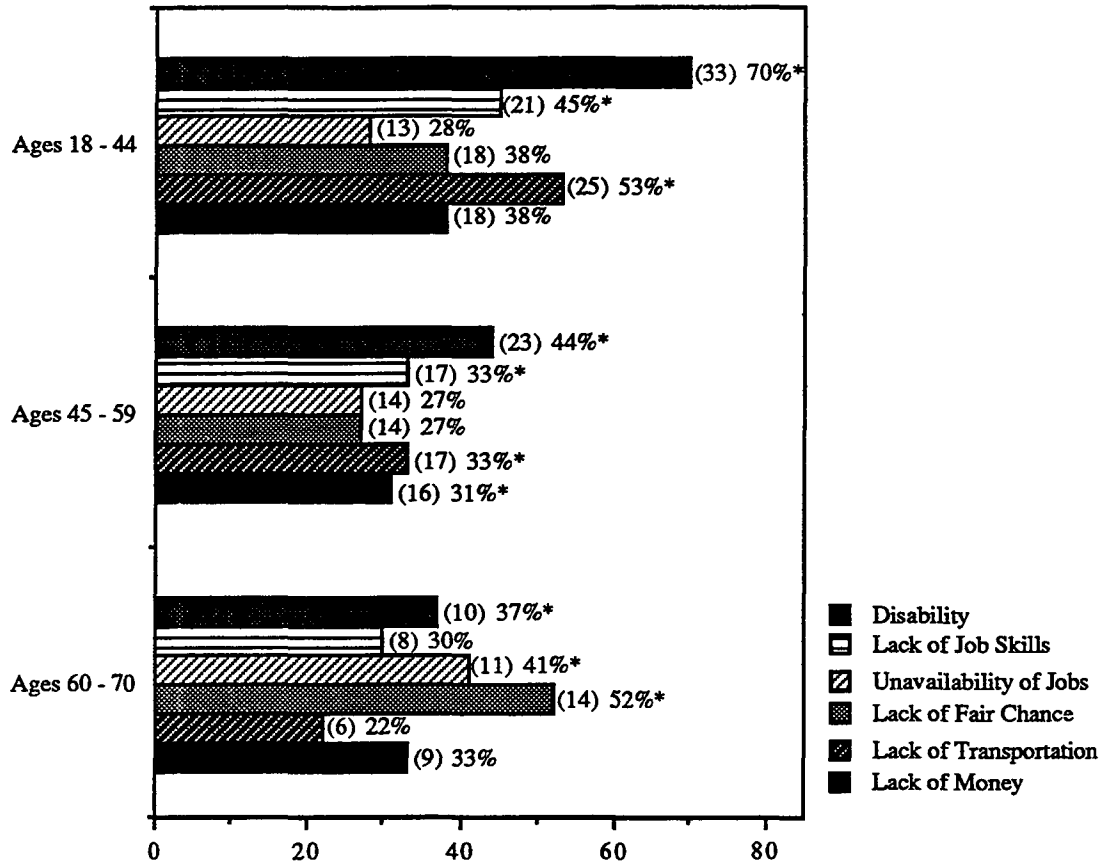


keeping employment, it was a problem for the majority only in ages 18 - 44 (see Figure 26). The majority of interviewees ages 60 - 70 cited “Lack of Fair Chance” as a primary problem.

A large majority, across all age categories, reported that they could count on someone to give them help when they needed it. Specifically, of those ages 18 - 44, 81% (n = 38) could count on help, with 66% (n = 25) reporting they received financial support.

Figure 26

Primary Problems in Finding or Keeping Employment by Age



Note. *Top three problem areas for age group; rank order can not be inferred beyond these three problems.

Of those ages 45 - 59, 83% (n = 43) could count on help, with 58% (n = 25) reporting they received financial support. Of those ages 60 - 70, 78% (n = 21) could count on help, with 62% (n = 13) reporting they received financial support. It is important to note that the item related to financial support was responded to only by those interviewees who initially reported that there was someone close to them on whom they could count. In fact, a great many interviewees reported having no one to assist them financially, and average annual incomes were low. Specifically, for interviewees ages 18 - 44, the annual average income was \$7,258; 47% (n = 25) reported no other financial assistance. For interviewees ages 45

- 59, the annual average income was \$7,021; 52% (n = 25) reported no other financial assistance. For interviewees ages 60 - 70, the annual average income was \$6,597; 52% (n = 13) reported no other financial assistance. Consumer concerns have also been analyzed by age categories, and can be found in Tables 14 - 19.

Table 14

Consumer Concerns - Relative Strengths - Age under 45 (n = 36)

Item #	Survey Question	Average Importance	Average Satisfaction
37	You feel safe in your home and neighborhood.	95%	56%
17	Handicapped parking is adequate and enforced.	82%	62%
4	You are not isolated from your friends and neighbors because of your disability.	82%	62%
19	Accessible public housing units are available to people with disabilities.	90%	56%
24	Checkout stands and aisles in stores are safe and accessible for shoppers who have disabilities.	87%	57%
23	You have control over choosing and managing your personal care attendants and housekeepers.	83%	59%
*18	Affordable housing is available to people with all types of disabilities.	95%	50%
38	In general, your community is a good place for a person with a disability to live.	88%	54%
1	Indian cultural/social events are accessible, including restrooms, to people with disabilities.	87%	54%

Note. *This item also reported as a relative problem.

Table 15

Consumer Concerns - Relative Problems - Age under 45 (n = 36)

Item #	Survey Question	Average Importance	Average Satisfaction
29	Streets and sidewalks in areas of public housing are safe and accessible.	90%	43%
9	Indians with disabilities advocate for their own needs at the local, state, and federal levels.	87%	41%
3	The Indian community understands the needs of its members with disabilities.	90%	45%
11	There is a central resource for information and referral for disability services available to Indians with disabilities.	83%	40%
28	You know your rights as a citizen with a disability.	91%	47%
*18	Affordable housing is available to people with all types of disabilities.	95%	50%
33	Qualified job applicants with and without disabilities are given the same opportunities.	84%	43%
14	Health service providers treat you with dignity and respect, and are sensitive to your disability and your culture.	90%	48%
6	As a citizen with a disability, you have a say in city, county, and state government disability programming and planning.	79%	41%

Note. *This item also reported as a relative strength.

Table 16

Consumer Concerns - Relative Strengths - Age 45 - 59 (n = 39)

Item #	Survey Question	Average Importance	Average Satisfaction
28	You know your rights as a citizen with a disability.	92%	55%
17	Handicapped parking is adequate and enforced.	80%	62%
4	You are not isolated from your friends and neighbors because of your disability.	78%	61%
31	Adequate mental health care is available to you.	80%	59%
* 37	You feel safe in your home and neighborhood.	92%	50%
27	Assistive devices (wheelchairs, braces, hearing aides, etc.) are available and affordable.	85%	53%
15	Affordable, accessible public transportation is available.	84%	54%

Note. *This item also reported as a relative problem.

Table 17

Consumer Concerns - Relative Problems - Age 45 - 59 (n = 39)

Item #	Survey Question	Average Importance	Average Satisfaction
18	Affordable housing is available to people with all types of disabilities.	91%	45%
20	Social agencies inform you of benefits and services available to you.	82%	38%
13	Sidewalk snow removal is adequate.	81%	40%
* 37	You feel safe in your home and neighborhood.	92%	50%
29	Streets and sidewalks in areas of public housing are safe and accessible.	86%	46%
3	The Indian community understands the needs of its members with disabilities.	84%	45%
19	Accessible public housing units are available to people with disabilities.	86%	47%

Note. *This item also reported as a relative strength.

Table 18

Consumer Concerns - Relative Strengths - Age 60 - 70 (n = 18)

Item #	Survey Question	Average Importance	Average Satisfaction
14	Health service providers treat you with dignity and respect, and are sensitive to your disability and your culture.	84%	73%
23	You have control over choosing and managing your personal care attendants and housekeepers.	75%	72%
28	You know your rights as a citizen with a disability.	91%	58%
24	Checkout stands and aisles in stores are safe and accessible for shoppers who have disabilities.	87%	61%
15	Affordable, accessible public transportation is available.	79%	64%
34	You can get help in applying for welfare, food stamps, and social services.	80%	63%
5	Indian service agencies are barrier-free and consider the needs of people with disabilities.	75%	67%

Table 19

Consumer Concerns - Relative Problems - Age 60 - 70 (n = 18)

Item #	Survey Question	Average Importance	Average Satisfaction
37	You feel safe in your home and neighborhood.	91%	43%
38	In general, your community is a good place for a person with a disability to live.	86%	48%
33	Qualified job applicants with and without disabilities are given the same opportunities.	75%	42%
27	Assistive devices (wheelchairs, braces, hearing aides, etc.) are available and affordable.	84%	50%
32	The public vocational rehabilitation agency is responsive to the needs of Indian people with disabilities.	84%	50%
29	Streets and sidewalks in areas of public housing are safe and accessible.	90%	54%
9	Indians with disabilities advocate for their own needs at the local, state, and federal levels.	86%	54%
20	Social agencies inform you of benefits and services available to you.	79%	50%
36	Local media provide adequate information about disabilities, programs, and services available.	72%	45%

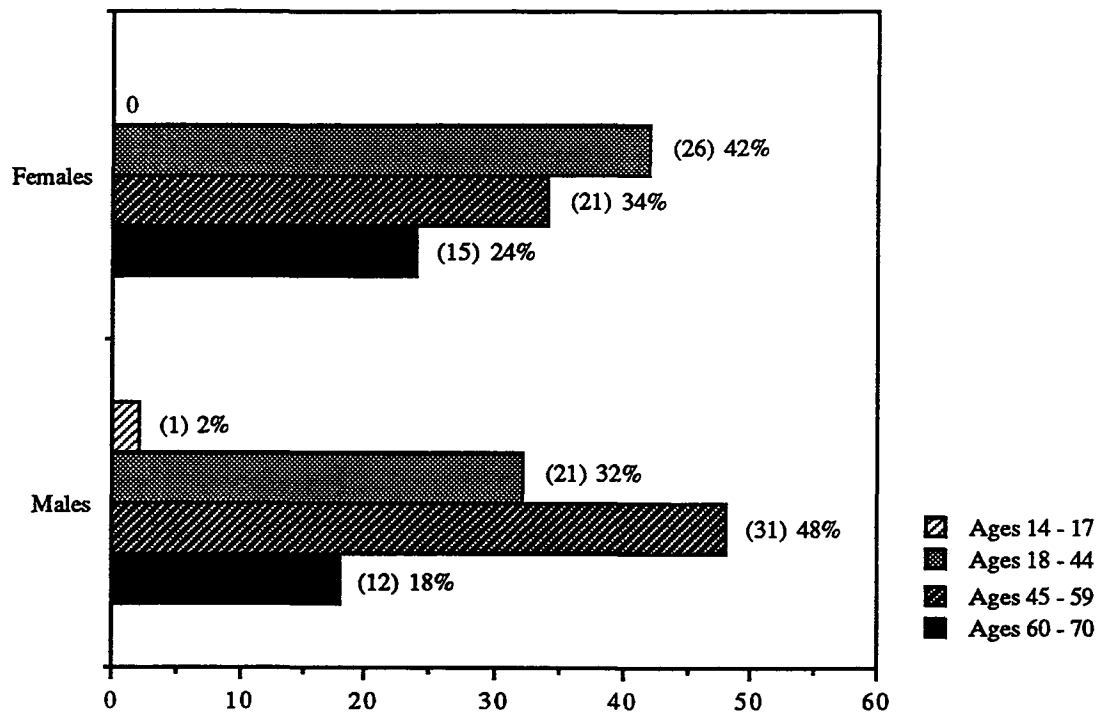
Selected Results by Sex Categories

As respondents were almost equally represented in terms of sex - males [51% (n = 65)]; females [49% (n = 62)], data were analyzed for each category in order to identify any sex-specific needs. Selected results are presented below.

The mean age for females was 47; the mean age for males was 48. A plurality of women were represented in the age category 18 - 44; a plurality of men were represented in the age category 45 - 59 (see Figure 27). In terms of marital status, over a third

Figure 27

Ages of Interviewees by Sex



(representing a plurality) of the men reported never having been married; just over a quarter of the women reported never having been married (see Figure 28). A plurality of women were divorced. Both men and women demonstrated strong affiliation to a tribe, as defined by the percentage who knew their tribal roll number, and who were registered to vote in their tribe (see Figure 29). However, a greater proportion of women than men were registered to vote in their county of residence (see Figure 29). On average, men reported having lived two years longer in the urban area than did women (see Figure 30). A large majority of both men and women preferred human service workers to use English when assisting them (see Figure 31). A considerably greater proportion of women reported the public bus system to be their primary form of transportation than did men; men relied more on their personal car and walking (see Figure 32).

Figure 28

Marital Status of Interviewees by Sex

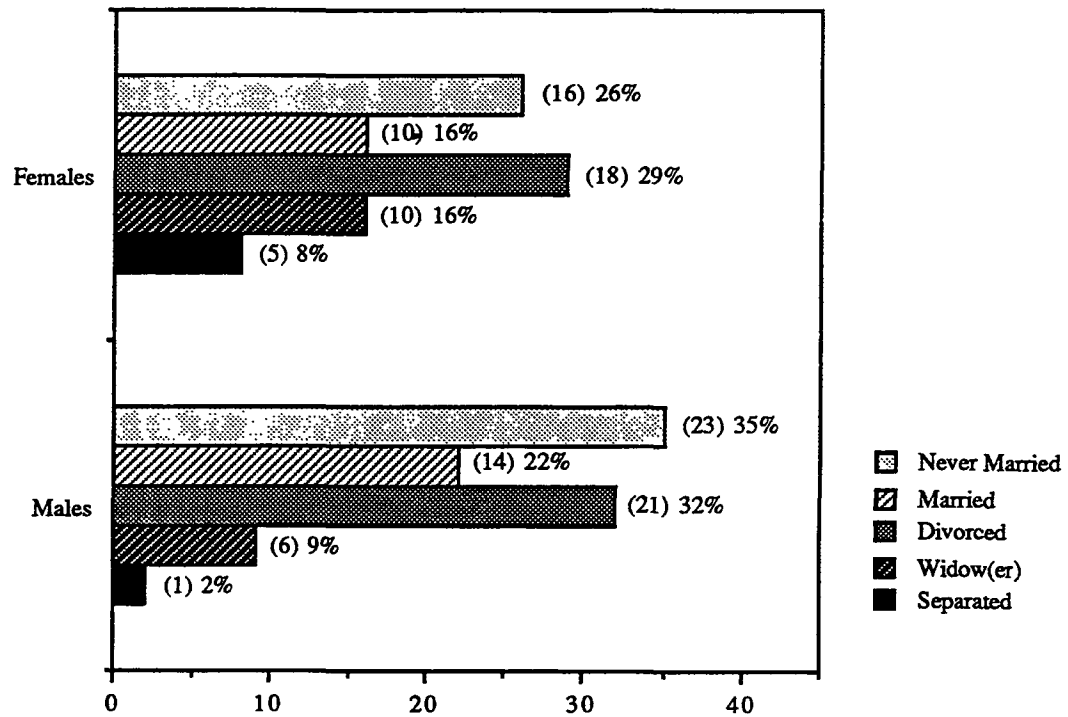


Figure 29

Affiliation to Tribe and Community by Sex

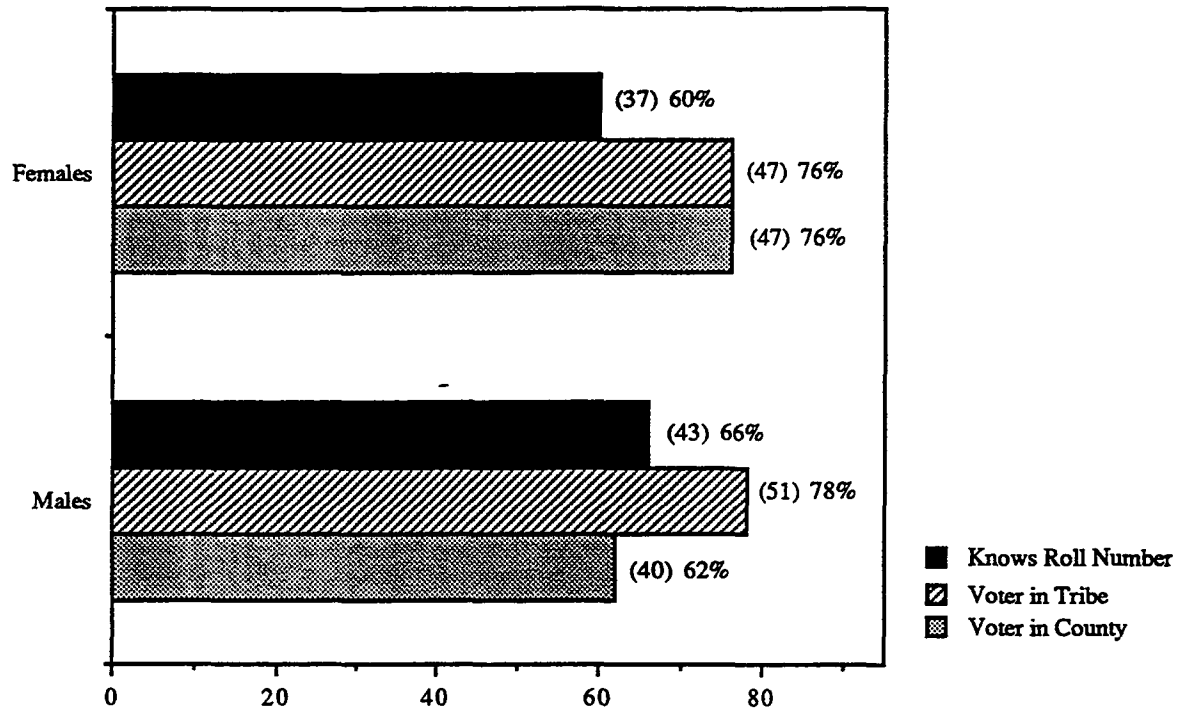


Figure 30

Average Years Lived in Metro Area by Sex

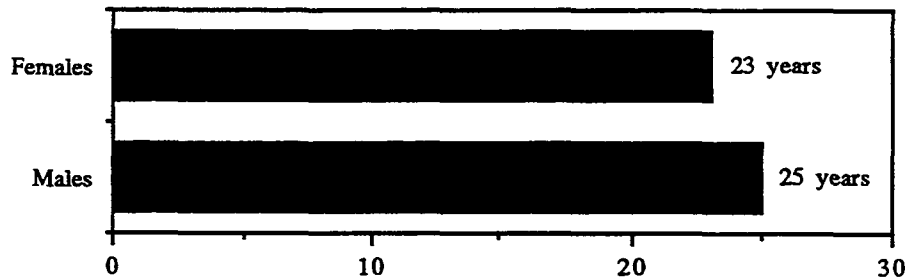


Figure 31

Preferred Language for Services by Sex

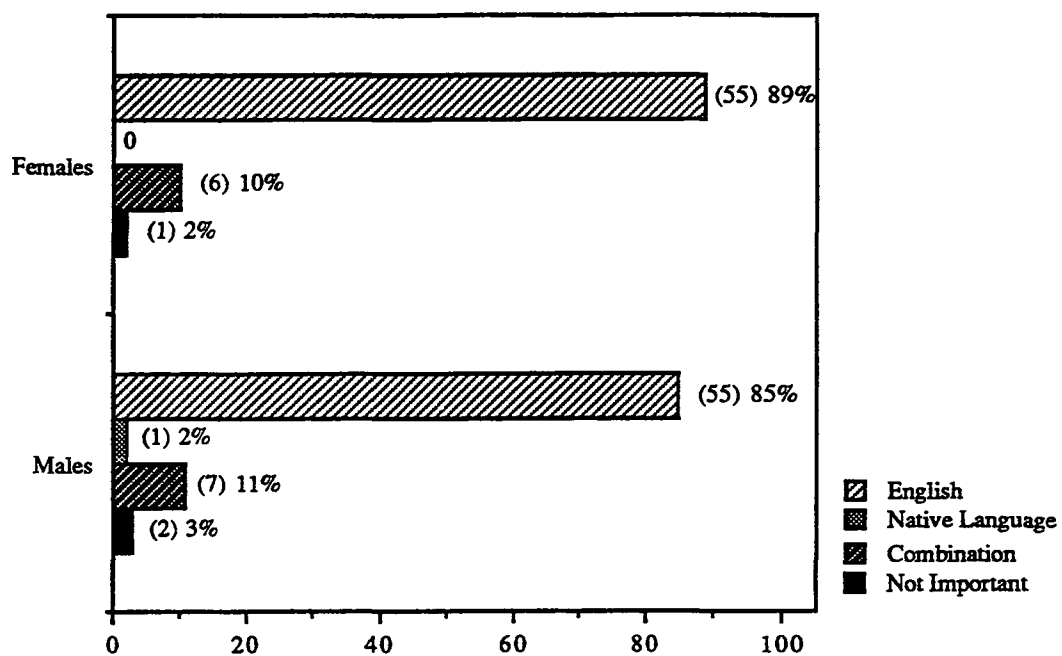
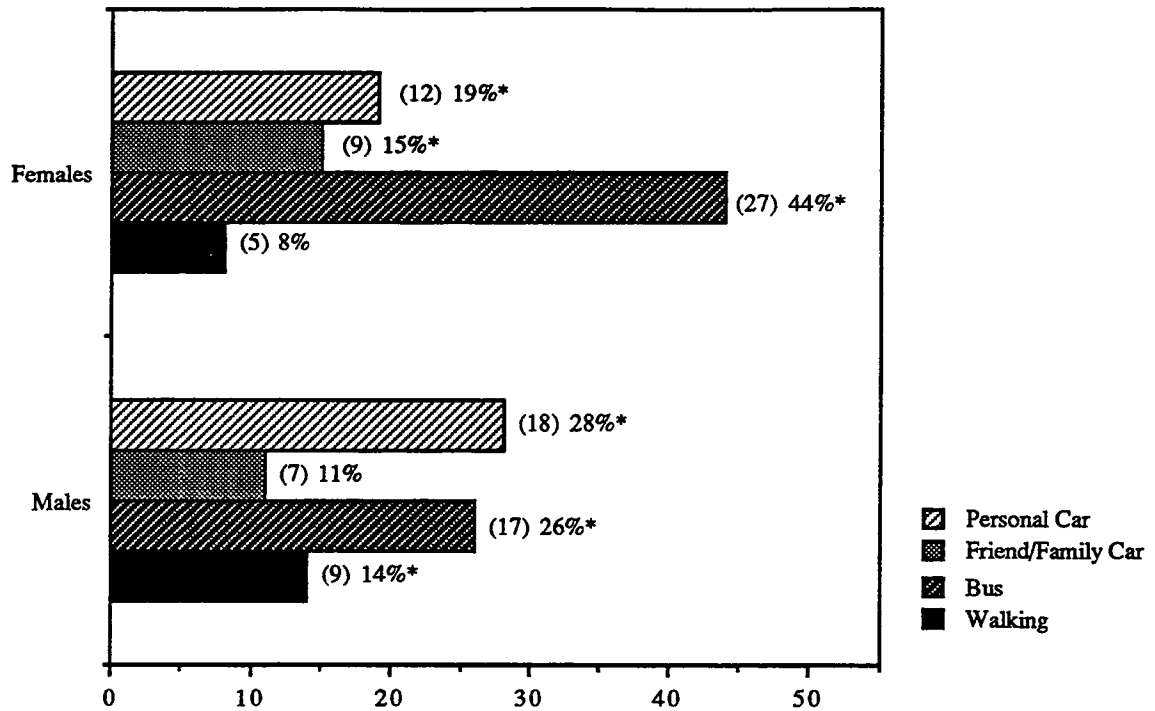


Figure 32

Primary Transportation Modalities by Sex

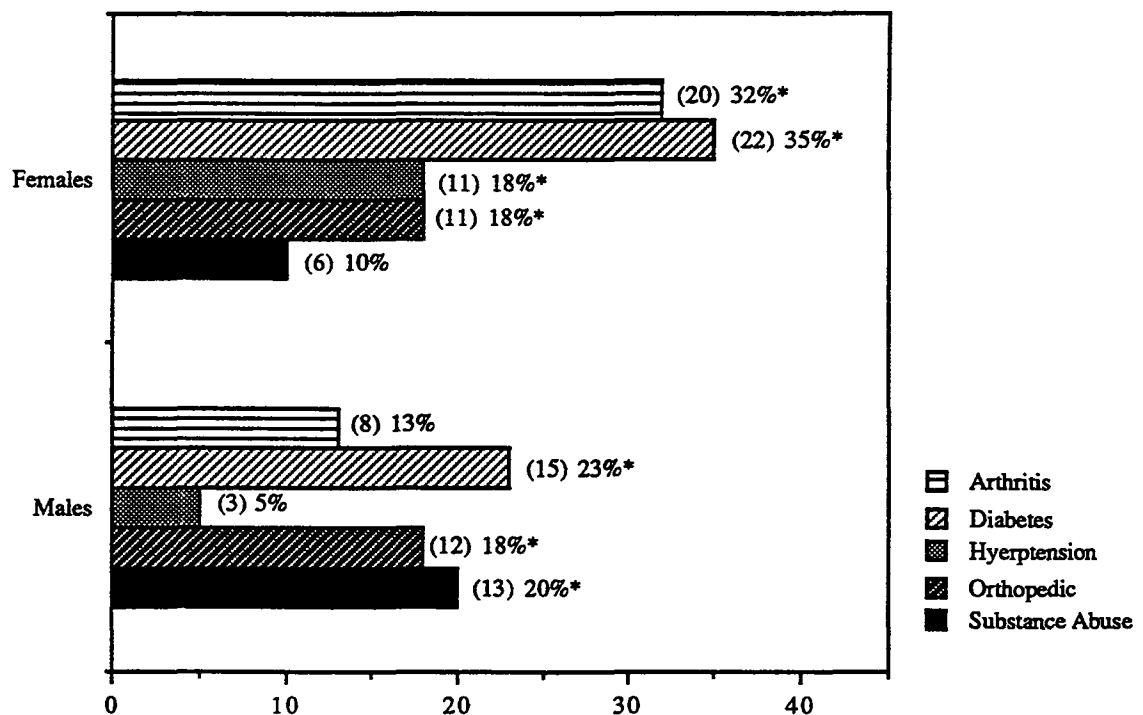


Note. *Top three transportation modalities in category.

In terms of disabling conditions, the plurality of men and women had diabetes (see Figure 33). For women, the second most frequently occurring disability was arthritis; for men, substance abuse. In terms of onset of disability, 11% (n = 7) of the women, and 9% (n = 6) of the men reported having had their disability since birth. For the remaining women, the average age of onset was 36; for the remaining men, the average age of onset was 35.

Figure 33

Primary Disabling Conditions by Sex

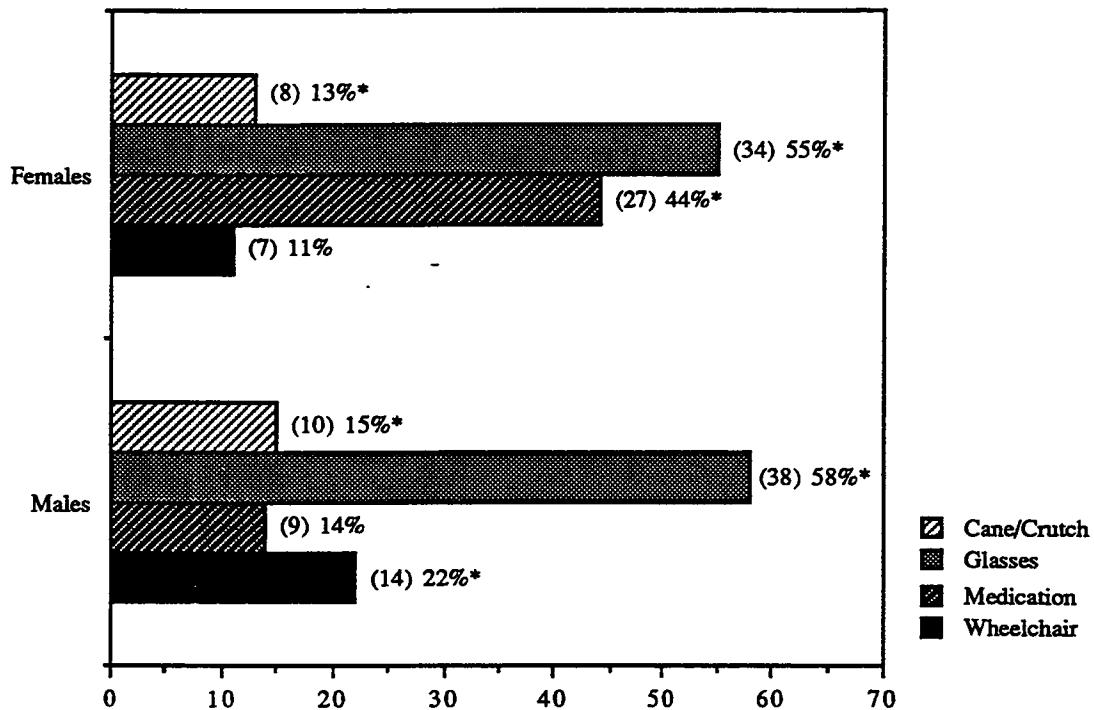


Note. *Top three disabling conditions in category; rank order can not be inferred beyond these three conditions.

In terms of assistive devices, the majority of both men and women reported needing glasses (see Figure 34). Considerably more women than men also need medication.

Figure 34

Primary Needed Assistive Devices by Sex

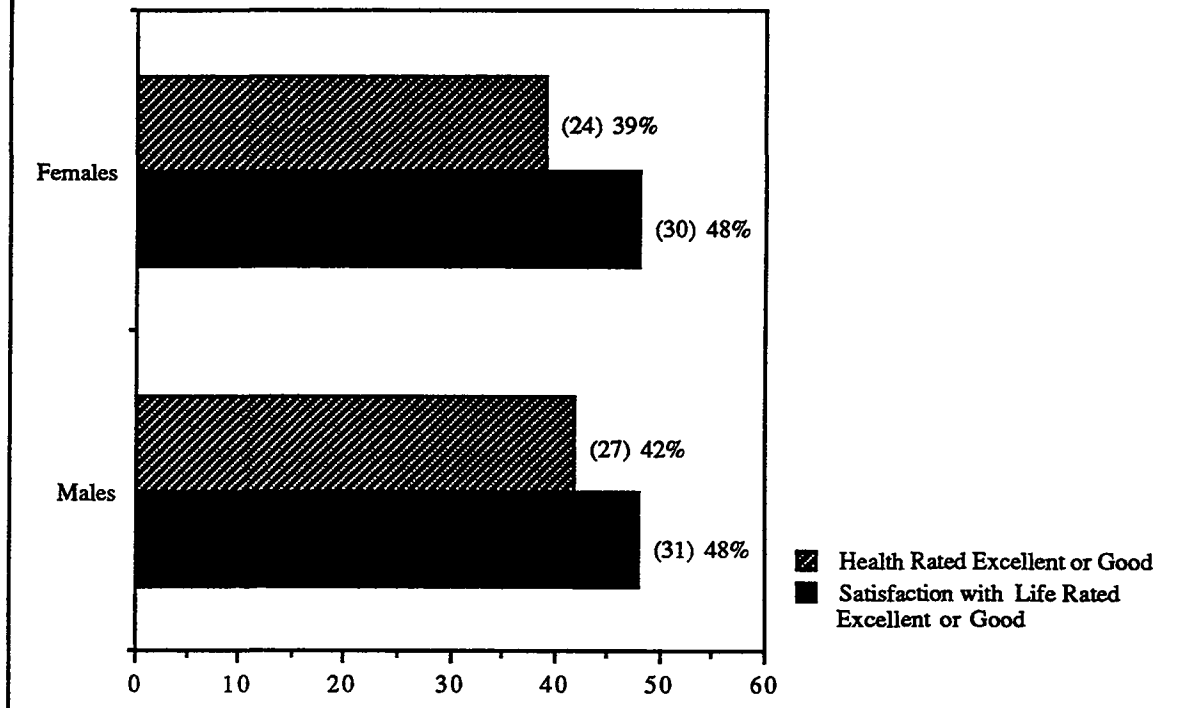


Note. *Top three needed assistive devices in category; rank order can not be inferred beyond these three devices.

Twice the number of men compared to women need a wheelchair. A greater frequency of both men and women rated as excellent or good their satisfaction with life compared to their health (see Figure 35). A larger proportion of men reported “Working on Job” as a

Figure 35

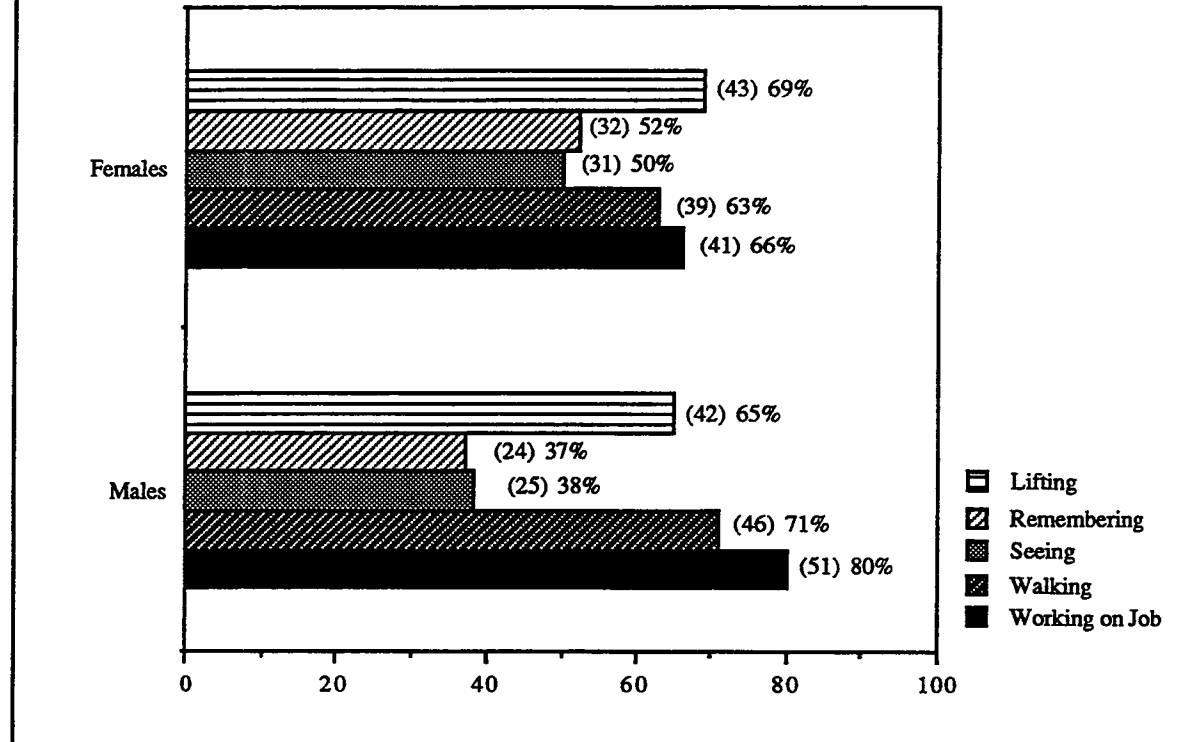
Health and Life Satisfaction Ratings by Sex



functional limitation than did women; larger proportions of women than men reported difficulties with “Remembering” and “Seeing” (see Figure 36). In terms of service needs, the plurality of both men and women reported needing help with receiving clothing (see Figure 37). For women, the second most frequently reported need was vocational training; for men, vocational training and dental care.

Figure 36

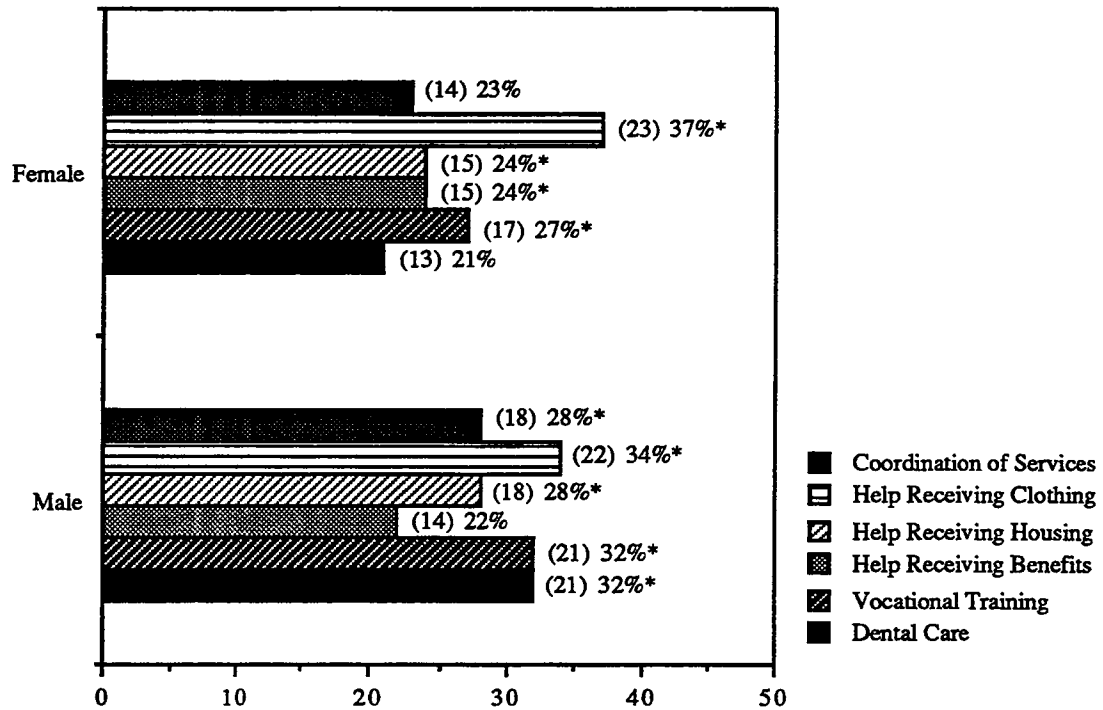
Primary Functional Limitations by Sex



Almost twice the proportion of women as compared to men reported having completed high school; the same is true for having obtained a bachelor's degree (see Figure 38). The majority (66%) of women had obtained at least a high school education or a GED; this was also true for the men (60%). For both men and women not completing high school or obtaining a GED, the average highest grade completed was 9th grade. The majority of women believed that their education adequately prepared them for education beyond high school; this was not true for men (see Figure 39). However, the majority of both men and women reported that they would like to increase their current educational level. In terms of content areas, women interested in increasing their education ($n = 40$), primarily identified an area of health and human services as their career goal [33% ($n =$

Figure 37

Primary Service Needs by Sex



Note. *Top three service needs for each category; rank order can not be inferred beyond these three needs.

Figure 38

Educational Degrees by Sex

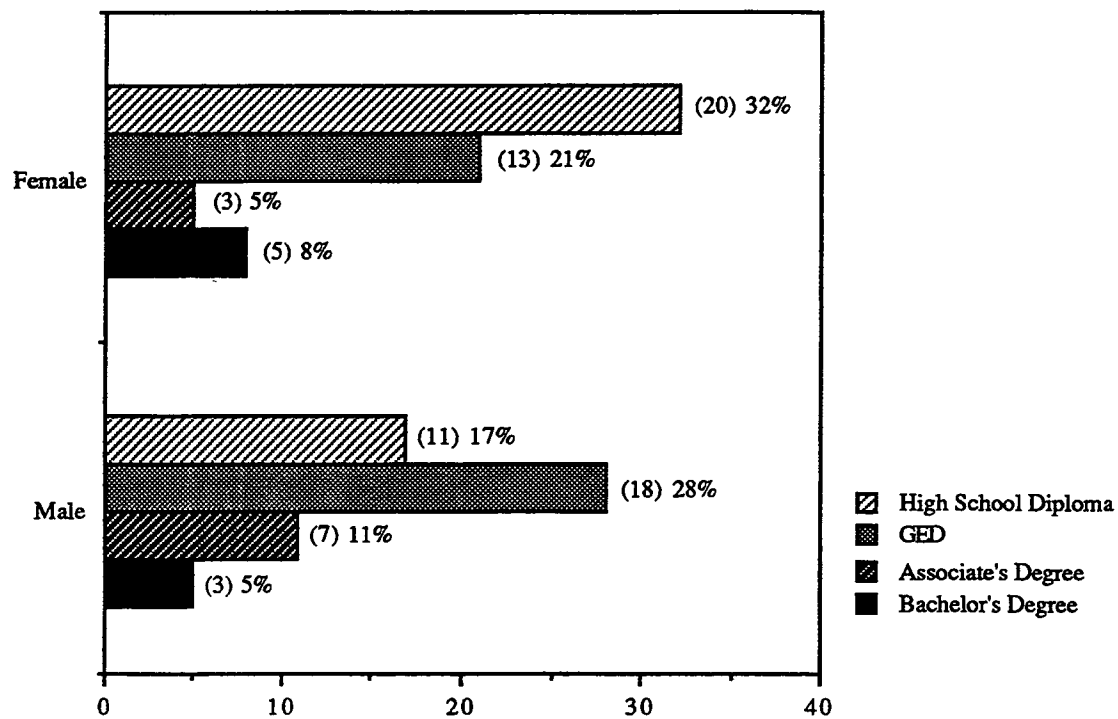
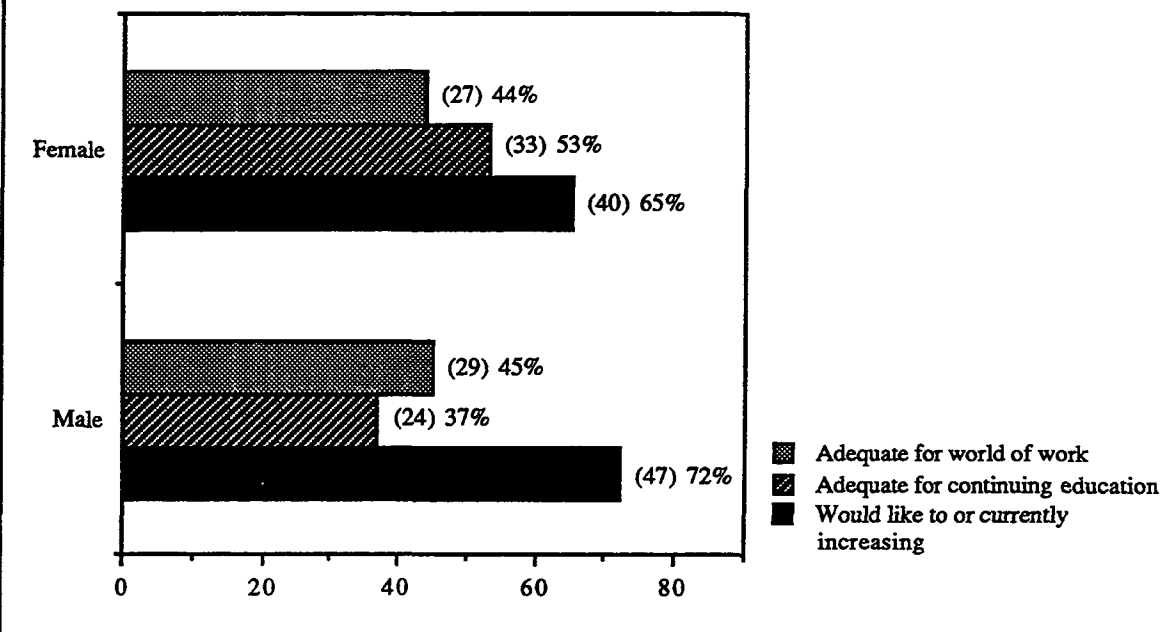


Figure 39

Adequacy of Education by Sex

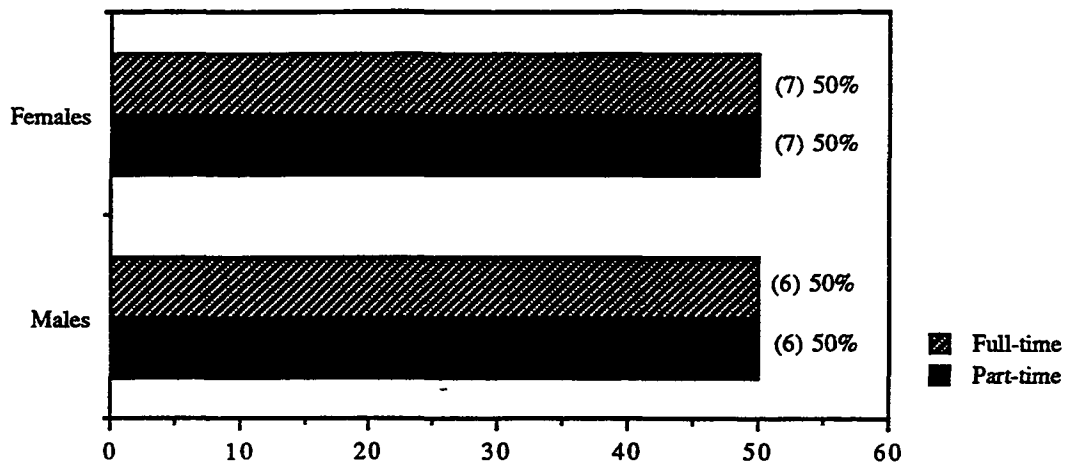


13]], followed by business [10% (n = 4)], and clerical/office work [10% (n = 4)]. Men (n = 47) primarily identified a field in math or engineering as their career goal [17% (n = 8)], followed by the arts and music [13% (n = 6)], and health and human services [11% (n = 5)]. As stated earlier, none of the interviewees reported having a graduate degree; in terms of career goals, 15% (n = 6) of the women interested in increasing their education specified desiring a graduate degree (Ph.D. - 2 persons; M.S. - 4 persons). Of the men interested in increasing their education, 4% (n = 2) specified desiring a graduate degree (Ph.D. - 1 person; M.S. - 1 person).

The same proportions of men and women worked in full-time and part-time positions (see Figure 40). However, in terms of those working to those not working, 23% (n = 14) of the women were working compared to 18% (n = 12) of the men. On average, the working women reported an annual income of \$10,153; working men reported an annual income of \$16,033. Men reported holding positions such as electronics assembler,

Figure 40

Full-time vs. Part-time Employment by Sex



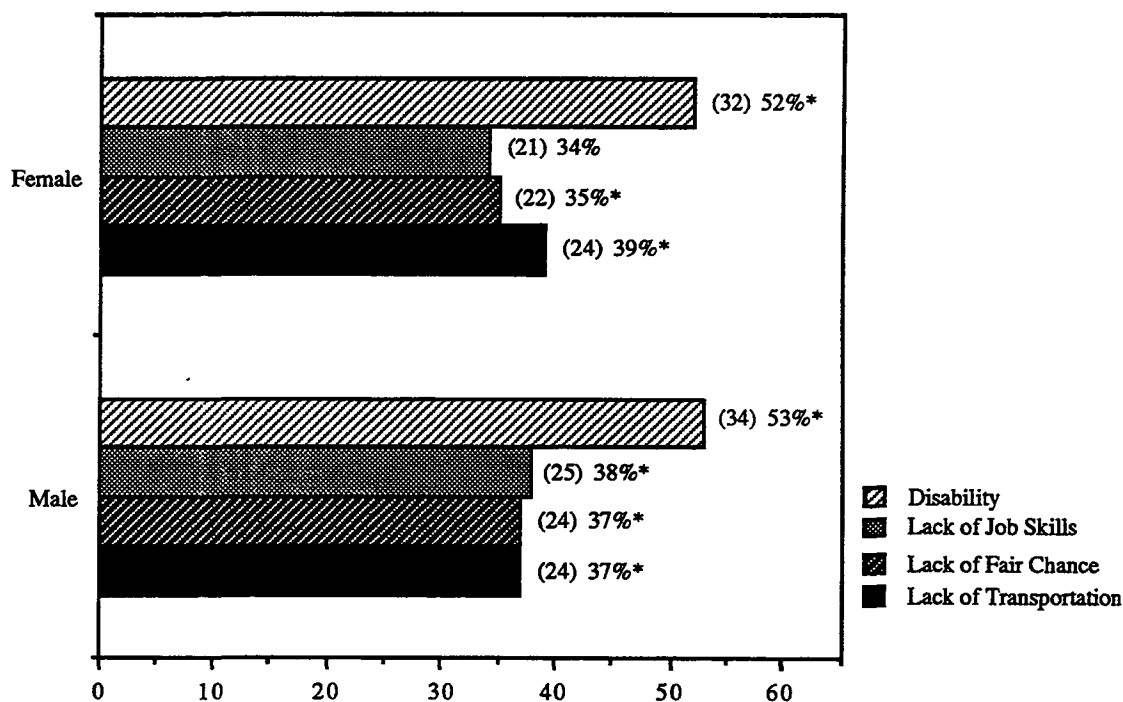
kitchen assistant, cook, bingo announcer, teacher, foster grandparent, health care worker, and machine operator. Women reported holding positions such as outreach worker, seamstress, cashier, business owner, senior office assistant, babysitter, Indian health advocate, inspector, phlebotomist, and office coordinator (2 persons).

In response to the question, “What are your best job-related skills?,” women most frequently reported “factory work” [16% (n = 10)], followed by skills associated with health and human services [15% (n = 9)], office or clerical work [15% (n = 9)], and service work such as cooking [11% (n = 7)]. Men most frequently reported some type of skilled labor, for example, ceramic tile setter [18% (n = 12)], followed by skills associated with health and human services [15% (n = 10)], “factory work” [11% (n = 7)], and manual labor [8% (n = 5)]. In response to the question, “What type of job would you like to have?,” nearly a third of the women reported that they would like to have a position related to health and human services, for example, nursing, or working with the elderly [32% (n = 20)]. This was followed by positions in office work [14% (n = 9)], and business or administration [8% (n = 5)]. Men desired most frequently to have positions which

involved skilled labor, such as a mechanic [18% (n = 12)], followed by positions in health and human services [14% (n = 9)], service (e. g., taxi driver, truck driver, custodian, security officer) [13% (n = 8)], self-employment [8% (n = 5)], teaching [5% (n = 3)], and the arts, including music [5% (n = 3)]. The majority of both men and women reported that their disability posed a problem in finding or keeping employment (see Figure 41).

Figure 41

Primary Problems in Finding or Keeping Employment by Sex



Note. *Top three problem areas for each category.

A large majority of both men [80% (n = 52)] and women [82% (n = 51)] reported that they could count on someone to give them help when they needed it. Of these men, 58% (n = 30) reported that they received financial support; of these women 67% (n = 34) reported that they received financial support. On average, women reported annual incomes

that were less than men, that is \$6,614 compared to \$7,305. The majority of men [54% (n = 35)] reported having no other financial assistance; 45% (n = 28) of women reported having no other financial assistance. An analyses of consumer concerns by sex can be found in Tables 20 - 23.

Table 20			
<u>Consumer Concerns - Relative Strengths - Female (n = 48)</u>			
Item #	Survey Question	Average Importance	Average Satisfaction
17	Handicapped parking is adequate and enforced.	84%	60%
14	Health service providers treat you with dignity and respect, and are sensitive to your disability and your culture.	91%	52%
15	Affordable, accessible public transportation is available.	87%	54%
31	Adequate mental health care is available to you.	86%	54%
27	Assistive devices (wheelchairs, braces, hearing aids, etc.) are available and affordable.	89%	51%
24	Checkout stands and aisles in stores are safe and accessible for shoppers who have disabilities.	88%	51%
30	Churches are barrier-free and sensitive to the needs of members who have disabilities.	78%	58%

Table 21

Consumer Concerns - Relative Problems - Female (n = 48)

Item #	Survey Question	Average Importance	Average Satisfaction
38	In general, your community is a good place for a person with a disability to live.	91%	42%
37	You feel safe in your home and neighborhood.	95%	46%
28	You know your rights as a citizen with a disability.	93%	45%
13	Sidewalk snow removal is adequate.	82%	37%
20	Social agencies inform you about benefits and services available to you.	86%	41%
18	Affordable housing is available to people with all types of disabilities.	92%	46%
29	Streets and sidewalks in areas of public housing are safe and accessible.	90%	45%
3	The Indian community understands the needs of its members with disabilities.	88%	44%
11	There is a central resource for information and referral for disability services available to Indians with disabilities.	86%	42%
33	Qualified job applicants with and without disabilities are given the same opportunities.	83%	41%
8	Non-Indian service providers understand the range of Indian services and make appropriate referrals.	83%	42%
9	Indians with disabilities advocate for their own needs at the local, state, and federal levels.	82%	41%

Table 22

Consumer Concerns - Relative Strengths - Male (n = 44)

Item #	Survey Question	Average Importance	Average Satisfaction
28	You know your rights as a citizen with a disability.	90%	59%
23	You have control over choosing and managing your personal care attendants and housekeepers.	80%	66%
17	Handicapped parking is adequate and enforced.	79%	66%
24	Checkout stands and aisles in stores are safe and accessible for shoppers who have disabilities.	83%	62%
4	You are not isolated from your friends and neighbors because of your disability.	77%	66%
*37	You feel safe in your home and neighborhood.	90%	56%
7	As an Indian, you do <u>not</u> encounter racial discrimination from service providers.	84%	58%
38	In general, your community is a good place for a person with a disability to live.	81%	60%
19	Accessible public housing units are available to people with disabilities.	85%	57%

Note. *This item also reported as a relative problem.

Table 23

Consumer Concerns - Relative Problems - Male (n = 44)

Item #	Survey Question	Average Importance	Average Satisfaction
29	Streets and sidewalks in areas of public housing are safe and accessible.	86%	49%
9	Indians with disabilities advocate for their own needs at the local, state, and federal levels.	81%	48%
18	Affordable housing is available to people with all types of disabilities.	88%	53%
32	The public vocational rehabilitation agency is responsive to the needs of Indian people with disabilities.	80%	48%
33	Qualified job applicants with and without disabilities are given the same opportunities.	77%	46%
*37	You feel safe in your home and neighborhood	90%	56%
3	The Indian community understands the needs of its members with disabilities.	83%	53%

Note. *This item also reported as a relative strength.

Discussion

One purpose of this study was to identify the needs of American Indians with disabilities who lived in an urban area, and not on a reservation. This study took place in the metro areas of Minneapolis and St. Paul, Minnesota (also referred to as the "Twin Cities"). Priority was given to interviewing persons living in Hennepin and Ramsey counties, followed by (in alphabetical order) Anoka, Carver, Dakota, Scott, and Washington (see Appendix 0). According to the 1980 U. S. Census (U. S. Department of Commerce, 1983), there were 9,953 American Indians ages 16 and older who lived in the metropolitan areas of Minneapolis and St. Paul. The 1980 Census identified 15% ($n = 1,450$) of these individuals as having either a work or public transportation disability. The 1990 Census has demonstrated a substantial increase in the number of Indian people living in the Twin Cities ("Minnesota's American Indian population," 1991); however, specific information regarding disability status is not expected until 1993.

The present study did not attempt to be a census study; that is, it did not attempt to interview all Indian people with disabilities in the Twin Cities. Its findings are limited in that they may not represent the needs of all Indian people with disabilities in the Twin Cities. Interviewees were identified through service agencies, through widely circulated flyers and announcements, and through the informal networks of Indian people hired as interviewers. An understanding of the history and current living situations of many urban Indian people, including knowledge of the relocation program of the U. S. Federal government, would provide an important context for interpreting the results of this research (see, e.g., Marshall, Johnson, Martin, & Saravanabhavan, 1991). Also, as the majority of Indian people who participated in this study identified themselves as being Chippewa or Ojibway, it is recommended that the reader have an understanding of the culture and history of this tribe. Those persons unfamiliar with the customs and traditions of the Chippewa/Ojibway people are encouraged to consult texts such as Night Flying Woman: An Ojibway Narrative (Broker, 1983), The Anishinabe of the Minnesota Chippewa Tribe

(Roufs, 1975), History of the Ojibway Nation (Warren, 1957), Wild Rice and the Ojibway People (Vennum, 1988), Chippewa Customs (Densmore, 1979), Indians in Minnesota (Ebbott, 1985), and The People Named the Chippewa (Vizenor, 1984).

A second 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. They were also hired as interviewers; their evaluation regarding the process of the research can be found in Appendix P. Interviewees and service providers were asked to comment on the results at a public meeting held in Minneapolis, and to provide written critiques of the final report.

The survey was conducted through face-to-face interviews during the spring and summer of 1991. Data were analyzed from 127 interviews. Interviewees reported an average mean age of 47, and were almost evenly split between males and females, with slightly more than half being male. The majority (62%) were age 45 or older, and reported an annual average income of \$6,971. Interviewees had lived in the Twin Cities metro-area for an average of 24 years; the majority reported that they planned to always live in the Cities. A majority of interviewees stated that they had a "home reservation," and that they were able to visit the reservation at least once a year. In fact, the majority of interviewees reported having been born on or near a Minnesota reservation. The majority knew their tribal roll or allottee number, and were registered to vote in both their tribes and in their counties of residence.

Interviewees reported having an average of 2.14 disabling conditions each, primarily diabetes, arthritis, orthopedic disorders, and substance abuse. The majority reported that their disability(ies) limited them in working on the job, lifting, walking, remembering, and seeing. In terms of assistive devices, they did not report needing expensive, state of the art, high-tech equipment. Instead, the majority reported needing

very basic assistive devices such as glasses. Specifically, 81% reported using glasses, and 57% reported needing them, or needing new glasses. While most of the interviewees assessed their overall health status to be “fair,” they reported their satisfaction with life to be “good.”

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. The majority reported that English was the language spoken most often in their home, and that they preferred health and human service workers to use English when providing services. At the time of the interview, the largest numbers of interviewees reported utilizing services which provided financial and medical assistance, versus programs that would involve rehabilitation, or the teaching of skills to cope with a disability. For example, 50% reported utilizing services through the Social Security Administration, while 10% reported utilizing public vocational rehabilitation services.

A large majority (86%) reported having received medical care in the year prior to the interview, with 79% reporting that the care they received was helpful. In terms of services needed, the majority reported that they needed dental care. Of those who needed dental care, the most frequently reported reason for not receiving it was that they could not afford it. Typically, however, as regards other service needs, the most frequently reported reasons for not receiving services were “service not offered” and “did not know of service.” Data regarding the extent to which outreach is being conducted by human service agencies in the Twin Cities were not collected as a part of this study. However, interviewees were asked to identify the resource which gave them the most useful information about services that could help them with their disability--the most frequent responses included friends, family, and “none.”

A lack of transportation was also given by many interviewees as the reason they were unable to access needed services, or employment. The public bus system was cited by just over a third as being the form of transportation they used the most. (Just under a

quarter of the interviewees used their personal car the most.) In 1989, a consumer group, American Disabled for Accessible Public Transit (ADAPT) topped its list of the ten least accessible transit systems with the Minneapolis Metropolitan Transit Commission ("ADAPT's ten best/worst," 1990), yet the statement "affordable, accessible public transportation is available" was identified as a relative strength of the community by interviewees. While public transportation may be affordable, and accessible to persons with mobility impairments, it may not be convenient, or even possible to use if work hours and work location extend beyond its schedule and route. Paratransit systems may not be flexible as regards "pick up" times and locations, making it difficult to schedule more than one or two activities a day, and making it impossible to arrange health care or other business appointments that may have an "unknown" termination time. Thus while such systems are "available," they may not be useable to American Indians with disabilities.

A strength of the Twin Cities metro area includes the fact that when American Indians with disabilities do receive a service, they find it helpful. Several relative strengths were identified through the "issue statements" contributed to the survey by Indian people with disabilities. For example, interviewees reported being satisfied with the number and enforcement of "handicapped parking" slots. A number of health and human service agencies in the Twin Cities are managed and staffed with Indian personnel; this fact, no doubt contributed to interviewees reporting as a strength that "Health service providers treat you with dignity and respect, and are sensitive to your disability and your culture," as well as, "As an Indian, you do not encounter racial discrimination from service providers." In general, however, satisfaction levels with disability issues were relatively low, around 50% - 60% average satisfaction.

Satisfaction levels with issues identified as problems, were only slightly lower, around 40% - 50% average satisfaction. Interviewees were frequently divided half and half as regards the identification of "strengths" versus "problems" in the community. For example, when describing their quality of life, the majority [53% (n = 67)] of the

interviewees agreed with the statement, "I feel safe from danger;" the remainder, 60 individuals or 47% of those interviewed, did not agree that they felt safe. Certainly the areas of safety and legal rights require further discussion and exploration on the part of both service providers and people with disabilities.

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 a lack of a central information and referral service for Indian people with disabilities.

The majority of interviewees reported that they could count on a combination of family and friends for emotional support, for "help around the house," for transportation, and for financial support. One-half (50%) of the interviewees reported having had daily face-to-face or telephone contact with an immediate family member in the year prior to the interview; just under a quarter (23%) reported having had daily contact with an extended family member.

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 interviews 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 women, the average was \$10,153; for men, \$16,033.

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.

Conclusions and Recommendations

While summary statements such as those made above are useful in terms of discussing the data in general, it is important for the reader to pay attention to the actual results, and to remember that a significant number of people may not be included in "the majority." The results of this study must also be carefully considered in terms of "sub-populations." For example, a plurality of interviewees were between the ages of 45 to 59. Among American Indians, this is a population which may require services typically associated with an over age 60 population (see, e. g., Saravanabhavan & Marshall, 1992).

Indeed, the concerns and service needs of American Indians with disabilities who participated in this study varied according to age. Interviewees under age 45 identified the safety of their home and local neighborhood as being the top relative strength of the Twin Cities area; interviewees age 60 and older found the lack of safety to be the top relative problem. Persons under age 45 most frequently reported vocational training as a service need, while persons ages 45 - 59 most frequently needed assistance with clothing, and persons over age 60 most frequently needed help with housing.

Several issues surface as one reads, and re-reads the results of this research--issues related to disability and access, as well as ethnicity and access. Issues which, when barriers to accessing services and employment are summarized, involve a lack of outreach by service providers, a lack of transportation by Indian people, and a lack of education for both. The question, "To what extent has discrimination on the part of service providers

and employers kept Indian people from accessing the services they need, and from participating more fully in the work force?,” was not asked in this study, and can not be answered with the data collected. In fact, concern over interviewer influence and bias [in the case of one interviewer] resulted in researchers counting as “invalid” several written comments which described discriminatory behavior. The decision to exclude these comments from the data analysis could have resulted in an underrepresentation of this issue--both in terms of accessing services and accessing employment.

However, there is no doubt but that discrimination is very much a reality for many of the people interviewed. As one interviewee told the senior author of this report, “In my neighborhood, there is no point in calling the police--they won’t help you.” Referring to the era immediately following World War II, Broker (1983) wrote that:

People gave to each other because times were bad. No Indian people dared approach the relief and welfare agencies of the Twin Cities. They knew that they would only be given a bus ticket and be told to go back to the reservation where the government would take care of them as usual. This was the policy of the public service agencies, and we put up with it by not asking for the help to which we had a legal right (p. 6).

Close to 50 years have passed since the time referred to by Broker. Nonetheless, several interviewees did refer to discrimination as being a barrier to accessing services. American Indians with disabilities who spoke at the public meeting also referred to the discrimination they experienced in seeking services. The senior author of this report, a non-Indian, was involved in a situation while in Minneapolis during November 1990 where medical personnel refused to come down a flight of stairs to assist a young Indian man. The Indian man was, in fact, seeking services for a non-Indian woman in a wheelchair who could not go up the flight of stairs. Only after the able-bodied, non-Indian woman went up the stairs and asked for assistance, did medical personnel come down the

stairs. Was this ethnic discrimination? Was this just a typical “run-around,” and the non-Indian woman was more assertive and demanding than the Indian man?

It was certainly discrimination which set the stage for this event--discrimination against the person in the wheelchair. Hahn (1991) has recently reminded us that “a series of historic laws including Section 504 of the Rehabilitation Act of 1973, P.L. 94-142, the Civil Rights Restoration Act, and the Americans with Disabilities Act have implicitly or explicitly identified discrimination as the major barrier to the employment opportunities of disabled Americans” (p. 18). Untangling the issues enmeshed in discriminatory behavior will require American Indians with disabilities to know their legal rights. However, as many Indian people and people with disabilities can attest, knowing their legal rights does not necessarily result in obtaining what is rightfully theirs. Service providers must acknowledge, and be responsive to, the issues which have barred American Indians with disabilities from available services. In particular, for Indian people to experience better health, and improved employment opportunities, service providers must engage in active outreach within the Indian community.

In addition, American Indians with disabilities must obtain advanced education and training. There are, however, critical issues to be addressed even in terms of very basic education. According to Beaulieu (1991):

In Minnesota, one-fourth of all American Indians and one-third of American Indian boys are in special education categories. As with dropout rates, the figures for special education are significantly higher in urban areas. A large number of students who do remain in public high schools to their senior years do not graduate. For those who do, their preparation for post-secondary education is often inadequate (p. 32).

Where to begin? Kidwell (1991) has suggested that “institutions must find ways of encouraging Indian students to pursue graduate degrees and college teaching careers, such as giving Indian faculty members special support in their efforts to recruit students and

serve as role models for them” (p. 23). Kidwell described “special support” as being, for example, “some release time from teaching, or special assistance to meet the demands of research, or substitution of service to an Indian community for service to the university . . .” (p. 23). In this study, Indian women with disabilities completed high school, and obtained an undergraduate degree in greater proportions than did the men. The majority of women also believed that their education adequately prepared them for continuing their education; the majority of men did not. Further research is needed to identify those factors which operate to keep Indian women in school, and those which keep Indian men from even finishing high school.

The issues uncovered through this research are not new, nor are the conclusions. The solutions must be creative, full of energy, and, yes, there must be more money, and more programs to ensure that Indian people with disabilities are aware of the educational and employment opportunities which do exist, and have the supports necessary to take advantage of them. For example, involvement in research activities enables more Indian people to become aware on a first-hand basis of the needs of people with disabilities. Hopefully, this exposure to research will also enable Indian people to become more aware of the professional opportunities available in rehabilitation service delivery (e. g., Marshall, Martin, Thomason, & Johnson, 1991). In the words of one interviewer, voiced at the public meeting:

I got into this interviewing quite accidentally. I had seen it as a way to make some extra money, and I went through the training sessions . . . just for the money. But after awhile, after some interviews, I became more and more absorbed in the people and getting into the community and going to their homes. I looked forward to each interview each day, and it brought me closer to the community, closer to my people. I found out I learned a great deal about one population of our community that I never really had thought about very much, and it was a good experience, a very good learning experience. I appreciate the chance and the opportunity I had to bring myself out and learn

Whyte, Greenwood, and Lazes (1991) have noted that "in situations of major social change, the prevailing ground rules are likely to block the path to creative solutions of serious new problems. Creative solutions will depend upon the ability of the organization to change the organizational and intellectual ground rules" (p. 42). Again, the problems presented here are not "new;" however, health care and human service organizations will need to break the ground rules in order for change to occur. Dr. Robert Davila (1991), Assistant Secretary, Office of Special Education and Rehabilitation Services, U.S. Department of Education, has acknowledged that an "area of concern involves improving outreach to minority communities" (p. 3). At a recent workshop attended by the senior author, staff from the Agency for Health Care Policy and Research, Public Health Service, Department of Health and Human Services, stated that "the outreach of community health workers of the 1960's may be a model for cost-containment for the 1990's." Service providers who have spend the past decade waiting for people to come into the office for services, will hopefully find themselves in the community offering to assist people before they develop chronic health care problems.

Recommendations

In referring to creative problem-solving, Elden and Levin (1991) stated that, "the key is overcoming the expert's monopoly in defining what is possible for others" (p. 141). With this philosophy in mind, the authors of this report make the following recommendations, and ask the reader to work toward their implementation. However, the authors also encourage the reader to reflect on the results of this study, and to determine her or his own course of action in working with American Indians who have disabilities.

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 such recruitment and outreach efforts.

7. Universities which receive Federal funds to train professionals in rehabilitation counseling, and other health and human services professions, 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 the worker with a disability, her or his family, and the added expenses that disability often brings.

Note

Interested service providers in the Twin Cities, as well as all consumers who were interviewed as a part of the study, were invited to read and critique a draft of this report. Where possible, their recommendations for changes have been incorporated into the published report. Their comments and ideas generated by the report can be found in Appendix Q.

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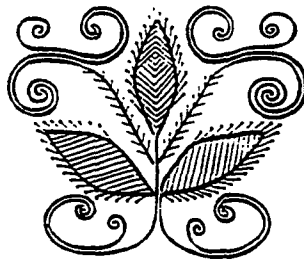
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Appendix A

Correspondence Regarding Initial Meeting



American Indian Rehabilitation Research and Training Center



October 9, 1990

Michael Arfsten
Director
American Indian Health Care Association
245 E. 6th St.
St. Paul, MN 55101

Dear Mr. Arfsten,

I am writing to invite you to a meeting to be held at the Minneapolis American Indian Center, 1530 East Franklin Avenue on Wednesday, November 7 from 10:00 until noon. At the meeting, I will ask your help in conducting a research project sponsored by the American Indian Rehabilitation Research and Training Center (AIRRTC) to identify the needs of American Indians with disabilities in the Minneapolis area. I will also present the results of a similar study which was recently completed in Denver, Colorado (please see attached summary).

The AIRRTC is located at Northern Arizona University in Flagstaff, Arizona, and is dedicated to research and training efforts designed to improve the quality of life for Indian people with disabilities. As the AIRRTC is committed to involving Indian people with disabilities throughout the process of our research, I would like to ask you to invite any Indian people with disabilities that you may know to also attend this meeting.

I have enclosed a proposed timeframe for the study, as well as a flyer describing the AIRRTC. Please feel free to contact me at (602) 523-4791 if you have any questions regarding our proposed research in Minneapolis.

If you are unable to attend the meeting at the Minneapolis American Indian Center, I will be happy to meet with you at your office. Just give me a call so that we can schedule a time; I will be in Minneapolis November 7 through November 9.

Cordially,

Catherine Marshall

Catherine A. Marshall, Ph.D.
Research Associate/Associate Professor

Appendix B

Job Description of On-site Research Coordinator



American Indian Rehabilitation Research and Training Center

Northern Arizona University
Institute for Human Development
P. O. Box 5630
Flagstaff, AZ 86011-5630
(602) 523-4791



JOB DESCRIPTION

TITLE: **Research Technician** (On-site Coordinator for AIRRTC Project R-24: *The Replication of a Model for Determining Community-Based Needs of American Indians with Disabilities through Consumer Involvement in Community Planning and Change*)

PRIME FUNCTION

Under the supervision of Dr. Catherine Marshall, performs work of considerable difficulty in directing or performing a wide variety of standard and specialized tasks on a research project.

DUTIES AND RESPONSIBILITIES

- A. **Training Tasks**
 - 1. Assists with **Interviewer Training** as needed.
 - 2. Provides supplementary training to interviewers as needed.
- B. **Supervisory**
 - 1. Under supervision, performs specific tasks related to investigating the needs of American Indians with disabilities in the Minneapolis metropolitan area, e.g. assignment of interviewees to interviewers.
 - 2. Assists interviewers in scheduling appointments with interviewees (individuals with disabilities or family members).
 - 3. Assists with monitoring interviews (including the observation of at least one interview by each interviewer), verification of interviews, and the supervision of interviewers to ensure their professional conduct.
 - 4. Assists the interviewers in submittal of project paperwork, e.g., invoices for payment.

- C. Other Tasks
1. Will collect and compile information, brochures, pamphlets and other information regarding resources and services available to American Indians with disabilities in the Minneapolis area.
 2. Maintains close communication with the Principal Investigator, Dr. Catherine Marshall, and relays immediately any difficulty relative to the interviews or any other related issues.
 3. When no other interviewer can carry through on a given interview, will complete the interview.

KNOWLEDGE AND SKILLS

Considerable knowledge and/or experience in working with American Indians

Skill in effective interpersonal relations

Skill in written and verbal communication

Supervisory and monitoring skills

MINIMUM QUALIFICATIONS

Bachelor's degree in area related to field of work **OR** four years related experience

Considerable experience in working with American Indians is preferred.

Knowledge and/or experience in research methods and techniques is preferred.

Knowledge and/or experience in working with persons with disabilities is preferred.

HOURS

Part-time (approximately 10-20 hours per week 12/1/90 - 9/1/91)

SALARY RANGE

\$7.13 - \$9.04 per hour

WORKSITE

Minneapolis, Minnesota

For more information, contact:

Dr. Catherine Marshall

AIRRTC

P. O. Box 5630

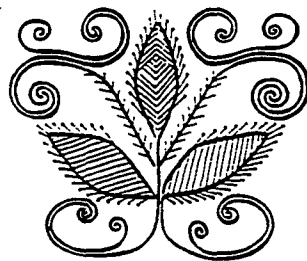
Northern Arizona University

Flagstaff, AZ 86011-5630

(602) 523-4791

Appendix C

Correspondence/ Agenda for First Working Group Meeting



American Indian Rehabilitation Research and Training Center



January 7, 1990

The purpose of this letter is to inform you of a survey to be conducted in the near future by the American Indian Research and Training Center.

The Center, a project of the Northern Arizona University, will contact and survey American Indian people in the metro area with disabilities. The purpose of this survey is to help those people with disabilities to identify both strong points and problems areas in our community, meet to discuss issues identified in the survey and plan ways to improve the community for persons with disabilities.

Finally this information will be presented to decision makers and service providers in order to expand and improve services. The Center asks your help in developing this survey, and your participation in the planning process. A planning group meeting has been scheduled for:

Thursday, January 17, 1991
3:00pm - 5:00pm

Phillips Community Center
2323 11th Avenue South
Minneapolis, MN
Phone: 870-7570

Refreshments Will Be Provided

Please think of issues or concerns related to your own experience with disability, positive or negative and plan to share your concerns with the group. If you would like more information prior to this first planning meeting, please contact me at 487-2044. We look forward to meeting and working with you!

Sincerely,

Charlene A. Day-Davila
Charlene A. Day-Davila
On-site Research Coordinator

A G E N D A

Consumer Concerns Survey
Working Group/Advisory Meeting

Thursday, January 17, 1991
3:00 p.m. - 5:00 p.m.

PHILLIPS COMMUNITY CENTER
2323 13th Avenue South
Minneapolis, Minnesota

I. Welcome

Charlene Day-Davila, On-Site Coordinator
American Indian Research and Training Center

Dorene Day, Executive Director
Indian Family Services, Inc.

II. Explanation of Research Project

Chalene Day-Davila, On-Site Coordinator

III. Facilitation of Working Group

Barbara Bradford, Consultant
American Indian Research and Training Center

IV. Wrap-up of meeting

Collection of Information Sheets

Question and Answer Period

Announcement of second meeting

Appendix D

Correspondence/Agenda for Second Working Group Meeting



American Indian Rehabilitation Research and Training Center



January 8, 1991

Frances Fairbanks
Director
Minneapolis American Indian Center
1530 E. Franklin Avenue
Minneapolis, MN 55404

Dear Ms. Fairbanks:

Based on the results of meetings with service providers and consumers in Minneapolis and St. Paul in early November, the American Indian Rehabilitation Research and Training Center will be conducting a study of the needs of American Indians with disabilities who live in the Twin Cities area. Charlene Day-Davila has been hired as our on-site coordinator and can be contacted at 622-1117. [This is a page number; please enter your phone number, press the # sign, and hang up. Charlene will return your call.]

A meeting has been scheduled for Thursday, January 24 from 3:00 to 5:00 at Indian Family Services, 1305 E. 24th Street, Minneapolis. The purpose of this meeting will be to review the enclosed draft of the survey instrument. This draft contains primarily demographic information. Please feel free to add or delete items; in particular, please add any items which would be of benefit to your agency. Issues of concern to consumers will also be added to the instrument.

I hope you will be able to attend the meeting on January 24 to share your ideas for the survey instrument. If, however, you are unable to attend the meeting, please mail your ideas to me, or call (1-800-553-0714) by January 31. I will mail out a second draft of the instrument shortly thereafter.

Cordially,

Catherine Marshall

Catherine A. Marshall, Ph.D.
Research Associate/Associate Professor

pc: Ms. Charlene Day-Davila
Dr. Marilyn Johnson
Dr. William E. Martin, Jr.

A G E N D A

Consumer Concerns Survey 2nd Working Group/Advisory Meeting

Thursday, January 24, 1991
3:00 p.m. - 5:00 p.m.

INDIAN FAMILY SERVICES, INC.
1315 24th Street
Minneapolis, Minnesota

I. Welcome

Jeff Jaskolka, Transportation Coord./Case Aide
Indian Family Services, Inc.

Charlene Day-Davila, On-Site Coordinator
American Indian Rehabilitation/Research Training Ctr.

II. History of RTC Project and Activities to Date

Charlene Day-Davila, On-Site Coordinator

Dr. Catherine Marshall, Ph.D.
Research Associate/Associate Professor
American Indian Rehabilitation/Research Training Ctr.

III. Finalize Issue Statements (break into groups)

Charlene Day-Davila & Barbara Bradford
Consumer Concerns Group

Catherine Marshall
Demographics/Service Providers/Agency Representatives

IV. Wrap-Up

Timeframe For Final Comments

Appendix E

List of Issue Statements in Order of Average Satisfaction



**NORTHERN ARIZONA UNIVERSITY
INSTITUTE FOR HUMAN DEVELOPMENT
ARIZONA UNIVERSITY AFFILIATED PROGRAM**

**American Indian Rehabilitation
Research and Training Center
Consumers Concerns Report
Minneapolis-St. Paul, Minnesota**

**Concerns Report Survey Results in
Order of Average Satisfaction**

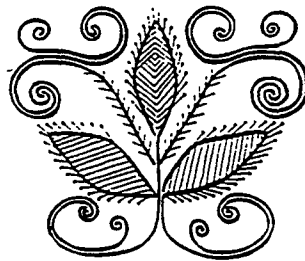
Item #	Survey Question	Average Satisfaction	Average Importance	n per item
6	As a citizen with a disability, you have a say in city, county, and state government disability programming and planning.	40%	72%	102
33	Qualified job applicants with and without disabilities are given the same opportunities.	43%	80%	104
8	Non-Indian service providers understand the range of Indian services and make appropriate referrals.	43%	76%	100
9	Indians with disabilities advocate for their own needs at the local, state, and federal levels.	45%	82%	104
11	There is a central resource for information and referral for disability services available to Indians with disabilities.	45%	81%	103
36	Local media provide adequate information about disabilities, programs, and services available.	45%	78%	104
26	Transportation to and from public events is available on weekends and holidays.	45%	77%	102
20	Social agencies inform you about benefits and services available to you.	46%	84%	101
13	Sidewalk snow removal is adequate.	46%	81%	103
29	Streets and sidewalks in areas of public housing are safe and accessible.	47%	88%	106
32	The public Vocational Rehabilitation agency is responsive to the needs of Indian people with disabilities.	47%	83%	102

Item #	Survey Question	Average Satisfaction	Average Importance	n per item
3	The Indian community understands the needs of its members with disabilities.	48%	86%	102
18	Affordable housing is available to people with all types of disabilities.	49%	90%	103
38	In general, your community is a good place for a person with a disability to live.	50%	86%	105
21	Social services are provided on an equal basis to people with and without disabilities.	50%	82%	103
22	Trained personal care attendants are available.	50%	79%	95
37	You feel safe in your home and neighborhood.	51%	93%	107
27	Assistive devices (wheelchairs, braces, hearing aids, etc.) are available and affordable.	51%	82%	101
12	Public services (library, police, etc.) are provided on an equal basis to people with and without disabilities.	51%	80%	103
25	You have access to respite care or attendant.	51%	70%	90
28	You know your rights as a citizen with a disability.	52%	92%	107
10	You can go to and from the reservation because the reservations have the services you need.	52%	68%	89
19	Accessible public housing units are available to people with disabilities.	53%	86%	103
14	Health service providers treat you with dignity and respect, and are sensitive to your disability and your culture.	54%	87%	106
34	You can get help in applying for welfare, food stamps, and social services.	54%	84%	102
1	Indian cultural/social events are accessible, including restrooms, to people with disabilities.	54%	78%	102
16	Public transportation from city to city is available.	54%	75%	103
15	Affordable, accessible public transportation is available.	55%	85%	104
7	As an Indian, you do not encounter racial discrimination from service providers.	55%	83%	104

Item #	Survey Question	Average Satisfaction	Average Importance	n per item
5	Indian service agencies are barrier free and consider the needs of people with disabilities.	55%	80%	104
2	Indian ceremonial/spiritual events are accessible to people with disabilities.	55%	74%	97
35	You can meet with other persons with disabilities to discuss and solve problems.	55%	72%	100
24	Checkout stands and aisles in stores are safe and accessible for shoppers who have disabilities.	56%	86%	104
31	Adequate mental health care is available to you.	56%	81%	101
30	Churches are barrier free and sensitive to the needs of members who have disabilities.	57%	72%	92
23	You have control over choosing and managing your personal care attendants and housekeepers.	58%	81%	94
4	You are not isolated from your friends and neighbors because of your disability.	61%	78%	101
17	Handicapped parking is adequate and enforced.	62%	81%	100

Appendix F

Pilot-test Interviewer Training Agenda





Institute for Human Development
Arizona University Affiliated Program

**American Indian Rehabilitation
Research and Training Center**



**American Indians with Disabilities
Community Needs Assessment**

PILOT-TEST INTERVIEWER TRAINING AGENDA

February 28, 1991

8:30 - 9:00	Introduction
9:00 - 9:30	Review of Project Goals
9:30 - 10:00	Overview of Training and <u>Training Manual</u>
10:00 - 10:15	BREAK
10:15 - 11:15	Disability Information
11:15 - 12:30	LUNCH
12:30 - 1:30	Services Information
1:30 - 2:30	Culturally Sensitive Interviewing Strategies
2:30 - 2:45	BREAK
2:45 - 4:00	Review of Instrument
4:00 - 5:00	Interviewer Practice
5:00 - 6:00	Exercise in Buffalo Park (optional)

March 1, 1991

8:00 - 12:00 Making of Demonstration Videos

12:00 - 1:30 LUNCH

1:30 - 3:00 Critique of Videos

3:00 - 3:15 BREAK

3:15 - 4:00 Review of Record Keeping

4:00 - 5:00 Wrap-Up
Questions and Answers

Appendix G

Agenda for Interviewer Training



**American Indians with Disabilities
Community Needs Assessment
Minneapolis and St. Paul, Minnesota**

INTERVIEWER TRAINING

**Pillsbury United Neighborhood Services Waite House
2529 13th Avenue South
Minneapolis, MN 55404
(612) 721-1681
April 29-May 1, 1991**

April 29, 1991

8:30 - 9:00	Coffee and Bran Muffins	
9:00 - 9:30	Introductions and Overview of Project	Charlene Day-Davila <i>On-Site Research Coordinator, American Indian Rehabilitation Research and Training Center (AIRRTC)</i>
9:30 - 10:00	Overview of Training	Catherine A. Marshall, Ph.D. <i>Research Associate, AIRRTC</i>
10:00 - 10:30	Confidentiality Interviewer's Influence Safety Precautions	Charlene Day-Davila
10:30 - 10:45	BREAK	
10:45 - 12:00	Arranging the Interview Asking Questions/Recording Answers	Charlene Day-Davila
12:00 - 1:00	LUNCH	
1:00 - 2:00	Instructions for Specific Questions	Catherine Marshall
2:00 - 2:30	Interviewer Skills	Charlene Day-Davila
2:30 - 2:45	BREAK	
2:45 - 3:15	Record Keeping	Catherine Marshall
3:15 - 4:15	Definitions	Catherine Marshall
4:15 - 5:00	Questions and Answers	Charlene Day-Davila Catherine Marshall



HOMEWORK

- (1) Review Instrument
- (2) Review Training Manual
- (3) Prepare any additional questions for tomorrow

April 30, 1991

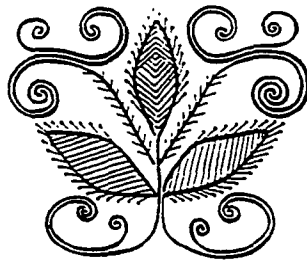
8:30 - 9:00	Coffee	
9:00 - 9:45	Interviewing Techniques: Lessons learned from Pilot Test!	Charlene Day-Davila
9:45 - 10:00	Questions and Answers Regarding Training Manual	Catherine Marshall
10:00 - 11:00	Services Available to American Indians with Disabilities in the Twin Cities	Dorene Day <i>Director, Indian Family Services</i>
11:00 - 11:15	BREAK	
11:15 - 12:30	Minnesota Vocational Rehabilitation	Sharon Johnson <i>Career Counselor</i> <i>Minnesota Vocational Rehabilitation</i>
12:30 - 1:30	LUNCH	
1:30 - 2:00	Interviewer Practice: Services Information (SI-1 to SI-11)	Catherine Marshall
2:00 - 2:30	Consumer Concerns	Barbara Bradford <i>Barrier Breakers</i>
2:30 - 3:00	Interviewer Practice: Consumer Concerns	Catherine Marshall
3:00 - 3:15	BREAK	
3:15 - 4:00	Review of Record Keeping	Catherine Marshall

May 1, 1991

8:00 - 8:30	Coffee	
8:30 - 10:00	Interviewer Practice in Dyads	Charlene Day-Davila Catherine Marshall Barbara Bradford Sharon Johnson
10:00 - 10:15	BREAK	
10:15 - 11:00	Group Feedback	Catherine Marshall
11:00 - 12:30	Interviewer Practice in Dyads	Charlene Day-Davila Catherine Marshall Barbara Bradford Sharon Johnson
12:30 - 1:30	LUNCH	
1:30 - 1:45	Group Feedback	Charlene Day-Davila
1:45 - 3:30	Establishment of Reliability	Charlene Day-Davila Catherine Marshall Barbara Bradford
3:30 - 3:45	BREAK	
3:45 - 5:00	Questions and Answers Scheduling of first interview with Charlene Day-Davila as observer	

Appendix H

Interviewer Job Description



**American Indian Rehabilitation
Research and Training Center**
Northern Arizona University
Institute for Human Development
Arizona University Affiliated program
P. O. Box 5630
Flagstaff, AZ 86011-5630
(602) 523-4791



INTERVIEWER JOB DESCRIPTION

TITLE: Interviewer/American Indian Rehabilitation Research and Training Center
(Project R-24: *The Replication of a Model for Determining Community-Based Needs of American Indians with Disabilities through Consumer Involvement in Community Planning and Change*)

EXAMPLES OF DUTIES AND RESPONSIBILITIES

1. Contacts all assigned interviewees (persons being interviewed) prior to interview, explains the purpose of the interview, and makes appointments for interviews.
2. Obtains signature on **Informed Consent Form** of person to be interviewed.
3. Checks completed questionnaires for clarity of recorded responses.
4. Keeps a record of all contacts, interviews completed, and mileage on **Contact Log**.
5. Mails completed **Consumer Interview** and **Interviewee Billing Statement** to supervisor on schedule.
6. Informs supervisor **immediately** of any problems related to the project.
7. Submits **Interviewer Billing Form** and **Contact Log** to supervisor to receive payment.
8. Re-contacts interviewees just prior to public meeting to remind them to attend meeting

KNOWLEDGE AND SKILLS

1. Has knowledge of values and communication styles of the various American Indian tribes represented in Minneapolis.
2. Can demonstrate making and keeping appointments and meeting deadlines.
3. Has some skill in written and verbal communication.

MINIMUM QUALIFICATIONS

1. Has or can access reliable transportation.
2. Can attend 3-day training scheduled for April 29, 30, and May 1, 1991.

WORKSITE

Minneapolis, Minnesota
St. Paul, Minnesota

For more information, contact:

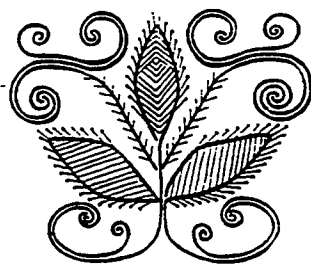
Catherine A. Marshall, Ph.D.
1-800-553-0714

OR

in Minneapolis/St. Paul
Charlene Day-Davila
622-1117 (Pager)
[please enter your phone number,
press the # sign, and hang up]

Appendix I

Interviewee Recruitment Flyer



American Indians with Disabilities Community Needs Assessment

Minneapolis-St. Paul
May-June 1991

- Purpose** To understand the needs and concerns of American Indians in Minneapolis-St. Paul who have disabilities.
- Procedure** You will be asked to participate in an interview that should take approximately two hours.
- Voluntary** You may refuse to answer any questions or stop the interview at any time.
- Compensation** You will receive \$20.00 for completing the interview.
- Benefits** Improved service delivery to American Indians in Minneapolis who have disabilities.

For more information, contact:

Catherine A. Marshall, Ph.D.
American Indian Rehabilitation
Research and Training Center
P. O. Box 5630
Flagstaff, AZ 86011-5630
1-800-553-0714

in Minneapolis/St. Paul
Charlene Day-Davila
On-Site Coordinator
622-1117 (Pager)
[please enter your phone number,
press the # sign, and hang up]

Appendix J

Interview Certification Form



R-24 Interview Certification

Name _____

Phone _____

Interviewer _____

1. Was your interviewer courteous? Yes No
2. Did the interview seem relevant to your concerns? Yes No
3. Do you plan to attend the public meeting scheduled for September 19? Yes No
4. Do you have any questions about this project? Yes No

Signature _____

Date of Certification _____

Appendix K

Public Meeting Agenda



American Indians with Disabilities

Minneapolis American Indian Center
1530 E. Franklin Avenue
Minneapolis, Minnesota 55404
(612) 871-4555

PUBLIC MEETING & FEAST

September 19, 1991

5:00 p.m.

Moderator

Jim Clairmont, Educator/Spiritual Leader

Invocation

Jim Clairmont

Welcome

Frances Fairbanks, Executive Director
Minneapolis American Indian Center

Roger Head, Director
Minnesota Indian Affairs Council

Dorene Day, Executive Director
Indian Family Services

Sharon Johnson, Career Rehabilitation Counselor
Minnesota Division of Rehabilitation Services

Overview of Project

Charlene Day-Davila
On-Site Research Coordinator
American Indian Rehabilitation Research and
Training Center

*Experiences of
Interviewers*

Joseph Fairbanks

Summary of Results

Charlene Day-Davila
Catherine Marshall, Co-Director of Research
American Indian Rehabilitation Research and
Training Center

"Open Mike"

Concerned community members, program directors, service providers. All are encouraged to comment on the results of the study and to make recommendations for community services which will better meet the needs of American Indians with disabilities in the Twin Cities.

Cultural entertainment provided by metro-area youth

Research conducted by
American Indian Rehabilitation
Research and Training Center
NORTHERN ARIZONA UNIVERSITY
INSTITUTE FOR HUMAN DEVELOPMENT
ARIZONA UNIVERSITY AFFILIATED PROGRAM
P. O. Box 5630
Flagstaff, AZ 86011-5630
(602) 523-4791



Appendix L

Flyer Announcing Public Meeting



American Indians with Disabilities

Results of a recent survey conducted by the Northern Arizona University American Indian Rehabilitation Research and Training Center will be presented at the

Minneapolis American Indian Center

1530 E. Franklin
Minneapolis, Minnesota

September 19, 1991
5:00 p.m. - FEAST

For more information/transportation, contact

Charlene Day-Davila
On-Site Research Coordinator
(612) 331-3380

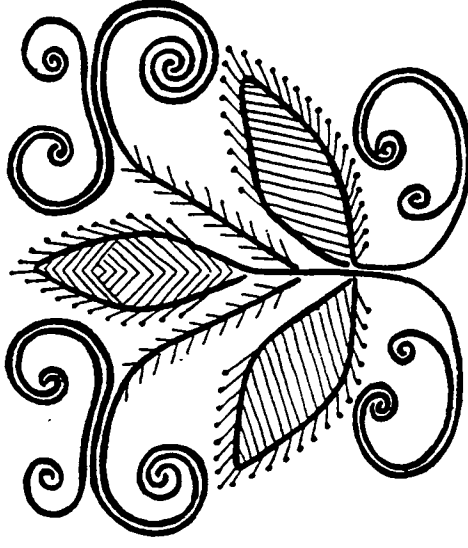
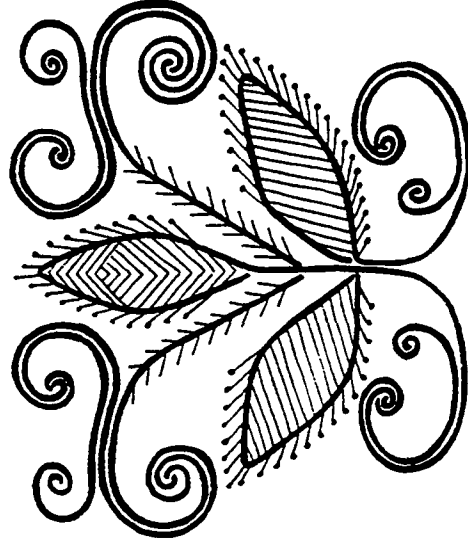
or

Dorene Day, Executive Director
Indian Family Services
(612) 348-5788

American Sign Language interpreter will be available.

Indian Family Services
Minneapolis American Indian Center
American Indian OIC
The Office for Students with Disabilities-
University of Minnesota

Red School House, Inc.
Minnesota Division of Rehabilitation Services
St. Paul American Indian Center
Upper Midwest American Indian Center
Minnesota Indian Affairs Council



Appendix M

Native City News Article



The Twin Cities Native Weekly - Volume 1, No. 7

Thursday, September 19, 1991

Racism Strikes Disabled Natives Twice

by Dale Kakkak

"You have to make this society realize you're a human being." Al Wensman, 57,

Red Lake Ojibwe, has been disabled since 1965. His conversation is punctuated with the hurt he has endured, not because of his disability, but because of the racism he has faced since day one with his disability.

When he was 24 and out of the service, he had to walk with a cane and the police would stop him and ask him if he had been drinking. This was the early sixties. Today doctors still ask him how much he has been drinking or doing drugs.

Wensman participated in a survey of disabled Native Americans. He said the biggest problem according to those questioned was racism.

"I waited in line for a week for physical therapy while the average white guy would wait maybe a half day, and that's being generous," Wensman said. "Racism was the top of the list, for Indian people in the survey. You get it at hospitals, clinics and programs. According to Wensman the system (health care) is not designed for Native Americans with disabilities. He has had nothing but problems with home health care workers. They are not in tune to the Indian persons idea of selfsufficiency. "There has been a complete lack of understanding of Indian persons," Wensman said.

Of all the agencies I've dealt with or talked with, none have any American Indians attendants, Wensman said.

"There are cultural differences. They come into your home and get bossy. They disregard other family members' input," Wensman said.

"Maybe they think an American Indian isn't suppose to get disabled. They think you should just go away or something. I don't know what it is."



Al Wensman has had to confront the 'system' for services. The ramp to his home was only built last year, 13 years after he started looking for help.

Photo by D. Kakkak

Wensman had to be taken by ambulance to a local hospital and was sent back home diagnosed with the flu by a doctor. It turned out to be complications of diabetes. He was weak and his vision was greying that time.

He knows that health care programs and

agencies give him as well as other Indian people low priority, if any at all. Others have had exactly the same experience with home health care workers. They just don't understand Indians and thus can't get along.

He said that if he wanted to get a ride somewhere, like to the doctor or to the store he might have to wait up to three months. Sometimes if you have an appointment for a ride and you are to sick and have to cancel, the agencies think you're a problem, they put you way down on the list.

"It's been my experience that they simply eliminate American Indians as candidates for rehabilitation," Wensman said.

Without hesitation Wensman says that Indian Family Services has done everything in their capability to help the disabled. "In all these years Indian Family Services seem to be the only organization that has helped meet our needs.

"The real hardship is for the immediate family members. The pressure and the stress on family members is tremendous, he said.

Wife and companion, Anita Wensman said the responsibilities are sometimes too much and families send their people to nursing homes. She and Al have been married for 21 years.

She said it is easier with Al because he can express his needs. We've been able to adapt to conditions as they change. She has their home set up so it's possible for Al to do as much for himself as he can.

One of the major issues with disabled persons is the isolation. People seem to just stop coming to see you. "It's like being deserted," Wensman said. That is true of Indian families as well as non-Indian people, he said.

What is lacking is communication, according to Wensman. About 12 years ago we

Racism Strikes Twice

continued on Page 6

talked about starting some type of community center where we could get together and play cards or whatever we could do together. To his knowledge there hasn't been anything done toward this goal.

"You can become isolated even from the culture," he said. Wensman mentioned that it was hard to get to a pow-wow and then it may be difficult to get around the pow-wow grounds.

Wensman does hope what will happen will be the development of a community center and hopefully peer groups. He said that the results of this survey of disabled Indian persons was that they wanted to be able to participate more in the Indian community. This would mean finding more transportation with less bureaucracy. "It's very difficult to find a ride," he said.

It's very hard for the disabled to get out he said, and once you do, you can easily become discouraged by the barriers. Curbs, doors that are too narrow and too heavy. It's hard facing the unknown. There are sidewalks with sections raised up and you can't get past.

"But I never gave up. I don't want to be too negative. They are always finding new ways for the handicapped and disabled to adjust into society.

There is adaptive equipment that allows a person in a wheelchair to pick up even a coin dropped on the floor. There is equipment called self-reachers and extend-a-hand that will reach things across a table or wherever. It makes a person more independent. These things are psychological aids while being practical, they save a lot of grief, Wensman said.

"It's easy for me to say it now I've been through some rough times, some winners. Things do seem to be changing for the better. I'm real thankful for what I can do now. I am proud of what I am, an Indian man. Culture and tradition are very important.

But everything is not all right. Participants in a recent survey on American Indians with Disabilities have been meeting. What we're hoping is that this meeting of the 19th will be a vehicle for better communication. "We hope it can help to better express our problems and our needs," Wensman said.

The results of the survey will be shared with the community at a one day conference, September 19 at the Minneapolis American Indian Center 1530 Franklin Ave S. It will start at 5pm with a feast.

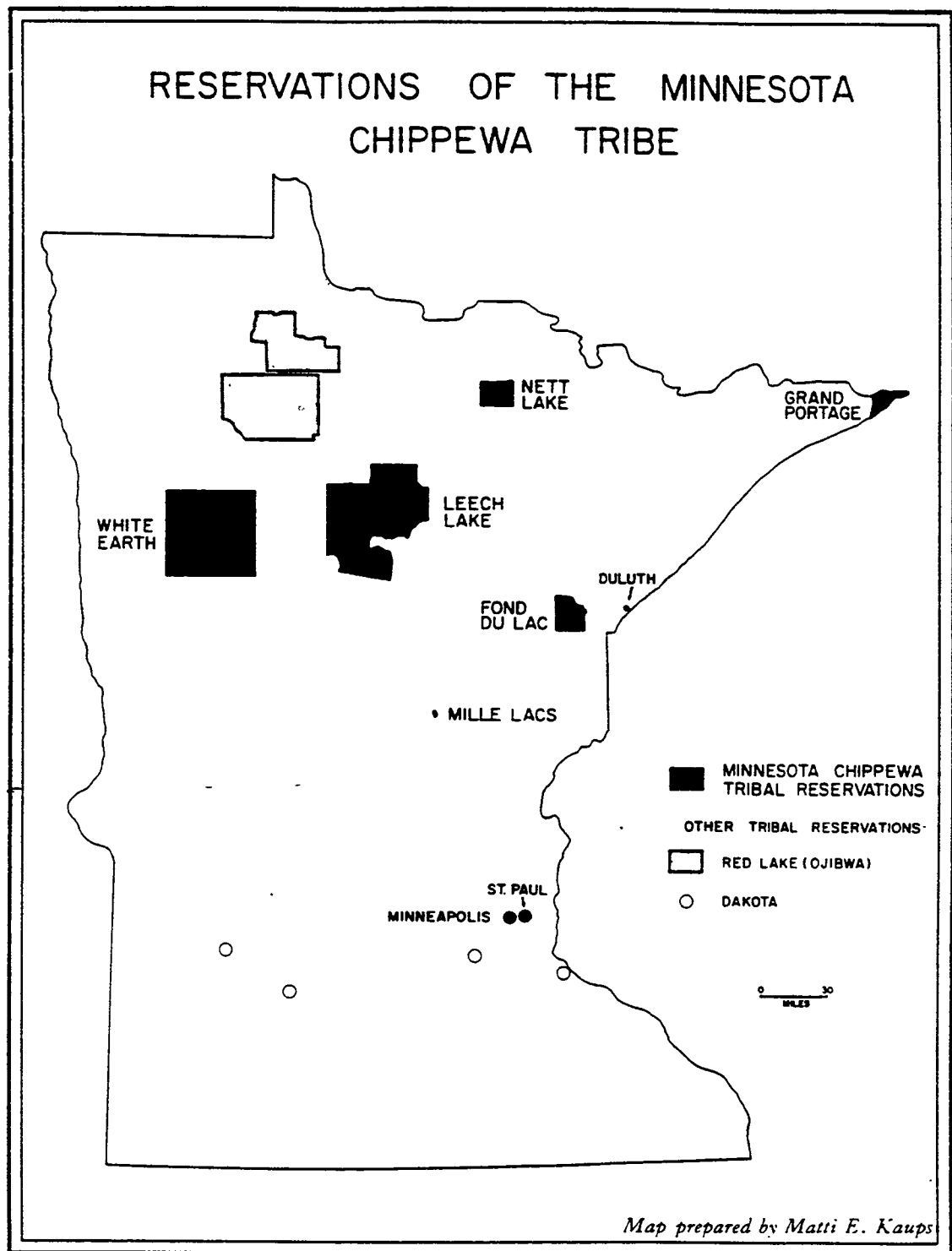
For information or transportation call Charlene Day-Davila at 331-3380, or In...

Appendix N

Reservation Map



From: Roufs, T.G. (1975). The Anishinabe of the Minnesota Chippewa Tribe.
Phoenix, AZ: Indian Tribal Series and the Minnesota Chippewa Tribe



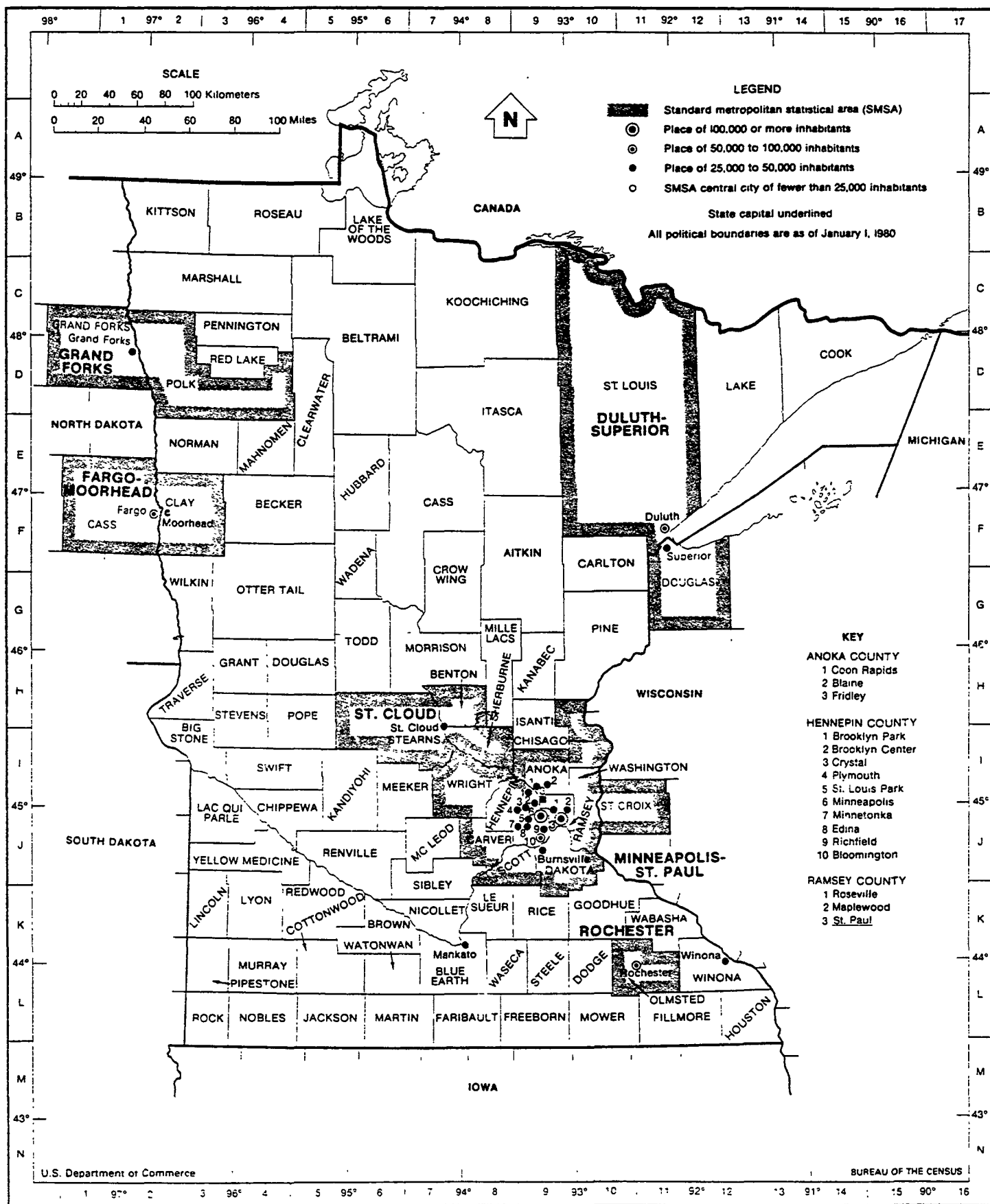
MAP 4.

Appendix O

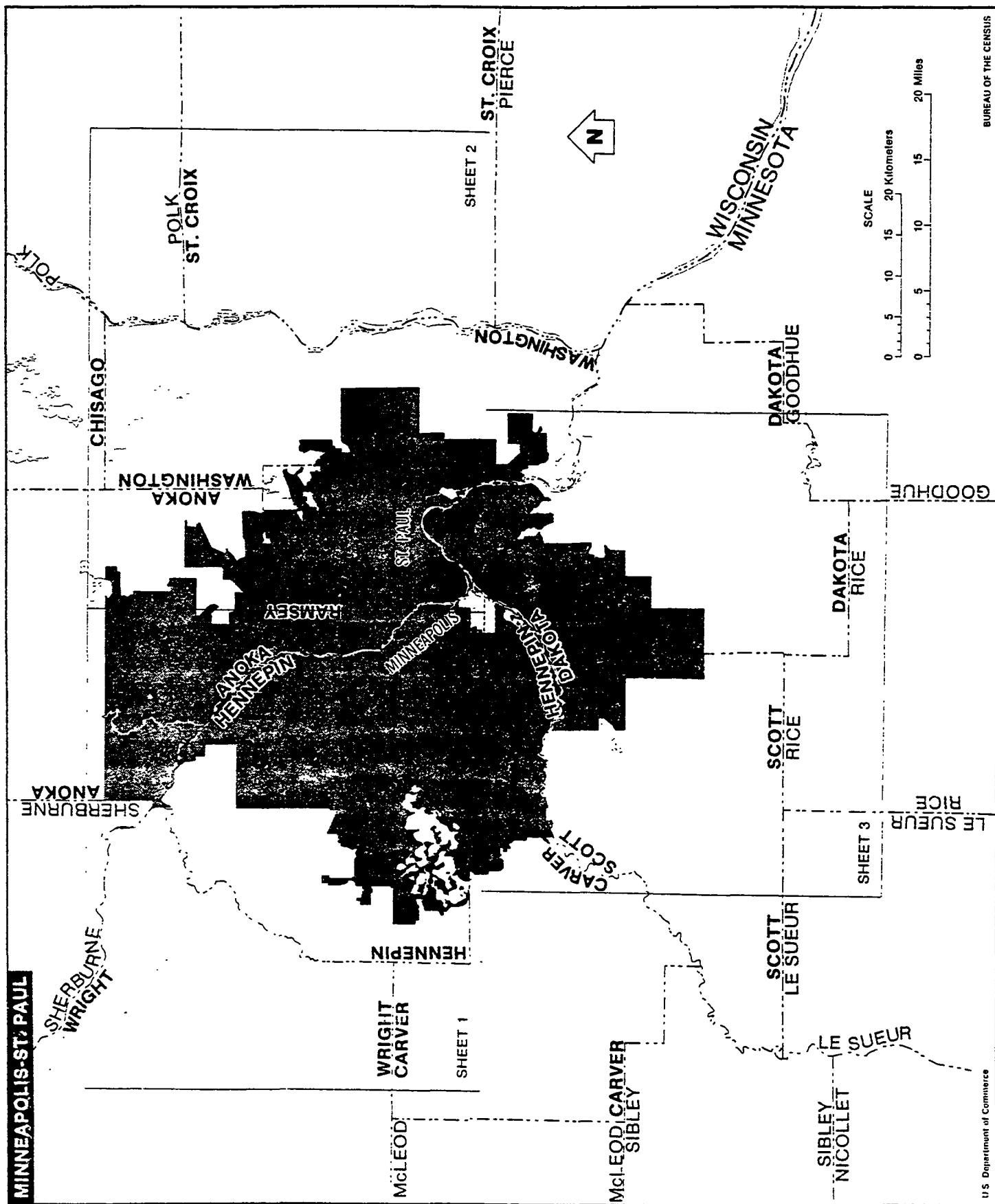
Minneapolis - St. Paul Urban Area Maps



Standard Metropolitan Statistical Areas, Counties, and Selected Places



Urbanized Areas



Appendix P

Interviewer Project Evaluation



American Indians with Disabilities

Minneapolis-St. Paul, Minnesota

PROJECT EVALUATION FORM RESPONSES

- 1. Did the training prepare you to conduct the interviews in an effective manner?
(n = 6)**

Strongly Agree - 67% (n = 4)

Agree - 33% (n = 2)

- 2. In what ways could the training you received as an interviewer have been improved?**

A little training on specific disabilities that are common. A list of medications and the side effects that are common so we could ask good questions about medications.

None.

The training could have been shorter, and more practice could have been made with each other instead of the talking we did.

Less time spent on revising and more time on techniques.

More time to practice interviewing skills.

3. Are there any items which you believe could be *removed from* or *added to* the interview instrument? Please give your reasons for removing or adding items.

Added Items

Interview Instrument Items	Reasons
DI-3; DI-3a; DI-3b	<i>More space for writing down information</i>
CC-1 & CC-2,	<i>Combine to one question.</i>
CC-25	<i>Change to home care</i>
<i>None</i>	
<i>None</i>	
<i>None</i>	
<i>More on family/social systems</i>	<i>To know more about the family support systems</i>

Removed Items

Interview Instrument Items	Reasons
CC-6	<i>99% of respondents aren't in the position to change policy</i>
CC-9	<i>The word "advocate" scares people.</i>
<i>None</i>	
<i>None</i>	
<i>Use of word tribe</i>	<i>Technically this is not a word to use for American Indians</i>
<i>Social Security #</i>	<i>Crazy to ask folk if they have a social security number when we know that a social security number is required for payment prior to completion of interview.</i>

4. What specific problems, if any, did you have when working as an interviewer?

Setting up interviews with people with no phones.

*On-site research coordinator contacts. General area (city) interview contacts.
(coordinator was hard to contact and interviews were for from home.)*

None.

Trying to pretend Caucasians were Native Americans. Need more real Native Americans to interview. Left a lot of disabled "real" Native Americans out.

Scheduling problems.

5. What additional supports or help would you have liked to have while conducting the interviews?

Help making appointments especially with people that have no phones.

None.

Maybe some information on different things where people could go besides IFS. For the younger people who have disabilities.

I needed more time.

6. What follow-up activities might be conducted during the next year to continue the process of improving services to persons with disabilities in the Twin Cities area?

Sending out a questionnaire to people we interviewed, and ask them specific questions pertaining to the instrument.

Don't know--not enough contacts.

This is a hard question! I really don't know right off hand!

Some follow-up, including reinterviewing some by real Native Americans, especially concerning services.

Ad-hoc group or long range planning committee to address issues/concerns.

7. Do you feel working as an interviewer was of benefit to you? If yes, in what ways?

It gave me a chance to get out into the community and into people's homes to see first hand how they cope with their various disabilities.

I have better insight into problems of disabilities with the few contacts that I've had.

It showed me that there are people who need help in different ways, and that they are my people, and I have to try to find ways of helping them! People take care of their own people and that's what I need to do!

I learned to truly have compassion and respect for my fellow Native Americans in a deeper and meaningful way.

A better understanding of the many types of disabilities, and their effects on American Indian people.

Appendix Q

Critiques of Final Report



I would like to commend you and the many members of this study for your fine efforts. Your focus of identifying these people and how they perceive issues and problems they have is wonderful.

I am Ojibwe from Leech Lake and have resided in Minneapolis for twenty years. My extended family and myself have faced these issues countless times. I believe your study accurately identifies the concerns and problems people in this community face.

Your recommendations are right on target. I also believe that educating the specific population about their rights and the types of services that are available to them can be a powerful tool to get their issues addressed. In working with large bureaucratic organizations, I've learned that if you stop "scratching the sore spot it heals quickly and is forgotten."

Empowering these people with the knowledge they need to access services will keep the "wound itching" until services are provided.

The resilience and strength of Indian people came through in your study.

Hopefully your efforts will be used to improve services for Indian people.

Marcella Ardito, Interim Director
American Indian Learning and Resources Center
University of Minnesota
Minneapolis, Minnesota
April 2, 1992

I found the Draft Report very well written and very informative. I commend you on your hard work and diligence in addressing the needs of Native Americans with disabilities.

My only comment would be that I did not know what was next, and did not know if that was part of Phase II. The report provided a lot of information and the next obvious question would be -- and now what? If that is Phase II, then that question would be answered, but it should be so stated.

The report kind of left me wondering what was going to happen next?

All and all an excellent report that we will be using.

Michael Arfsten, Executive Director
American Indian Health Care Association
St. Paul, Minnesota
April 6, 1992

The consumer comment throughout is excellent, so is offsetting it in italics. The Consumer Concerns section - pp. 30-33 - is well presented and clearly explained.

I like the attention to detail and chronological order in describing the processes of developing a base of support for the survey within the community (this is not mentioned in any final report for any other concerns report I have seen over the years), the working group, and the public meeting.

The only change I would make is your ten recommendations on pp. 93-94. These are extremely important. I would not just stick them on the last couple pages, but would make them a separate 2 - 3 page section at the end, and put an extra space between each recommendation to make it stand out.

Barbara Bradford Knowlen
Barrier Breakers
South St. Paul, Minnesota
March 24, 1992

I do not totally agree that your data is straight. My friend is Ojibwa and she is moving back to the reservation. She is the assistant director of The Branch in south side Minneapolis. She is so burnt out on the lack of services provided in the community... I too have to use the food shelf where they cut food down to 1/4 a bag--I also still have to eat there because I'm hungry. I've been discriminated against with housing, friends, especially where I can go to AA. What I do know from the streets is that we do not fit into AA. After people come out of detox and treatment (if God lets you in because you're poor), they still come out and drink again. The criminal activities have tripled as far as robbery, assault, lack of medical attentions. The cost is so high that Indians are forced to wait for the injury or disease -- wait until it is almost curable. Personally, my doctor has abused me because of my Indian culture. I have not found a doctor who doesn't stereotype me before she treats me. This is a commonality.

Consumer (Ojibway)

Thank you for letting me read this study prepared from research done right here in Minneapolis and St. Paul. I am a non-Indian person whose professional responsibility is providing services to older adults (60+) to enable them to live in the community. I work in the Hennepin County Community Services Department.

I am aware that Indian Elders have not been reached very effectively by our programs and I have been working to help fund Indian Family Services to help enable that agency to provide the services that Indian Elders need. I have had the privilege of learning about the Indian culture through my association with Dorene Day, Director of Indian Family Services in Minneapolis and through participation in the Minority Seniors Network here. We also have some excellent work being done through the staff at the American Indian Center here. Francis Fairbanks is the Director.

I have one suggestion for your report if it is not too late to make changes. It is to eliminate your use of the term "majority" and go with the specific percentage in each case. Some places it stands for 97% and some places 54%.

Over all I found the study east to read, well-illustrated by figures and tables. I believe that we in the large mainstream organizations need to be aware of the unmet needs of our brothers and sisters in the American Indian community.

This study have motivated me to look with greater scrutiny at how my agency responds to these needs. I pledge to you that I will work toward improving services to the best of my ability.

Shirley Harper, Program Manager
Services to Seniors
Hennepin County Community Services
Minneapolis, Minnesota
March 6, 1992

I have thoroughly reviewed the draft to your Final Report regarding the needs of American Indians with disabilities in the Twin Cities area and thank you for the opportunity to do so.

This work was very well organized and thought-out. All aspects of the research project were covered in the organizational phase. The operational and coordination phases show the extent of how well the training and use of interviewers were able to collect and report the information that was needed. Finally, in the control or follow-up phase, your research technician monitored the interviewers and responses from the interviewees to ensure all is consistent and valid.

As a consequence of the above, you have a foundation of valid research information that can now be utilized in at least two or three ways. First, actions can now be taken within the disabled American Indian community of the Twin Cities area to reach out and assist those in need. Second, the Final Report strongly suggests repeated recruiting, training, and use of American Indian individuals as interviewers, who may very well later become advocates and outreach workers. And third, the Final Report contains documentary evidence of the need for more funds and services.

The Final Report may have a shorter version to it, but that may need to stand by itself. The important aspects appear to be (1) Need to have access workers, enthused about their mission and eager to achieve results; and (2) members in the disabled American Indian community of the Twin Cities area willing to trust and open to receive help.

Additional coordination with the various public and private agencies to find ways to better access services is recommended.

Thank you for this opportunity.

Allan A. Heide, Senior Social Worker
Social Services to the Adult Disabled Program
Hennepin County Community Services
Minneapolis, Minnesota
March 31, 1992

Thank you for the opportunity to review the study. The results can be the foundation from which to pursue the recommendations listed.

Of the study itself, I am particularly impressed by the Consumer Report Method of generating useful information. While organizations want to be responsive to their consumers, they often don't know how to "weight" expressed needs. This can result in making choices without a way to gauge relative importance thereby limiting the overall impact of their programs or services. The method used in your study provides for a better description of the important issues.

I would add to your existing recommendations a greater discussion of methods to assure competence for working with people from other cultures. While training through a university or by consultants is helpful, ongoing consultation and advice is better. The recommendation is to use advisory councils of consumers, in this case American Indians, to assure that cultural norms are addressed when designing and providing services.

I would highlight the recommendation to recruit American Indian staff. The presence of American Indian staff has been a significant factor in the development of those vocational programs successful in serving Indian people with disabilities in Minnesota.

Please contact me if I can be of any further assistance. I look forward to receiving the final report.

James House
Vice President of Program Services
Goodwill Industries, Inc.
Easter Seal Society of Minnesota
St. Paul, Minnesota
April 6, 1992

I would like to begin by thanking the American Indian Rehabilitation Research and Training Center, and more specifically Dr. Catherine Marshall, for choosing the Minneapolis/St. Paul Metro area as the site for their research into the needs of American Indians with disabilities. The dedication, concern and sensitivity shown by the researchers contributed to the total success of the research experience and to the comprehensive and informative document which we now have.

There has long been a lack of hard and specific information which could be used in proposals, grants and requests for programs to help not only the disabled population within the Minnesota American Indian community, but to help that population as a whole. Results of this study have provided information which cannot be refuted and which can be used in innumerable ways to strengthen the case of those people who seek to provide more and better service to Minnesota's American Indians. It will go a long way toward curing some of the frustrations of the professionals who are constantly striving for attention for the problems and adverse situations that, to some of us, are so glaring, but without the kind of concrete evidence which has now been provided there was no way to clearly and statistically show how desperately needed some of those services were.

People who have participated in this study, whether as an interviewer, an interviewee, a service provider or research staff, have all had their awareness heightened by actually seeing the concerns of the Indian people in black and white; however, I have to believe that the people who agreed to be interviewed will be the most satisfied, because when reading

this document, there is one thing that comes through very clearly: **SOMEBODY LISTENED!**

Despite the frustration of the American Indian population in the Twin Cities area, which is expressed frequently in many different ways, it has been relatively easy for those service agencies which should be providing significant service to turn their backs with excuses about funding, time, commitment of workers, etc. I do not believe that they will be able to as easily turn their back in light of the concise and specific information with which they will be presented with the publishing of the final report of this study.

The recommendations of the researcher are, in my opinion, extremely pertinent and clear. Running throughout those recommendations is acknowledgement of the need for well trained Indian people serving Indian people. Further, they clearly express the need for those people to be served in their own environment, whether that be a metropolitan enclave or a remote reservation. It has been for many years the clearly stated position of the Division of Rehabilitation Services in Minnesota that Indian people should not have to leave the reservation in order to receive the services of the agency. I think that this study clearly shows that, by extension, people should not have to leave the safety and protection of their neighborhood, their community environment, to receive the services to which they have legal rights. In addition, I find the very strong point about the need for non-Indian service providers to be assessed for knowledge and sensitivity with regard to Indian culture and traditions, and agencies to be held responsible for making certain that that type of knowledge and sensitivity exists within the people who work with American Indians with disabilities, to be absolutely essential.

Of course, one point that was not addressed in the study is how all of these things will be accomplished. And that, of course, is the challenge to our State, to our public service agencies, to our American Indian population: find a way to make this happen! I also believe that this study will have such far-reaching effects and such a strong response that I would hate to see the method for providing such good clear information lost to the American Indian populations in areas other than the Twin Cities Metro Area and Denver. I would, consequently, propose that the model, which clearly works and works well, be referred to the regional RSA offices for replication in smaller areas, or perhaps to the Regional Rehabilitation Continuing Education programs.

I am most grateful for the opportunity to have worked on this study and to have made some small contribution to changing the lives of the American Indian with disabilities in the State of Minnesota.

Sharon R. Johnson, Career Counselor
Division of Rehabilitation Services
Minnesota Department of Jobs and Training
Duluth, Minnesota
March 16, 1992

Regarding the complexity of determining racism, what may be construed as racism could have roots in many other areas. This makes it so difficult to define and report. Some of the issues involved in encountering "double racism" include:

- I. Economic:
 - A. People tend to associate with people of similar economic backgrounds. The rich with the rich, etc.
 - B. Many people don't want to be around "poor people"
 - 1. May be asked for help repeatedly.
 - 2. May refuse to help and make excuses.
 - 3. See the need, but unable to help and feel guilty.
 - 4. Do not see how people without material wealth contribute with their ideas, spirit and humanity.
- II. Political:
 - A. View only as welfare system versus free enterprise.
 - B. Some problems (homelessness) seen as insurmountable, or "just keep the people out of my neighborhood."
- III. Education:
 - A. The system set up as white European/WASP values, non-inclusive of other cultures.
 - B. Those with "degrees" or those who "want degrees" often form exclusive groups or "clubs."
 - C. In the choice to identify with one's roots, people actually have to "hide" their education and life experiences. Person with a high status in the military may not reveal this in civilian life. Whereas, the vet who brags on his exploits in the service is suspect of exaggeration or worse.
- IV. Occupation:
 - A. People tend to group with co-workers who speak the same technical language, e. g. Lawyers, Accountants, etc.
 - B. Tendency to group with whom we feel comfortable. Natural for a manager to hire someone from his own heritage and common interests.
 - C. Ego/Racism: Everyone should have equal human value. The doctor or Ph.D. with 1,000 ideas should respect the ideas from every other member of the community, be able to listen to others' opinions, and respect the chair even if he/she only had an 8th grade education.
- V. Age Differences:
 - A. A person can be ignored by others or his ideas dismissed, either because he is older or younger. If you are 20 years older, you're over the hill -- an "old person." A 21 year old views a 55 year old as ancient. Someone 55 years old views a 21 year old as a "kid."
 - B. Social and physical activities will also group by age.

VI. Cultural background: Many books can't cover this subject.

A. Differing values: Physical world vs. Spirit world;
material things vs. nature, animals

B. Family structure: White family will hire a baby sitter.
Indian family will include the extended family from the baby
in the cradle to Grandma in all activities.

C. Mannerism and communication have roots in culture.

Society may clash in our habits:

Fast talking - thoughtful response

Impatient and loud - soft and tolerant

Not listening, brash - respectful listening

Talk directly, bold - talk indirectly, avert eyes

VII. Geographical Background: Having lived in many parts of the United States, and traveled and lived in many countries of the world, I know that we are all human beings with similarities, and yet there are differences based on where we were born.

VIII. The Unknown A. Many people actually shy away from someone who is different than their culture because they don't know what to say, or how to react.

B. Some people are narrow in their life experiences in
cross/cultures, and so associate only with mirror images.

IX. True Racists Unfortunately there also exists those who condemn and judge based solely on looks.

These people are dangerous and destructive and are truly
"Savages." They may turn on someone as a "group," usually
because they are cowards individually. They compensate for
their inadequacy by prejudice to others.

Racists play a game of power. He has the ball and you can't
play. "You can't be in the pool unless you follow our rules." If
you follow the rules, they are changed.

A racist can't fit into the natural order of harmony of creation
because he has no respect for nature or order.

Maurice "Al" Wensman
Ojibway-Red Lake, Minnesota
March 1, 1992

First, I want to congratulate you on a job very well done! The report is thorough and yields a great deal of information which is both interesting and useful. It adds greatly to our awareness of the perceptions and needs of disabled persons in the American Indian community. The results in themselves make a compelling case for the development of more services specifically targeted toward this population. Certainly this report will be very useful to any agency engaged in planning and fundraising for programs for disabled American Indians.

The process of research was very clearly outline in the methodology section of the report. Although I do not have significant experience in primary research, the process appears to have been scientific and thorough. I am confident, therefore, that the results and conclusions are highly valid.

One area the research may have probed more deeply into is the issue of discrimination. I think you more or less acknowledge this in the report. Also, I am just a bit curious about the incident of interviewer bias which led to the discounting of some interviewee comments on discriminatory behavior. You may want to explain this matter in more detail.

I noticed just a couple of other minor problems in the report. On page 6, in the first sentence under Interviewer Characteristics, you used the term "interviewees" when I believe you meant to say "interviewers." In Figure 2 on page 13, the tribal affiliation "Chippewa" is distinguished from the tribal affiliation "Ojibway". In fact, "Chippewa" and "Ojibway" are interchangeable terms for the same tribe, with "Ojibway" being the more correct and preferred usage.

With regard to ways to produce change in service delivery to American Indians, I feel that:

- 1) The report needs to be widely disseminated to public and private agencies that reach, or should reach, disabled American Indian people;
- 2) Conferences or training sessions on the subject of American Indians with disabilities should be held in several regions across the country. The sessions should reach American Indian groups and organizations as well as public agencies dealing with disabilities. It should stress practical ways in which outreach and services can be improved and expanded, and a discussion of grant opportunities.

Catherine, thank you for giving me the opportunity to respond to your work, and thank you for your sense of caring for disabled American Indians. It was a pleasure to contribute, albeit in small way, to the study.

Michael Wiebe
Program Planner, Minneapolis American Indian Center
March 22, 1992
