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Reese, Sharon E., Access to Health and Social Services for Poverty Level Adults with Chronic Disease or Disability. Doctor of Public Health (Health Management and Policy), December, 2006, 79 pp., 7 tables, 51 references. This dissertation reports the results of research into the difficulties poverty level adults with disabilities have in accessing vital health and social services. Chapter one gives a background of the problem, the purpose of the research, the research question, limitations and constraints, and the importance of the study. Chapter two is a review of the literature concerning this population and access. Chapter three reviews the methodology used in the study, with chapters four and five presenting results, conclusions and recommendations. Qualitative methods using a focus group and individual interviews provided the data for this research. In the analysis of the focus group and individual interviews five major themes emerged: health issues, access or obtaining care, interactions with providers, obtaining medication, and transportation (table 6). A review of these themes and the particular responses of participants in these areas highlighted the need for policy change in the area of access to services for this special group. This dissertation also makes recommendations for policy changes and potential barriers to those changes.

**Access to Health and Social Services for Poverty Level**

**Adults with Chronic Disease or Disability**

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**ACCESS TO HEALTH AND SOCIAL SERVICES FOR POVERTY LEVEL ADULTS  
WITH CHRONIC DISEASE OR DISABILITY**

**DISSERTATION**

**Presented to the School of Public Health University of North Texas Health Science  
Center at Fort Worth In Partial Fulfillment of the Requirements**

**For the Degree of  
Doctor of Public Health**

**By**

**Sharon E Reese, BSN, MPH**

**Fort Worth, Texas**

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## TABLE OF CONTENTS

	Page
LIST OF TABLES	v
Chapter	
I. INTRODUCTION	1
Background	3
Statement of Purpose	5
Research Question	6
Delimitations	6
Limitations	6
Constraints	7
Assumptions	7
Importance of Study	8
II. LITERATURE REVIEW	9
III. METHODOLOGY	23
IV. RESULTS	25
Study settings	25
Demographic Characteristics	26
Key Informant Interview	30
Issue Trends	34
General Health	36
Access/Obtaining Care	37
Interaction with Provider	42
Medication	43
Transportation	44
V. CONCLUSIONS AND RECOMMENDATIONS	46
Summary	46
Discussion	47
Limitations	52
Conclusions	52
Recommendations for Policy & Practice	53

APPENDICES

A.	Demographic Information	57
B.	Focus Group Guide	59
C.	Informed Consent	66
D.	Key Informant Interview	70
E.	Participant Handout	74

REFERENCES	87
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## LIST OF TABLES

	Page
Table 1. Percent of Non-elderly Adults with Chronic Conditions who Lack Health Insurance Coverage	14
Table 2. Percent of non-elderly adults with chronic conditions who lacked a health professional visit in the past 12 months, overall and by insurance status	16
Table 3. Percent of Adults with Chronic Conditions Reporting Unmet Need for Health Care in the Past 12 Months, Overall and by Insurance Status	17
Table 4. Demographic Characteristics of Study Participants	27
Table 5. Themes of Issues Identified By Participant Responses	28
Table 6. Responses to the question: When you were sick or had a problem over the last year what did you usually do?	35
Table 7. Responses to the question: When you were sick or had a problem over then past year what did you usually do?	38

## CHAPTER 1

### INTRODUCTION TO THE STUDY

According to the National Health Interview Survey of 2004, in the United States approximately 34.2 million persons were limited from usual activities due to one or more chronic health conditions. Of those, approximately 17.5 million (approximately 51%) were between the ages of 18 to 64. (Adams & Barnes, 2006) The report further states that individuals with the least education and lowest incomes were more likely to have an activity limitation. This raises a serious concern regarding access to health and social services for these individuals who have an increased need for assistance due to their disability status. This dissertation examines the difficulties individuals with chronic disease or disability face in accessing the care or services they need.

During volunteer work through a church, the author had the opportunity to work with an individual with renal disease and uncontrolled hypertension. He was unable to work but had been denied Supplemental Security Income (SSI). He had been turned down for food stamps for lack of a disability physical and had no idea where to get one. His limited transportation options required hours for him to get to the county clinic at the Fort Worth Medical Center (John Peter Smith- JPS where he would spend hours getting in to see a health care provider, just to get back on a bus and ride several hours home, all to get a distance of approximately 10 miles. He was frequently seen through the emergency department of John Peter Smith Hospital and admitted to the hospital due to an extremely high blood pressure. Upon discharge, he was given an

appointment for follow up in the clinic and a hand full of prescriptions to have filled in the pharmacy. Since he had no money and the hospital would provide only one free medication fill a year, he had no medication to control his blood pressure which caused a worsening of his overall condition.

In attempting to assist this individual the author's eyes were opened to the difficulties people with disabilities face in trying to get the public assistance they so desperately need. After calling the food stamp office on his behalf, the author was informed that he would need to see his doctor (at JPS) to obtain a disability statement. The author went with him to the clinic where we waited approximately four hours. With his permission, the author went in to the examination room with him to speak with the physician about his medications and a disability statement. We were told that disability physicals were not done at that clinic. After much explanation and discussion the author was able to talk the physician into writing a statement on a return to work slip and to get some assistance for medication at the pharmacy. While we were waiting, the individual told me, "If you weren't here, they wouldn't be doing all this." When calling and talking with the same person as before at the food stamp office about accepting the statement we had been given, the author was told she would accept that statement but "I'm going to set him up an appointment with our physician. That's who does the disability physical." This case illustrates why a person who is disabled and with limited resources may give up while facing so many barriers to services.<sup>1</sup>

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<sup>1</sup> Since this study began, this individual's condition continued to worsen until he finally required dialysis. Currently he goes to

## Background

DeJong, Batavia & Griss (1989) recognized that the needs of this population had been overlooked and that their health care needs were not well understood. They saw a need for research on the working-age disabled adult. Almost eight years later, DeJong, (1997) still saw health care needs for the disabled as one of the major unresolved issues. Scotch (2002) noted that most initial research on disability used a medical model that looked from a diagnosis and treatment point of view, rather than a social one. Social research perspectives look at problems and limitations from the holistic view point, taking into account the impact of the problem from all areas of the individual's life. Once more money began to be available for research in the area of disability and policies began to change for the disabled, social research began to evolve.

While much has been written regarding the utilization of health care services among the low income and in particular the homeless (Liebow, 1993; Kushel Vittinghoff, & Haas, 2001; O'Toole, Gibbon, Selrzer, & Hanusa, 1999.), little is found that identifies the difficulties an individual who is disabled and living at the level of poverty has in running the gamut necessary to obtain medical and financial assistance through the welfare system. One article (Cunningham & Hadley, 2004) identified financial barriers as the main reason the poor do not receive the health care they need. This article used the 1998-99 Community Tracking Study (CTS) and the

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dialysis twice a week and will do so for the rest of his life. The "good news" is that once on dialysis he was assured approval and benefits as a disabled person.

data from studies of community health centers (CHC) to look at access to care and the availability and capacity of CHC resources. The study showed that insurance coverage expansion was more effective in increasing access to care than access to community health centers. This presses the point that the ability to apply and obtain financial assistance is vital to accessing good, consistent health care.

Working through the social service system to obtain eligibility for health and social services is a long and tedious process for anyone. Completing the numerous forms correctly, gathering the required information (tax forms, birth certificates, marriage documents for example), scheduling the many appointments and follow up appointments are all time consuming and tedious. Often the workers on the other end of the telephone or opposite side of the desk are not the most helpful. The applicant is often told that the process will take months and to be prepared to be denied two to three times before successful completion and approval for benefits. If a client fills out a form incorrectly or fails to include back up documentation the person is often sent away from the appointment with instructions to complete them and return or the application may be denied.

The overall problem is lack of service coordination. There are many services available for the disabled depending on income level and need. Different services require appointments at different agencies and different forms filled out for each. The process is difficult enough for the person with resources available and assistance from family or friends, but for the person without those resources and also living without income the process is confusing and prohibitive.

There are usually no "one stop shops" or coordinating office for these appointments. Some clients may be assigned a social worker or case manager through a hospital or city/county

office but often the client is on his/her own. There may be several telephone numbers to call and different office locations to get to before even an initial application may be made.

On top of these difficulties the possible lack of a telephone by the applicant, the need for transportation to the locations (which may be scattered throughout the city), and possible limited reading or comprehension skills on the part of the disabled, add to the chances of a decrease in the likelihood that a person with disabilities can successfully complete the process.

Aside from the ethical issue of access to care for all, there is the impact on the health care system from the use of hospital emergency care departments by persons with no other health care option. O'Toole, Gibbon, et al. (2002) found that persons with an identified usual health care source were less likely to go through the emergency rooms for services than those with no usual source of care. This impacts the cost of health care.

Individuals with a lack of insurance and the inability or limited ability to pay for medical care are less likely to obtain medical checkups and preventive services (Culica, Rohrer, Ward, Hilsenrath, & Pomrehn, 2002).

### **Statement of Purpose**

The study gathered data to better understand the barriers poverty-level disabled adults face in acquiring the support they need to access health care and social services. The study examined social security disability and Medicaid eligibility, and also access to social services such as food stamps, housing and transportation, to get a full picture of the barriers.

## **Research Question**

**What specific difficulties do poverty-level disabled adults have in accessing and maintaining consistent health care and social services? In particular, are lack of service coordination and lack of public transportation for them major factors in access to services?**

**By determining the existing difficulties this population faces, it will then be easier to develop health policy recommendations that might assist communities in working not only with poverty-level disabled adults but also other disabled persons attempting to access the health care and social service systems.**

## **Delimitations**

**The researcher included both males and females between the ages of 18 to 64 with a chronic disease or disability in the study. This decision influenced the outcome of the study because individuals over the age of 65 are eligible for Medicare and do not have the same problems as those in the included age range.**

## **Limitations**

**One possible limitation to this study was the fact that the sample was taken from three apartment complexes within the same county. This may limit potential for generalizing the results across the state or nation, but the study should still provide insight into problems that persons in other locations who have similar characteristics face in access to care.**

## Constraints

Due to constraints required by the Internal Review Board (IRB), recruitment of participants was limited to individuals who responded to the flyers distributed at the various apartment complexes rather than using a snowball method of recruitment although the snowball method often is a much more effective one in obtaining participants. In the snowball method, once an interview takes place, new potential interviews are identified from that interview. In other words, the interviewer asks for anyone the participant knows who has disabilities. Those individuals are then asked if they would be willing to participate. They in turn are asked for referrals and the numbers continue to grow like a snowball rolling down hill.

Time constraints were another issue in the completion of this study. Because this study was done as part of a dissertation, certain requirements had to be met and completed before the investigator was able to move to the next stage. The proposal and IRB application had to be completed before starting on any research. By the time these steps were completed, the remaining time before another constraint was met (that of completion of the graduate program within the period allowed by military educational leave) limited the actual time available to do the research and write the results.

## Assumptions

The following assumptions were made:

- Having focus groups and interviews onsite at the apartment complexes would increase the chance of participation.

- Verbal interviews rather than completing a questionnaire eliminated any problem of poor or lack of reading skills.
- Participants answered honestly.

### Importance of the Study

The research increases our knowledge of the problems and barriers that those disabled adults on the low-income or poverty level commonly face on a daily basis when they attempt to obtain the health and social service resources they need. By better understanding these problems public health agencies can work to influence policy change and help to improve the overall health of the community.

## CHAPTER 2

### Review of Literature

Working-age adults with disabilities are a large proportion of those persons in the United States who rely on public assistance programs. In addition, those individuals are much more likely to be below the poverty level than those without disabilities. In fact, in one study (She & Livermore, 2006) it reported that annual poverty rates were two to five times higher in the working age disabled than in those with no disabilities. The study also found that these large numbers of poor working age individuals may indicate:

“A variety of deficiencies in the welfare safety net, such as: inadequate levels of assistance provided by the SSI program; inadequate provisions of the Food Stamp program concerning qualifications and benefit levels for people with disabilities; inability of the two major public health insurance programs, Medicare and Medicaid, to address the medical care needs of individuals during the early stages of disability onset, or of those experiencing relatively short-term disability; and adequate provisions of Medicare and Medicaid to cover many disability-related long-term supports (e.g., personal care assistance)”(She & Livermore, 2006, p.4).

Brown and Cousineau (1991) assessed the effects of the loss of Medicaid benefits as it related to access to health care services. This study looked at the change in programs and policy in California which resulted in the loss of benefits and subsequently the reduction in health care usage by the poor population. The study addressed the question, how much more is the disabled

person affected by the loss of benefits or the difficulty in completing all that needs to be done in order to qualify for assistance. For the low income individual, working through the system in order to get good, consistent basic health care is often a difficult and frustrating process. Having the resources to not only see a health care provider but to also be able to get needed medications to take care of the identified health problem is essential. The person may see the health care provider but then not have the money to purchase prescriptions (even at a low co-pay) to care for the condition. For a person who is unable to work but also has not qualified for social security disability and Medicaid, and has no income, there is no money for prescriptions.

For example, a person with chronic hypertension may not be able to get blood pressure medication to treat hypertension. He/she may require frequent hospitalizations due to uncontrolled hypertension because he/she was unable to get medication. The result is a “revolving door” of hospitalizations and discharges all resulting from inability to obtain needed goods and services. This also causes a drain on the health care financial resources of the community who pays for those hospital services that could possibly have been avoided had there been a better policy for health and social services.

Nearly half of all uninsured, non-elderly adults reported in the National Health Interview Survey having a chronic health condition (Davidoff & Kenney, 2005). The survey showed that many of these adults do not have a usual health care location and almost half those with chronic conditions go without needed medical care and prescriptions due to the cost involved. Also identified in the survey was the fact that those with a family income of less than \$20,000 who did seek care spent at least 10 percent of their family income on out of pocket expenses for health care. This reinforces the fact that those uninsured were more likely (4.5 times) than those

insured to report unmet medical care or prescription drug need in the 12 months before the survey.

Another impact on poverty level individuals was made by The Welfare Reform Act (The Personal Responsibility and Work Opportunity Act of 1996) that affected eligibility for Medicaid and social services. This act eliminated the automatic eligibility linking Medicaid and welfare programs and made access to Medicaid more difficult. It also allowed states the opportunity to tailor their Medicaid programs which caused more variation across the states. The study reported that even though the Act gave the states the opportunity to restructure to establish Medicaid as a health insurance program for low-income families, most did not do so. Because of the new legislation, Medicaid enrollment became more difficult and enrollments declined (Maloy & Rosenbaum, 2003).

The Americans with Disabilities Act (ADA) of 1990 was intended to eliminate discrimination based on disability. The Act looked in particular at access to jobs, goods and services for the disabled. Rather than the expected effects of this law, one study (Hinton, 2003) did not find the perception of improvement in accessibility by persons with disability. Brandwein & Scotch (2001) identified disagreements regarding the meaning of the ADA, leading to questions in the interpretation of the Act, and identifying the need for easy to understand policy.

Another study (Fouts, Anderson, & Hagglund, 2000) showed a relationship between satisfaction with access to care and disability. In this study, individuals with a disability were more likely to be dissatisfied with access to care than those without a disability. Coughlin, Long, and Kendall(2002) used a 1999-2000 New York Survey of Working-Age Disabled Medicaid Beneficiaries on common patterns in reported unmet needs. Dental care and mental health care

were included in unmet needs. Among barriers were the limited availability and accessibility of providers: location, transportation, language or physical barriers. Along with the barriers to health care, participants showed a low level of satisfaction with their care.

Neri & Kroll (2003) used qualitative methods to look at the consequences of barriers to health care access. They used in-depth telephone interviews to look at access, utilization, and satisfaction of disabled in a managed care or fee-for-service plan. Consequences of managed care included a delay in treatment and worsening of primary and secondary health issues. As well, the need for education among health care providers and insurance companies was identified in dealing with clients with disabilities. Chan, et al. (1999) presented a study looking at access to preventive services and found that those with disabilities were less likely to obtain routine screening exams. They further identified that health maintenance organizations (HMO) provided more screenings than fee-for-service care providers.

In their study on access to health care for individuals with Osteoarthritis and Rheumatoid arthritis (Hagglund, Clark, Hilton, & Hewett, 2005), the authors determined that the U.S. health care system continues to focus on acute disorders rather than adapt to growing chronic illness and disability. Problem areas identified were high cost and limited coverage by health plans for chronic disease and disability. The authors recommend that models of health delivery be refined for those with chronic illness and disability.

While low-income women and children, and institutionalized elderly tend to be viewed as the primary recipients of Medicaid, spending by Medicaid on the non-elderly disabled rose higher than any other group over the last twenty years. (Valadeck, 2003) In addition, this article addresses the increased problem of disabled Medicaid beneficiaries enrolled in managed care

programs that lack the specialized capabilities to care for this complicated population. The authors see the challenge as improving community based service systems for this group to address their special needs. However, others (DeJong & Frieden, 2002), found that problems individuals with disabilities have with health care are not necessarily specific to managed care but to the larger health care system. Researchers found that “health status and income levels, not type of health plan, were the strongest and most consistent predictors of health care status” (p4). They further stated “people reporting poor health, more significant impairments, or lower household incomes had greater difficulties in obtaining the health services that they need”.

The uninsured are also treated by the millions in emergency departments across the country. A national survey conducted by Public Opinion Strategies, Alexandria, Virginia asked 1,954 emergency physicians who provide direct patient care in emergency departments. These physicians reported the following health risks of the uninsured seen in the emergency department:

- 67 percent of physicians agree uninsured patients seen in the emergency room tend to be sicker and have more serious medical conditions than those seen with health coverage.
- 74 percent agree uninsured patients are more likely to die prematurely than patients with health coverage.
- 94 percent agree that arranging follow-up care for the uninsured patient’s serious problems is more difficult than for insured patients. They noted that routine follow-up care, specialist referrals and ensuring prescriptions are filled are particularly difficult (Robert Wood Johnson Foundation, 2004).

Another study (Davidoff & Kenney, 2005) documented “the prevalence and impact of selected chronic health conditions among the uninsured.” Here researchers used data from the 2003 National Center for Health Statistics’ National Health Interview Survey (NHIS), a household probability sample survey conducted by the U. S. Census Bureau for the Centers for Disease Control and Prevention’s National Center for Health Statistics. Interviewers talked with 92,148 people in 35,921 households with an 89.2% response rate. Five areas were analyzed in the study: lack of a health professional visit within 12 months of the survey; lack of a usual source for health care at the time of survey; presence of unmet health needs in the 12 months prior to the survey; out-of-pocket spending on health care in the 12 months prior to the survey; and lack of dental care in the 12 months prior to survey. Tables 1,2,3 show the results of that study giving the breakdown of lack of insurance coverage, lack of health care visits over a one year period, and reported unmet needs over the past year for non-elderly adults.

**Table 1. Percent of Non-elderly Adults with Chronic Conditions who Lack Health Insurance Coverage**

<u>For adults with:</u>	<u>Percent Uninsured</u>
Any chronic condition <sup>1</sup>	17%
By race/ethnicity	
White	13%
Black	19%
Hispanic	35%
Other	21%
Hypertension (2+ visits)	14%
High cholesterol (ever)	11%
Heart disease (ever) <sup>2</sup>	13%
Asthma (current)	18%
Diabetes (ever)	15%
<u>Arthritis-related conditions (ever)<sup>3</sup></u>	<u>12%</u>

Source: Urban Institute Tabulations of 2003 National Health Interview Survey

**Notes:**

1 Hypertension, high cholesterol, heart disease, asthma, diabetes, arthritis-related conditions, anxiety/

depression, severe headache/migraine, cancer, chronic bronchitis, liver condition, stroke, and emphysema

2 Coronary heart disease, angina, heart attack, and any other kind of heart condition or disease

3 Arthritis, rheumatoid arthritis, gout, lupus, or fibromyalgia

Table 1 identifies Hispanics as the highest percentage of non-elderly adults with chronic conditions and no health insurance as specified in note 1 of the table. Blacks follow as the second highest race or ethnicity group followed by whites and then the broad “other” category.

**Table 2. Percent of non-elderly adults with chronic conditions who lacked a health professional visit in the past 12 months, overall and by insurance status**

<u>Percent who lacked a health professional visit</u>			
<u>For adults with:</u>	<u>All Adults</u>	<u>Uninsured</u>	<u>Insured</u>
Any chronic condition <sup>1</sup>	10%	27% *	7%
By race/ethnicity			
White	9%	27% *	6%
Black	10%	28% *	5%
Hispanic	14%	27% *	7%
Other	14%	24% *	10%
Hypertension (2+ visits)	5%	18% *	3%
High cholesterol (ever)	7%	20% *	6%
Heart disease (ever) <sup>2</sup>	8%	25% *	6%
Asthma (current)	7%	22%	4%
Diabetes (ever)	3%	7% *	2%
Arthritis-related conditions (ever) <sup>3</sup>	6%	19% *	4%

Source: Urban Institute Tabulations of 2003 National Health Interview Survey

**Notes:**

\*Difference between uninsured and insured is significant at  $p < 0.05$ .

1 Hypertension, high cholesterol, heart disease, asthma, diabetes, arthritis-related conditions, anxiety/depression, severe

headache/migraine, cancer, chronic bronchitis, liver condition, stroke, and emphysema

2 Coronary heart disease, angina, heart attack, and any other kind of heart condition or disease

3 Arthritis, rheumatoid arthritis, gout, lupus, or fibromyalgia

In table 2, the uninsured are compared to insured for non-elderly adults with chronic conditions. In this instance the table shows the difference in health professional visits over a 12 month period. The table clearly shows that a higher percentage of individuals with a chronic condition who are uninsured had no health professional visit during the target timeframe than those with insurance.

**Table 3. Percent of Adults with Chronic Conditions Reporting Unmet Need for Health Care in the Past 12 Months, Overall and by Insurance Status**

	<u>Percent Reporting Unmet Need for:</u>			
	<u>Medical Care</u>	<u>Prescription Drugs</u>	<u>Mental Health Care</u>	<u>Dental Care</u>
<u>All Adults with:</u>				
Any chronic condition <sup>1</sup>	11%	12%	4%	15%
By race/ethnicity				
White				
Black	10%	11%	4%	15%
Hispanic	12%	15%	3%	16%
Other	13%	16%	5%	20%
	9%	10%	4%	14%
<u>Uninsured</u>				
Any chronic condition <sup>1</sup>	34% *	34% *	11% *	40%*
By race/ethnicity				
White				
Black	36% *	36% *	11% *	43% *
Hispanic	35%	36% *	9%	35% *
Other	26% *	29% *	10%	35% *
	32%	32%	11%	35%
<u>Insured</u>				
Any chronic condition <sup>1</sup>	6%	7%	2%	11%
By race/ethnicity				
White				
Black	6%	7%	3%	10%
Hispanic	7%	10%	2%	11%
Other	7%	9%	2%	11%
	3%	4%	2%	8%

Source: Urban Institute Tabulations of 2003 National Health Interview Survey

**Notes:**

\* Difference between uninsured and insured is significant at <0.05.

<sup>1</sup> Hypertension, high cholesterol, heart disease, asthma, diabetes, arthritis-related conditions, anxiety/depression, severe headache/migraine, cancer, chronic bronchitis, liver condition, stroke, and emphysema

Table 3 adds prescription drugs and dental care. There is a statistically significant difference between the insured and uninsured work-age adults in all areas of health care showing the increased risk this group of people face.

Persons with a disability have a higher risk of developing secondary health conditions, higher utilization of services other than primary care, increased need for supportive equipment, decrease in independence, and an increase in psychological stress (Scheer, Kroll, Neri, & Beatty, 2003). An environmental barrier that affects individuals with disability is transportation. Issues of transportation include whether there is a method of transportation (public or private) available that would provide the usual lifts for wheelchair access, also whether it is convenient for those who tire easily. Related questions are: Will the person have to wait long periods for a bus to arrive only to have to transfer to another making a long and exhausting trip. Will the individual have a long wait to see the medical or social care provider, all the while knowing that he/she will have to face the long, exhausting trip back at the end? Will that provider understand the comprehensive health care needs of that individual that require further services? These questions are addressed in this study.

A study by Cunningham and Hadley (2004) compared the benefit of increasing insurance coverage as opposed to expanding community health centers (CHCs). The CHCs in question are “free” or low cost services for those who are uninsured. Data sources were the 1998-99 Community Tracking Study (CTS) and included 55,000 people in the US population from sixty randomly selected communities. The study also looked at a subset containing people under the age of 65 with incomes below the 200 percent line of the federal poverty level (n= 12,700). The

CTS is a household survey and in addition supplemental information supplied on CHCs was included.

The study looked at measures of access to care and medical use. For the CHC capacity the study measured availability and capacity of the centers. Variations across the communities were analyzed and multivariate regression used to assess effects of insurance coverage and CHC capacity on access to care. The researchers adjusted for potential bias of greater health care needs by participants. The results showed that a high insurance presence made more impact than the presence of a community center. The conclusion for the study was that both expanded insurance and increased capacity or presence of CHCs in the community were needed for better access to care. For the disabled population, a lack of insurance combined with an inability to pay for health care visits and services is again a problem. Regardless of the availability of a community health center, if the individual cannot meet co-pay requirements or fees of the clinic, that center might as well not exist.

According to Hagglund, Clark, Conforti and Shigaki (1999), existing literature indicates that access to health care for persons with chronic disease or disabilities is poor. Women with disabilities are less likely to have preventive health screenings such as Pap smears, mammograms and breast exams (Lezonni, McCarthy, & Davis, 2001). In one study (Nelson, Brown, Gold, Ciemnecki & Docteur, 1997) persons with disabilities also report having difficulty in obtaining services. In particular, 32% of those surveyed reported difficulty obtaining prescription medication, 29% obtaining dental care and 21% with obtaining assistive equipment. The inability to access health and social services, or even the delay in access, by those with chronic illness or disability can cause a deterioration of health resulting in other health issues, an

increase in use of already taxed emergency services and hospitalization. A study by Beatty, Hagglund et al. (2003) found that of 800 disabled adults only half received needed rehabilitative services with those with the poorest health and the lowest income being least likely to receive health services. In a study by Hanson, Neuman, Dutwin, and Kasper (2003), 36% of those sampled said that they had skipped medication doses, split pills or gone without filling a prescription because of the lack of money.

DeJong, Palsbo, et al. (2002) warn against attempting to generalize the needs of people with disabilities. One of the challenges in providing services to this population is that “one size does not fit all.” There are any number of combinations of problems that this group faces depending on type of disability, any secondary health problems, age, employment, income, support system, location (housing, transportation, availability of services) to name a few.

Issues other than strictly health care impact access as well. A study by Gelberg, Gallagher, Anderson, and Koegel (1997) found that attempts to address health care needs for disabled persons must also look at social service needs for food, clothing, shelter and sanitation. Schlossstein, St.Clair, and Connell (1991) found that housing, finding employment, and child care, among other needs, was of higher priority for clients than medical care, meaning that individual health was placed lower. Health issues may wait and possibly become worse until finally requiring more resources to be addressed. This all has the potential to raise health care costs. For this population (low income, disabled) the higher costs must be passed on to the health care system but will finally be passed on to other health care consumers.

As previously stated, this research increases our knowledge of the problems and barriers that those disabled adults on the low-income or poverty level commonly face when they attempt

to obtain the health and social service resources they need. Using a qualitative method to conduct this research affords an in depth exploration of the barriers faced and helps to validate perceptions of these existing problems. Hopefully health and social service agencies will begin to better understand the need to improve access to services for this special population. By better understanding these problems public health agencies can work to influence policy change and help to improve the overall health of the community.

A limited number of resources are available for individuals with disabilities. The United Way has a program called the 211 system (United Way website, 2006). This service was developed to provide local individuals with information regarding services available in their area. These services include locations of food banks, physical and mental health resources, employment support, services and support for those with disabilities as well as for children, families and the elderly. This service is vital on a daily basis but can be especially helpful in times of disaster such as in 2005 with Hurricanes Katrina and Rita.

John Peter Smith Health Network has on their website information for potential patients giving eligibility requirements and required forms for services on a reduced fee for service basis. Individuals must meet certain criteria to be eligible for medical assistance (other than for emergency medical services). They must reside in Tarrant County, have identification, and meet income requirements. Eligibility is based on household size and gross monthly income according to the current federal poverty income levels and proof of current residence in Tarrant County. Clients that do not have Medicaid, Medicare with prescription benefits, or any medical coverage that covers all or part of medical services and prescription pharmaceutical costs are eligible.

Some transportation services are also available for individuals in Tarrant County with disabilities. The American Red Cross has a transportation program available to Tarrant County residents based on age and disability. Those programs are the Northeast Transportation Service (NETS), the Tarrant County Transportation Services (TCTS) and WHEELS. Each of these services is a non-emergency service available Monday through Friday between as early as 5 am to 6 pm depending on the service. Appointments must be made ahead of time to schedule a pick up time. The service is door-to-door. The service is also not available on specified holidays.

Another service available for transportation is the T Mobility Impaired Transportation Service (MITS). It provides door-to-door service but only in Fort Worth, Richland Hills and Blue Mound. For those living close to one of these bus routes, they may call for a pick up to meet them at a designated location close to the route. The individual must then get to the pick up location and wait for the bus to arrive. The requirement for riding on the MITS bus is an application form and a verified disability which results in the issue of a MITS card.

## CHAPTER 3

### METHODOLOGY

The grounded theory approach was used in this study to analyze focus group and interview information to

(1) identify categories and concepts that emerge, and  
(2) link the concepts into substantive and formal theories (Bernard, 2000). Grounded theory is used in many disciplines, in research areas from public health to business administration. In developing theory from data, the researcher produces transcripts from interviews, observations and/or focus groups, identifies potential themes that appear, places data into categories, compares them and describes the concepts. From these relationships or comparisons theoretical models may be developed. The results are then written using quotes from the interviews and groups as well as a summary of concepts and theory.

The IRB approval process was completed and approval received for the research. Criteria were developed to determine guidelines for subject selection. Participation was voluntary. The approved informed consent was reviewed with the participants and each individual was given a copy (see Appendix C).

Qualitative research methods were used to gather the data on the experiences adults with chronic disease or disability have had in obtaining health and social services in greater Fort Worth, Texas. NVIVO 7 software was used to assist in qualitative data analysis. A focus group and individual interviews were used. Participants were recruited from three different apartment

complexes housing primarily low income individuals and families. Those complexes were located in the Hurst, Richland Hills and North Richland Hills areas. The management from each apartment complex was contacted and permission was requested to place flyers and to hold a focus group on their property in a community room. All but one gave permission. This complex provided a list of addresses for the 286 apartments in their complex and a site to hold a focus group. Flyers were mailed to these apartments.

A focus group discussion guide (see Appendix B) was developed and used with questions for the group and with the individual interviews. The group discussion was taped, with one person facilitating the group and another taking notes during the session. All discussion was transcribed from the tape recording verbatim. From those transcriptions evaluation proceeded and comparisons were made. The individual interviews consisted of the same questions as were used in the focus group. During the focus group only first names were used or recorded in order to maintain the confidentiality of the subjects. No names were included in the transcripts resulting from the individual interviews.

Results of the focus group and interviews were categorized using N Vivo 7. Themes were identified and coded and analytic induction used to build causal explanations of the phenomenon found in the process. Once the phenomenon was defined an explanation was proposed. With that proposed explanation each theme was examined to see if the explanation fit. The result was used to address the research questions and then to develop proposals for policy change as indicated. Demographic information was obtained, using no identifiers on the form.

## CHAPTER 4

### RESULTS

#### Study Settings

Flyers to recruit participants were distributed to a total of 572 apartments over the three selected complexes. Half of the apartments (286) had flyers placed on the door and the other half received them via postal service due to restrictions of the complex management (No papers may be posted on apartment doors). Flyers were also posted in the laundry rooms. The two apartment complexes where flyers were passed out by hand received a second flyer on the door two weeks later.

At the first apartment complex six people responded to the flyers and a focus group was scheduled for 5 pm on a Monday night. The time and date were set after speaking with the volunteers and determining the best day/time. The group was to be held in the management office with the permission of the management. On the scheduled day I arrived 30 minutes ahead of the meeting time to find that the owners of the apartment complex had made an unexpected site visit. I was asked to wait to set up until the owners finished meeting with the staff and left. After 15 minutes (and 15 minutes prior to the scheduled meeting) the manager came out and apologized saying that the owner would not allow a meeting to be held there and I would have to cancel. Fortunately I was able to call or meet each participant outside of the office to inform them of what had happened. With no place to meet on the complex grounds and the majority of

the participants having no transportation, I attempted to set individual interviews. Four of the six agreed to individual interviews but the other two withdrew from the study.

Only one person responded from the third apartment complex. When no others called, an attempt was made to do an individual interview with this individual but she declined.

Each of the individual interviews was done in the participant's home. The participant and the interviewer were present at each individual interview. Each interview took an average of one hour. Participants ranged in age from 46 to 63. There were two males and two females.

There were three individuals who responded from the second apartment complex and a focus group was set. The focus group was held at a Baptist Church across the street from the apartment complex where the participants live. The church is well known by those living in the apartment complex as a place to find friendship, social activities, and, sometimes, assistance when there is not enough money to stretch to pay the bills. The focus group consisted of 3 individuals (1 female, 2 male) from the same apartment complex.

### Demographic Characteristics

Demographic data for all seven participants was voluntarily obtained from each participant (table 4) showing 57% (4) were male and 43% (3) female. A copy of the demographic questionnaire is included in Appendix A. Ages ranged from 25 years to the oldest at 63. The majority was married (57%) and 86% reported their race or ethnic group as white with 1 or 14% African American. Annual household income reported was 43% (3) less than \$10,000, 43% from \$10,000 to \$14,999, and 14% \$15,000 to \$24,999. There were 6 of the 7 (86%) who

reported at least a high school education and 2 (29%) of those with some college. One person did not answer the question on education.

**Table 4. Demographic Characteristics of Study Participants**

<b>Gender</b>	<b>Male</b>	<b>4(57%)</b>	<b>Female</b>	<b>3(43%)</b>
<b>Marital Status</b>	<b>Married</b>	<b>4(57%)</b>	<b>Single</b>	<b>3(43%)</b>
<b>Race/Ethnicity</b>				
	<b>White, non-Hispanic</b>	<b>6(86%)</b>		
	<b>African American</b>	<b>1(14%)</b>		
<b>Education Background</b>				
	<b>Completed High School</b>	<b>6(86%)</b>		
	<b>Some college</b>	<b>2(29%)</b>		
	<b>No answer</b>	<b>1(14%)</b>		
<b>Employed</b>				
	<b>Fulltime</b>	<b>0(0%)</b>		
	<b>Part time</b>	<b>2(29%)</b>		
	<b>Unemployed</b>	<b>5(71%)</b>		
<b>Annual income</b>				
	<b>&lt;\$10,000</b>	<b>3(43%)</b>		
	<b>\$10,000 to \$14,000</b>	<b>3(43%)</b>		
	<b>\$15,000 to \$24,000</b>	<b>1(14%)</b>		

Taken from the demographic information provided by the study participants.

Comparing the demographic information with that of Richland Hills, North Richland Hills, Tarrant County and Texas (table 5) we find that the number of females in the study group is less (43%) than that in the averages in the towns, county, and state. There is a lower percentage of whites (86%) compared to the North Richland Hills and Richland Hills, but more than that in both county (79.9%) and state (83.3%). The percentage of blacks in this group is higher (14%) than in the towns by 5-10 times (depending on the city) but slightly higher in the county (13.7%)

and state (11.7%). Education is similar between the subjects and compared areas. Both employment and annual income show the greatest differences other than for an annual income of 15,000-24,999 which is similar. The large variation in employment and other income may be explained by the fact that those in the study group are all individuals with disabilities while those in the other groups contain all individuals both disabled and non disabled.

Table 5. Comparison of Demographic Characteristics of Study Participants with Texas, Tarrant County, Richland Hills & North Richland Hills.

	Study Participants	Richland Hills	N Richland Hills	Tarrant County	Texas
Female	43%	53.8%	50.8%	50.2%	50.2%
Race/Ethnicity					
White	86%	90.4%	88.5%	79.9%	83.3%
Black	14%	1.4%	2.7%	13.7%	11.7%
Education					
High School	86%	84.5%	90.0%	81.3%	75.7%
College	29%	16.9%	26.1%	26.6%	23.2%
Employed	29%	63.5%	74.5%	69.5%	
Annual Income					
< 10,000	43%	5.3%	3.3%	7.2%	
10,000-14,999	43%	6.1%	3.2%	5.0%	
15,000-24,999	<u>14%</u>	15.0%	8.8%	11.6%	

Based on information obtained from the US Census Bureau retrieved on 20 September 2006 from [www.factfinder.census.gov](http://www.factfinder.census.gov).

In order to better describe the participants in this study a short profile is included on each of the seven participants. Individual interview one was a 41 year old married white male with no children. He completed high school. He is unemployed due to back pain. He spends most of his

day in the apartment in bed. He has been attempting to be qualified for disability assistance for the past two years but so far has been denied. His wife works and makes a little money for the family. He receives health care through JPS.

Individual interview two was a 48 year old single African American male with no children. He lives alone but does have several cousins and an aunt living in the area, along with several friends. He is unemployed and has been for approximately two years. He makes a little money by babysitting for neighbors. He has several health problems that were exacerbated by high risk behaviors including smoking and a history of drug abuse. He has been denied disability in the past but is now working on an appeal with the help of the MASH organization.

Individual interview three was a 46 year old single white female. She was the sole help for her terminally ill mother until the mother died three years ago. At that point she moved to this area but quickly was diagnosed with cancer herself. She suffers from mental health issues as well as recovering from surgery and radiation from her cancer. She stated she had been unable to work since before her mother died.

Individual interview four was a 63 year old married white female with three grown children. Her husband also has disabilities but still works part time. She was diagnosed with cancer three years ago and has had surgery, chemotherapy and radiation for her cancer. She has been unable to work since her diagnoses and treatment. She spends most of her day in her apartment. She is the only one of the study group that has successfully applied and been approved for disability.

The first individual in the focus group was a 28 year old married white male. He is a high school graduate with some college. He has work experience in sales but currently does not work.

He was displaced in the Katrina hurricane from Louisiana where he received welfare assistance. He and his family came to the Fort Worth area on their own and stayed with friends instead of coming through the official evacuation route. Because of that, they were unable to qualify for assistance through FEMA (according to the participant).

The second individual in the focus group was a 51 year old single white male. He lives alone in his apartment and has few friends in the area. He has been unable to work for two years. He does not like doctors and is more trustful of herbal medicine. He rarely goes to the doctor but prefers to "read up on" his problems and try to find an herbal treatment. Because he rarely goes to the doctor, he has little documentation of his medical condition so has been denied for disability because of lack of documentation.

The final focus group participant was a 25 year old married white female with one child age 2 years. She works part time as a telemarketer in the local area. She has medical services for her daughter but not herself or her husband. Her husband is unable to work so that she is the wage earner in the family.

### Key Informant Interview

A key informant interview (see Appendix D) was completed with an individual from the Medical Advocacy Services for Healthcare, Inc. (MASH). MASH is an organization that provides advocacy services to individuals going through screening and processing for public health benefits such as SSI disability and Medicaid. The interview took place in the office of the agency and lasted an hour and a half. Information from this key informant is included in the narrative to include an insight into the agency process.

The key informant interview, as previously stated, was conducted at the MASH offices in Fort Worth, Texas. The individual interviewed has worked for MASH for 9 years. She currently works as a trainer of other advocates while maintaining her own caseload of clients. She is one of a few staff at MASH authorized to attend appeal court cases for denial of benefits. Information received from the key informant interview is included in the following paragraphs.

MASH is a for profit organization founded in 1988 by a lawyer who saw a need in the community. MASH was founded to provide eligibility services to healthcare providers and assistance to clients trying to complete the application process for health and social services. MASH works on a referral basis from local hospitals and health care providers. MASH receives a fee from these hospitals or providers to work with the referred clients. Staff from MASH, called advocates, routinely goes to John Peter Smith Hospital (JPS) to review patient records to find those with frequent hospitalizations and/or disabling conditions to determine whether MASH could be beneficial to that patient in completion of the application process. MASH also receives referrals from other hospitals and health care providers but as JPS is the Tarrant County hospital, the majority of referrals come from that site.

From the MASH website we find that MASH:

“enjoys relationships with state social/human service agencies to help screen and process targeted individuals for government assistance. Everyday, healthcare organizations face the problem of having too few resources to serve patient needs on all levels -- needs that go beyond urgent medical care. Consider self-pay patients who commonly need assistance working through the complex applications processes for government healthcare assistance programs. Because the healthcare organization's resources are limited, these

patients often become overwhelmed and frustrated, and they surrender their pursuit for program eligibility, leaving the hospital uncompensated for the care and services provided. From a business office standpoint, these accounts are difficult if not impossible to collect and typically result in bad debt write-off. Each year, the healthcare industry loses billions of dollars due to uncompensated care.” (MASH, August 2006)

In helping its clients qualify for government assistance, MASH also helps healthcare organizations recover revenue they might otherwise never see. At the same time, however, MASH always remains the advocate for the client.

The advocates fill out all the paperwork and will even pick up the client and take them to appointments. They will work for the client by talking with staff from other agencies to determine problems and the solution to those problems. If the application results in a denial, the advocate will work for the client in resubmitting the application, speaking with the agency staff to determine what needs to be done, and then will go with the client to appeals court if necessary. While the application is going through the evaluation process (which can take a minimum of 5 months) the advocate contacts the client at least once a month and also checks with the agency to find out the status. If a case goes to appeals, each level of appeal takes 60 days. If an appeal goes up to the Federal District Court, the client must have their own lawyer at that point. An appeal at that level can take up to months. Once a client is accepted by MASH, they can continue unless they 1) go back to work or 2) refuse to give up drugs.

While MASH works strictly on a referral basis, other patients without a referral from a hospital or clinician found out about the success of the MASH program and began to contact MASH on their own. In answer to this problem, a sister company was formed in 1998 called Disability Help, Inc.

This company provides the same assistance in the complex application process for SSI and/or Social Security Disability benefits.

In the Fort Worth area MASH has 20 caseworkers or advocates. It is not unusual for each to receive 10 referrals a day. Sometimes the patient is still in the hospital but often he/she has been discharged and must be seen at home. MASH has offices across the United States with its corporate office in Fort Worth.

When asked about whether MASH advocates provide any other information to the clients the response was that information regarding other services is provided when needed such as the location of shelters and food pantries (a lot of the clients are indigent). They also provide information about where medication is available. The advocates are quick to say that they are not social workers but they do try to provide as much information as possible.

MASH has no contracts with other agencies but they do maintain contact and a good working relationship. As previously stated, the key informant reported that MASH advocates maintain at least monthly contact with their clients while the process of application for services or appeal is ongoing. Also during that time advocates make frequent contact with the agencies involved with the application to check status and any problems existing with the required forms and documentation. They find that most agencies are helpful when contacted by the advocate.

MASH has found several problems while working with their population. They have found that drugs and alcohol abuse are a significant problem with this group of people. Depression is another major problem with a lot of their clients. Added to that is inadequate medical care, because of the numbers of people with no insurance and an inability to self-pay. This paints a fairly dismal picture for this population.

## Themes in Focus Group and Interview Responses

In the analysis of the focus group and individual interviews five major themes emerged: health issues, access or obtaining care, interactions with providers, obtaining medication, and transportation (table 6). A review of these themes and the particular responses of participants in these areas highlight the need for policy change.

Table 6 shows the breakdown of the five major themes along with the number of respondent sources and the number of references to the particular theme. All but the theme interaction with providers is broken into sub themes. Each of the themes and sub themes will be discussed.

**Table 6. Themes of Issues Identified By Participant Responses**

	<u>Sources</u>	<u>References</u>
<b>Health Issues</b>		
General Health	5	10
Health problems *	5	12
<b>Access/Obtaining Care</b>		
Ability to obtain care	5	17
Follow-up care	5	6
Health Information	5	6
Location for health care	5	7
United Way Help Line	5	5
Assistance obtaining services	5	10
Ability to work	5	10
Appeals for denial of services	4	6
Services**	5	14
Dental	1	4
Glasses	1	2
<b>Interaction with providers</b>	5	14
<b>Medication</b>		
Prescription	5	12
Nonprescription	5	7
<b>Transportation</b>		
Usual method	5	8
Public transportation use	5	12

Source: NVIVO 7 output of transcripts from focus groups and individual interviews.

\* Identified health problems included (no specific order): gouty arthritis, pilonidal cyst, bipolar disorder, panic attacks, allergies, depression, asthma, Insulin dependent Diabetes, degenerative disk spine, hypertension, "kidney trouble", "heart trouble", thyroid cancer, low thyroid, breast cancer.

\*\* SSI, Food Stamps

## General Health/ Health Problems

The first theme to review is that of the health issues of participants. Responses when asked about their general health ranged from poor to pretty good, however, the individual reporting “pretty good” qualified the response by saying “Mine is, well, it has been from down right poor, to middle, to barely able to function.” Of those reporting “poor”, one replied “I’m sick a lot. I have trouble getting out of bed to see the doctor.”

Mental health issues were identified in four of the seven individuals. One reported a diagnosis of bipolar disorder diagnosed at age 9. He also stated he “stopped taking medication at age 13 because I chose a different route of alcohol and drugs and I just stopped taking them.” He does not see doctors now unless through an emergency room so he is on no prescription medication and states he has “bad mood swings and temper.” This individual is also a heavy smoker even though he has been told that smoking is dangerous given his health condition.

Cancer has affected two participants with both having had surgery, chemotherapy, and/or radiation treatments. The individual with thyroid cancer also deals with depression that is exacerbated when it is necessary that she be taken off her thyroid medication in order to screen for recurrence of the cancer. She may be off her thyroid medications for 2-3 months during which time she may become debilitated and unable to do routine things such as go to the grocery store.

Another participant focused on a pilonidal cyst he has had for 20 years reaching back to when he was in the military, and gouty arthritis. He stated that doctors over the years have refused to treat the pilonial cyst until recently. The “gouty” arthritis “just wiped me out. It got so bad that I could hardly walk ten feet.”

Two of the participants came to the area following Hurricane Katrina a year ago. Since they came on their own and stayed with family when they arrived, they did not receive Katrina assistance through FEMA. They had welfare in Louisiana but are still applying here. One of these two has asthma, other allergies, and depression that were affected by certain other medications given her for a panic attack she had last year. Because she is not yet certified as disabled and has no insurance for medical care, she has had no one to manage her diagnoses other than emergency room visits when necessary.

#### Access/Obtaining Care

When asked what they did over the past year when they were sick or had a health problem the responses were varied. One individual went to the emergency room for serious complaints or “other than that I would just deal with it myself.” Another went to “herbal type stuff” saying “I just do not have the money for it. It’s just one of those kinds of things.” One participant even offered to help others in the focus group with manic depression saying, “I have found out how to take care of mine (manic depression) believe it or not. It’s a very simple method. I just happened to find it in a store and I just opened it up and read it, tried what it said to do and it really worked. It was acupuncture.”

**Table 7. Responses to the question: When you were sick or had a problem over the last year what did you usually do?**

1. "If it was serious I would go to the emergency room."
  2. "Deal with it myself."
  3. "I would usually research it."
  4. Self treat with herbs.
  5. Acupuncture, self administered.
  6. John Peter Smith clinic.
  7. "I took over the counter medication, massage, ice packs, and heat. The problem never got any better."
  8. "A lot of time they put me in the hospital."
- 

Source: Focus group and interview responses.

One recurring theme expressed regarding visits for obtaining care is the need for personal assistance. "Sometimes I just don't have the energy to go anywhere. I can't drive myself when I am like this so if I don't have someone who can drive me, I can't go." Another stated "The only way I can go to the doctor is on the bus unless someone can take me. I don't have insurance and no money to pay so I have to wait until it's bad. One individual said, "A lot of time they put me in the hospital."

Follow up care is another difficulty. If the person goes to the emergency room due to a serious illness he/she is usually told to go for a follow up visit. The urgent care visit was only a beginning of a course of treatment for some illnesses. Only so much medication is given with the plan of getting the person in to a primary care provider. One participant reported an emergency

room visit where he received medication for an infection. He was told to return in a couple of weeks. "I had no way to get there and no way to pay them so I took the medicine they gave me, it went away, and that's all I did." If the individual is able to make a follow up appointment it may be an all day process between a bus ride to the clinic, waiting to see the provider, and returning via a bus. "If they want me to come back early (in the morning) I can't make it unless I can find someone with a car to give me a ride."

One participant told of an innovative way a therapist (mental health) has of working with her clients. "I talk with her on the phone 2 times a week." That seems to work in this situation and with this client. Another individual reported being seen for follow up at the same location-JPS but said it "feels like the doctor did not listen. Like talking to a cat, the cat will act like they were ignoring you."

Health information is another access problem for some. There was no consistent method of communicating health information to participants. All of those participants had at least a high school education with some reporting "some college." There were varying degrees of competence in gathering information. Unfortunately, very little of it seems to have originated with the health care provider. Only one person stated that JPS (or their health care provider) handed out health information and that statement ("Sometimes JPS gives me some information.") did not seem very consistent. The remainder ranged from the radio ("I'm not good at surfing the web. I'm in bed most of the time.") to sometimes books, internet and magazines, to the library ("I used to go to the library, get all the books, read about it and research, highlight and make notes."). Of the participants only 1 had ever heard of the United Way Help Line. The one

who was familiar with the United Way telephone line had called the number before and found the information helpful.

The only real assistance any of the participants mentioned was the nearby Baptist church and the counseling center located near the church. The type of assistance included the use of the telephone to make calls for resources, a list maintained of some services within the community and occasionally some bus passes. The church has occasionally helped with a few dollars to help make rent or buy some groceries. Otherwise, there is no one that the participants depend on to help unless there is family or friends nearby.

The majority of the group (71%) does not work. The two that do work are employed in telephone work as a telemarketer and registering individuals for insurance. Both jobs are less than part time (20 hours per week). The other participants have been unemployed at least two years with one reporting he "slipped and fell at work in 1998 but didn't report it". One participant had stayed at home to help care for her mother who had cancer until she died approximately 3 years ago only to find out after moving to this area away from everyone she knew, that she had cancer herself. Being out of the job market over a long period of time makes getting back in much more difficult.

Not all individuals with a disability are identified as disabled through the social system. Of the participants in this study only one of the group had successfully completed the application process and was receiving SSI. This individual attributed that success to having good documentation and a diagnosis of metastatic cancer. One individual stated, "I've been denied for SSI because they felt my injury was not severe enough to keep me from working. There was not enough medical evidence collected on my back to show the need." One other had tried to file for

SSI but “they will not really talk to me because I do not go to the doctor at all and they say I don’t have enough documentation.”

One individual applied in May of this year and at the time of the focus group (in June) had not received results as yet. When asked how he had started the application process he stated that he was contacted by letter with information to contact Social Security if he was disabled. Others started their application process either by phone or going to the office.

Food stamps are a different application process. An individual or family may initially be approved for food stamps only to be denied later because of lack of documentation. “The problem with these services is that I have to go to different offices. I have to take the bus but it takes a long time and irritates my back so I can’t stand or walk around.” One individual had initially been approved but “I got food stamps for awhile but now they won’t give them to me because I don’t have the documentation I need.” Another individual attempted to start the process to apply for food stamps and SSI on the phone but because of a speech impediment he had difficulty making himself understood so had to go in person. (It is difficult to understand this individual in person so attempting to take information from him over the phone would be even more difficult.)

For those who apply and are denied there is the appeal process. “I’ve tried to appeal but they just tell me I don’t have the documentation. They don’t want to talk to me any more.” Another stated they had “tried to appeal several times but always denied.” Most were uncertain about the process itself. Said one individual, “I don’t understand it and just can’t face it right now.” None of them have had assistance by any office or agency in making an appeal. Since the process is long and involved the individual usually gives up along the way.

Another problem area in access or obtaining care is in finding dental and eye glass services for this population. "Medicaid will take care of dental for children but not for adults," said one participant. Another mentioned dental services in Arlington "that you can go to if you are unemployed or do not have money," but then added that these services were for Arlington residents only. There are some services available by referral from JPS but only at a reduced fee, not free. One participant stated he had called Tarrant County Health Department but was told that nothing was available. One individual summed it up by saying "if you all keep doing me like this, you are going to have to knock all my teeth out."

For eye care the same problem exists. No one in the group was aware of services such as Prevent Blindness Texas who provides eye screening and services through local optometrists. One participant said, "I've kept the same prescription for 32 years." Another, "I get severe headaches or migraines every day."

#### Interaction with Provider

The participants' view of their interactions with health care providers seems to generally be a feeling that the provider does not listen to them. Before starting this research, the author accompanied an individual to JPS for a visit to his health care provider to discuss his difficulty in being compliant with prescribed medication (due to lack of money to pay) and to attempt to obtain a disability statement in order to be approved for food stamps that had recently been denied. While waiting in the examination room with the client for the staff to complete some assessments we had requested, the client turned to me and said, "If you weren't here they wouldn't be doing all this."

Participants in this study made comments such as “the doctor refused to listen to me,” or “He refused to look at my back until my wife insisted.” The participant said, “I was out of work, having trouble with just about everything from getting dressed to getting around the apartment. I was at the doctor’s office about my diabetes and he (doctor) said ‘let’s focus on one thing and worry about the rest later. But later never happened.’” When the participants were asked if their primary care provider understood about their disability, the response was no the provider did not understand. “No, he doesn’t understand about back pain. He seems uninterested. I feel really helpless when I see him.” One participant had trouble with low thyroid levels for years and had been on medication. She stated, “Every time I have to change doctors they test my thyroid and want to change the dose or stop it altogether. They won’t listen me.” Another response, “I don’t think the doctor looks at me as a person, just as a disease. I dread coming down with some other disease that he will ignore and I will die.” It’s difficult to have the time needed with the provider.

## Medication

With the costs of medicine, those with no or little income and no insurance have a difficult time getting the medication they need. The participants had several comments about medications. “When I got my eardrops for my ears I used my last few dollars I had on hand and bought that.” Another had been seen in the emergency room but did not have money to buy his prescription. “The doctor paid for it. If it was not for him I could not have got it all.” Another needed medication for her daughter before the daughter had Medicaid. “I talked to Barbara (from the nearby Baptist church) and the church helped me.” Another asks for free samples or asks for help from the church. “It keeps getting worse. I have to go into the hospital pretty often because

my blood pressure goes up. They say I am not taking my medication like I should but I can't take it if I don't have money to buy it. It's gotten so bad that I have to go to dialysis now." This individual reported that after being admitted to the hospital a few days to get his blood pressure down they discharge him with prescriptions. "How am I going to get them (filled) without money?" Only one individual had no trouble with filling prescriptions. He said "JPS will fill my prescriptions even without my co-pay." This points out a conflict showing one person having no trouble getting assistance from the same pharmacy system from which another person can only gain assistance once a year.

It is not always prescription medication that is the problem. More medication now has been reclassified as "over-the-counter" medication or medication that previously required a physician order that now can be purchased without an order. That causes complications even for those with insurance since over-the-counter medication usually will not be covered by insurance. About 43% of the participants responded that they had trouble getting nonprescription medication when their doctor advised them to take it. "I did not have any cough medicine and I asked them (at the clinic) if they had any I could have. They had some samples." Another participant is participating in a study for seborrheic dermatitis and receives medication free. And another reports a problem, "Yes, a medicine for heartburn. I couldn't afford it. My heartburn just keeps getting worse."

### Transportation

The last theme identified by the participants is difficulty with transportation. As one individual said, "We will all be on bare feet." All of the participants rely on the public bus,

family, friends, or they walk. One individual has a car but is unable to drive when she is off of her medication which is a period of about 2-3 months. As she says, "It's hard. I need some help."

Experience with the public transportation system is mostly time consuming and unpleasant. One individual describes it fairly well: "My experience with public transportation is bad. It's time consuming. We don't (have a) regular bus service here but have to call Rider Request. You have to make an appointment for a pickup and then wait at a place until they show up." Another says, "It is whenever they can get there. I might have to wait for an hour to an hour and a half sometimes to get a bus." Another describes their process, "He (husband) has to walk to the Counseling Center to get some free bus passes and make a phone call for the bus. Then walk over to the place to wait to get picked up." Once the individual completes their business or appointment they must call for a pick up and the whole thing begins again in reverse. Physical health determines whether a person can do what it takes to ride the bus. "I have a problem using the bus because it takes too long and the riding irritates my back so I can't walk." One participant mentioned interactions with the bus drivers. "The drivers are not very friendly or helpful. Once they picked me up but were going the wrong way and I was told I would have to make another trip back the same way and pay extra."

## CHAPTER 5

### CONCLUSIONS AND RECOMMENDATIONS

#### Summary

Poverty level adults with disabilities between the ages of 18 and 69 years exist in large numbers in the United States. Despite years of success and improvements in the area of disability (DeJong & Frieden, 2002), this group falls behind in many areas of life in the U.S., especially in employment and health care. Persons with disabilities are more likely to live in households with a combined annual income below \$15,000 and require support (NOD, 2000). This dissertation examined the difficulties individuals, below the poverty level, with chronic disease or disability, face when attempting to access health care and social services. The purpose was to better understand these barriers so that implication for policy improvements might be determined.

The sample included adults with disabilities between the ages of 25 and 63 years. There were a total of 7 individuals included through focus group participation (3) or individual interviews (4). There were 4 males and 3 females. Participants in this study live in apartment complexes in small towns in the Fort Worth, Texas area. The focus group was held in a local church across the street from the apartment complex where group participants reside. Individual interviews took place in the home of those interviewed.

This was a qualitative study using the grounded theory approach to analyze information gathered through focus group and individual interviews. Results were later organized into themes and categories. In this way, the researcher was able to summarize barriers to access of health and

social services for this particular group.

## Discussion

Through first hand observation while assisting individuals with disabilities in their quest to work through the gamut of red tape, this author has seen just some of the difficulties faced while applying for assistance. There is no one door to go through where one person can advise and assist in the application process. In order to complete the process one has to know what questions to ask and from whom to ask them. Only after a great deal of time and experience can the individual finally 'happen on' what they need to know to be successful in the process. If this same individual has no phone, no money for transportation, or, as in the case with this sample group, has very limited transportation resources available, and is physically disabled or depleted due to a chronic condition; the obstacles may seem to be insurmountable so that they give up.

This group of study participants helped, through their experiences, identifies themes of issues that can serve as barriers to their successful access to health and social services. It is important to explore those themes in light of looking at a "lessons learned' approach to policy change.

Individuals with disabilities often have several health issues to deal with, one of them frequently a mental health issue. We saw in the literature that people with disabilities have a higher risk of developing secondary health conditions, decreased independence and an increased psychological stress (Scheer, Kroll, Neri, & Beatty, 2003). This study shows a feeling of helplessness and a lack of control over their situation and environment. Their inability to get necessary treatment for chronic health conditions can lead to an increased use of emergency

services with more serious conditions that might have been avoided with better access to timely health care. It also may lead to frequent hospitalizations. This is also seen in the literature (Robert Wood Johnson, 2004).

Under the theme of Access/Obtaining Care, study participants had various ways of coping with illness which usually did not include a trip to the doctor. Health information seemed “hit or miss” with very little information routinely provided by the health system. The ability to gather health information on their condition seems to fall primarily on the individual and is dependent on their ability to search it out whether on the internet (if they have access), library, or radio/TV. For an individual with no family there is very little recourse seen for assistance. Even the United Way Help Line (often a wealth of information) was familiar to only one of the seven. There seemed to be no one place that the individuals could go, other than a local church, to get information on services available such as eye screenings and help with glasses, prescription assistance, employment training and more. At the end of the focus group and interviews resource information was provided to participants giving phone numbers, internet sites and more.

If there are friends with transportation, the individual may be able to get help in getting to appointments. But that may be difficult since appointments often must be made weeks in advance and, if cancelled, may be another long wait until another can be made.

The ability to follow up treatment as recommended when they are seen is dependent on the ability to pay for the visit and get there. Routine preventive care is basically nonexistent for these persons, which falls in line with literature regarding preventive health screenings and saying that women with disabilities are less likely to have these services (Lezonni, McCarthy, & Davis, 2001).

The majority of this group was unemployed but the question can be asked, has any effort been made to help provide training or support to aid them back into the job market? A Work Force Solutions office is located in the surrounding area but, because of lack of bus service, there is no way to get to the site. Could at least some of this group be brought back into the work force with some training and assistance (sheltered workshop programs)?

Individuals filing for social services (such as food stamps, SSI) must go to different offices, fill out multiple , often confusing forms, and deal with often conflicting information with little to no help along the way. Some may benefit from groups such as MASH to help with the process but that is not consistent. If paperwork is not done completely and appropriately, the application may be delayed or denied. Often there may be the “catch 22” of an inability to get medical care because of lack of funds but an inability to get approved because of a lack of medical documentation. For those denied there is the long, tedious appeal process. It is no wonder that many give up along the way.

The interaction with health care providers is another recurrent theme seen in this study. Often an individual will see a different provider with each visit, especially if their “routine” health care is the emergency room. This makes continuity of care difficult for both provider and patient. In order to see the large numbers of patients coming through clinics such as at JPS, providers are often under time restraints for patient visits. This is often the case in many doctor offices where the idea of a 15 minute routine visit may be the norm. With a person with a chronic disability this may not be sufficient as evidenced by the comments of wanting to focus on one thing. At a recent visit to my health care provider (not at JPS) I noted a sign in the examination room that stated “We care about all of your health care needs and will be glad to schedule another

appointment to discuss any other health problems you may have but please concentrate discussion today on the condition for which the appointment was scheduled.” Imagine the individual with a disability who has waited for days for their scheduled appointment, has spent hours getting to the clinic via a bus (making several changes), is worried about making their co pay for the visit, and does not have any extra money for the medicine they know they will probably need. On top of that, he/she is now told that he/she will have to come back again to see probably another doctor who will spend most of the allotted time going over the chart to try to catch up with the numerous health issues. This tends to cause these individuals to be frustrated with the system.

Medications are another theme seen in this study. As seen in the study by Nelson et al. (1997), 32% of those surveyed reported difficulty obtaining medication. This is confirmed in this present study. Participants reported an inability to pay for both prescription and non prescription medications. As medications are usually a vital part of treatment, this is a serious problem that this population faces. With more prescription medications being placed over-the-counter, we see this as increasing in difficulty.

Finally, transportation actually weaves a thread through all the themes. It is a critical part of this whole process. We have seen with this group a dependence on transportation in order to get to health care, application for social services, normal activities of daily living such as grocery shopping, work. Transportation may be by private vehicle, public transport, friend, family or, as the military say, LPE (leather personnel carrier)- your boots (or feet). In this particular group of apartment complexes public transportation is limited to a bus that must be called, and then met at a specified location, and then only goes toward Fort Worth, not around the local area. The

individual must be able to physically ride the bus, often for several hours. If a person does work he/she must plan on missing a day (possibly without pay) in order to make an appointment. This population often needs more assistance than most in making sure he/she is on the correct bus and just the mechanics of making the trip so need a helpful driver who can and will assist.

Schriner and Scotch (2001) identify the social environment as a cause for social isolation and dependency for individuals with disabilities. While improvements have been made in such areas as access for wheelchairs in buildings and public transportation, communication devises for the blind and hearing impaired, there remain many areas of consideration to truly make accessible to all disabled individuals basic services and the ability to be as independent as possible.

One of the difficulties of providing services to those with disabilities is that, as stated by Schriner and Scotch (2001), there is a diversity of disabling conditions and a variety of coping strategies used by individuals who have them that requires a need to tailor assistance to the individual involved. Further, "The diversity of physical and mental impairments and their consequences for function require recognition of different categories of disabilities (e.g., blindness, deafness, mobility, mental, emotional.)" (Schriner & Scotch, 2001). In addition, since individuals with disabilities often change in their requirements for assistance over time (requiring more or less) periodic reevaluations are required to reflect changes in the individual's impairment or changes in the environment. Leaving this to the client to initiate or to various offices to monitor on a prescribed time frame allows for confusion, inability to obtain vital services, and often, allows to person with disabilities to "fall through the cracks."

## Limitations

The unavoidable cancellation of one focus group which reduced the number of respondents may affect the generalibility of the study. Another possible limitation to this study was the fact that the sample was taken from three apartment complexes within the same county. This may cause difficulty in generalizing the results across the state or nation but this pilot study provides insight into problems that other persons in locations with similar characteristics face in access to care.

If given another opportunity to do this research, it would be important to would broaden the base from which subjects are sought. In addition to seeking apartment complexes where the majority of residents are lower or poverty income level, an attempt should be made to reach individuals through a variety of locations including area churches and community centers. It would also be helpful to speak to groups at these locations to get the attention needed to stimulate interest in the study and the support of influential individuals respected by the target group.

## Conclusion

Through this study the researcher was able to identify specific barriers or issues that low-income disabled adults encounters while applying for and accessing services. The issues may be divided into five themes: Health issues, Access/Obtaining care, Interactions with providers, Medication, and Transportation. Each of these themes is a major obstacle in itself, but if several are combined, they pose both an intimidating and frustrating barrier. Because of a delay in care and treatment due to these obstacles we see worsened conditions that take more time and

resources then might otherwise be required. This poses more of a threat to the health and wellbeing of the individual with disabilities but also increases health care costs and demands on the system.

### **Recommendations for Policy and Practice**

The first, most obvious recommendation would be to have one service entry point for those with disabilities. Transportation must be available to get individuals to the site. This site could be co-located with an already existing facility or office such as a clinic or food stamp office. At this point the individual would meet with a trained staff person who would do an intake interview, review with the individual their needs, and assist with forms to begin the application process. Any appointments, such as disability physical, food stamp appointment, registration for JPS services, should be set at that time or forms completed to be mailed if possible.

At that point there should be detailed (easy to read and understand) information about the different services, what the process entails and what to expect. An orientation program should be developed that will be available for both a group setting or available in video for viewing for those who are unable to make an organized group meeting. Such a program could be recorded with a live question and answer portion at the end. Attendance at either the group or individual orientation should be mandatory. Every effort should be made to combine as many appointments as possible to reduce the amount of time away from work, if employed, and travel time.

Bus tokens should be available or other assistance for transportation needs at this location. Connection with food banks, used clothing and household items locations, and sites for

medication assistance should be offered. Information on services such as self help classes and child care should be available.

Work screening should be a part of this process to determine if the individual has skills that could be used in a job or if work training would be appropriate. Jobs might be available that would be part time, flex time or work from home.

Discharge planning from hospital admissions should include a statement on ability to pay for medications and patients should be discharged with a one month supply of their medications along with their next medical appointment scheduled.

Lastly, communities should be required to establish transportation service within their communities. This could be in conjunction with other communities especially in areas where several towns or cities are close together.

Today, many churches are either beginning to develop programs or have established programs for people in the community. It is surprising how many volunteers are available through these groups. They go in to action during disasters such as Katrina or maintain an ongoing mission with food and clothing or medicine for those in need. Establishing a coordinated community effort could help to address some of these issues and could make a real difference in the lives of these individuals, not only those with disabilities but others with similar access issues.

More research is needed in this area in order to determine whether the issues identified here are indeed similar in other locations. Hopefully with more time and perhaps more researchers to conduct this study a larger sample could be recruited. This would enhance the importance of this study by replicating the outcome of the issues in this study and perhaps adding

other issues not identified here. Additional work in this area would lend credence to the study and more strength to the need for policy change.

The military has been working to streamline services for several years. One effort was in establishing a “one stop shop” in processing for soldiers reporting to a new assignment. The intent was to place all stations within a designated area where the soldier could in process all services within a confined area saving time and effort for this process and ensuring that needs were identified and less time was spent away from the new duty position. Service members with families with special needs could be identified so that services were provided, and soldiers needing to be scheduled for preventive care were identified to make sure that the soldier was ready to do his/her job.

Another way the military has attempted to cut costs is in identifying duplicated services in locations where there may be more than one military medical center due to other military services (Army, Air Force, Navy) located in the same area. An example is Bethesda Naval Medical Center and Walter Reed Army Medical Center both located in the Washington, DC area. Several years ago both hospitals identified duplicate services, such as labor and delivery and mental health, and combined to have mental health inpatient services at one location and labor and delivery at the other. Of course, an advantage the military has over the civilian sector is an efficient command and control structure over all its services.

### Barriers to recommendations

Access to care for persons with disabilities has improved only marginally over the years since 1987 (DeJong, 1997) while spending on the non elderly disabled Medicaid beneficiaries

has risen quicker in most states than on the elderly (Valadeck, 2003). This indicates an increasing need by this population for medical care. The recommendations made by this study are not new, so what are the barriers to making change happen? One barrier may be siloed funds or those funds identified for a specific task (such as transportation) in a specific organization. An example would be transportation assets available for individuals with cerebral palsy but, even though money is available, not authorized for disabled individuals with other conditions. This can cause duplication of services and an increase in spending due to the need for staff, facilities, equipment, and supplies for several groups offering the same service.

Another barrier for the recommendations is that there are many different advocacy groups that lobby for their specialty. Some of these groups are more powerful than others. The ones with a large advocacy group are more likely to be heard and receive funding but then again this is funding to be used only for that specific group and not the overall disabled. Those groups that are not as “popular” remain more or less overlooked.

Without collaboration among all the disability groups, making change will be a difficult process. Without change it is more likely that we will continue to see slow to no process for this special group.

## **APPENDIX A**

## DEMOGRAPHIC INFORMATION

Completion of this form is completely voluntary.

Please DO NOT include your name.

1. What is your sex? **Circle one** male female
2. What is your marital status? **Circle one**  
Married Single Separated Divorced Widowed
3. What was your age at your last birthday? \_\_\_\_\_
4. What would you say is your race or ethnic group? **Circle one**  
White African American Hispanic Asian Other
5. What language is spoken most in your home? **Circle one**  
English Spanish Other
6. What is the last grade of school you completed? \_\_\_\_\_
7. What is your occupation? \_\_\_\_\_
8. What is your annual household income? **Circle one**  
Less than \$10,000  
\$10,000 to \$14,999  
\$15,000 to \$24,999  
\$25,000 to \$34,999  
\$35,000 to \$49,999  
\$50,000 to \$74,999  
\$75,000 to \$99,999

## APPENDIX B

## **Focus Group Guide**

### **Access to Health and Social Services for Poverty Level Adults with Chronic Disease or Disability**

#### **INTRODUCTION**

Thank you for coming here today to be in this focus group. My name is \_\_\_\_\_. I am a student in the doctoral program at the University of North Texas Health Science Center School of Public Health. I will be the moderator for this group. This group will last approximately one and a half hours. In this group discussion we will be discussing your experiences with getting registered and enrolled for health and social services related to your disability. This may be anything from your routine health care to food stamps or housing. We are interested in the good experiences as well as any problems you have had. There is no right or wrong answers to these questions. We would like you to answer the questions just based on your own experiences, not the experiences of other people in your family or of your friends—just your experiences. We have given each of you a pad of paper and a pencil that you can use if you want to jot down ideas that you have so you will not forget them.

Now that we are ready to get started, we would like to begin by having each of you introduce yourselves to the group and tell us something about yourself. In this group we will just use our first names. Let me remind you that anything you say during our group is confidential and no names are being written down in our records that could identify you. Your participation in this group is voluntary and you are not required to answer any questions. (GO AROUND THE TABLE AND LET PARTICIPANTS INTRODUCE THEMSELVES. THEN ASK THE RECORDING ASSISTANT TO INTRODUCE HERSELF.)

Now that we are acquainted, I would like to ask you if we can tape record this discussion so that we do not miss any of the points that you make. We will destroy the tape once we have written our summary of our discussion today and no one other than the moderator will hear the tape. (WITH PERMISSION, START TAPE.)

Now, let's start with a discussion of your health.

#### **1. HEALTH**

How would each of you describe your health? Would you say it was excellent, pretty good, fair or poor?

**What problems do you have with your health?**

**In the past year, what would you say has been your major health problems?**

## **2. USE OF DOCTORS AND HEALTH CLINICS**

### **a. Usual experience**

**In the past year, when you were sick or had a problem with your health, what did you usually do? Where did you go?**

- Did you see a doctor for this problem
- Go to an ER
- Buy over the counter medicine
- See another kind of health care provider? (EXAMPLES OF OTHER CARE PROVIDERS MAY BE A CHIROPRACTOR, CURANDERO, FAITH HEALER, ACUPUNCTURE)

### **b. Not able to see a doctor when needed**

**In the past year, did any of you ever feel like you needed to see a doctor for a health problem but were not able to do so? Can you tell us about that experience?**

- What was the problem?
- Why couldn't you see a doctor?
- Were you ever able to see a doctor for this problem?
- If you did not see a doctor, did you see some other health practitioner?

**What happened as a result of that experience?**

- Did your health problems get better or worse?

### **c. Follow up care**

**If you were seen for a health problem, did you receive follow up care? Can you tell us where you received that follow up care? What were your experiences with follow up care?**

#### **d. Regular health care**

Do any of you have a regular health care provider? Where do you normally get your health care?

- Does your doctor ask about you about your overall health?
- Does your doctor understand any special health or disability problem you have?
- Where do you normally get your health information?
  - Doctor's office
  - Internet
  - Books
  - Magazines
  - Family
  - Other
- Are you familiar with the United Way Help Line?

#### **3. Assistance**

Do any of you have people to assist you either at home or with getting health or social services?

- Home health
- Social worker
- An advocate
- Case worker
- Family member
- Friend

#### **4. PRESCRIPTION MEDICINES**

In the past year, did any of you ever need to get a prescription medicine for a health problem but were not able to get this medicine? Can you tell us about that experience?

- What was the problem?
- Why couldn't you get the medicine?

What happened as a result of that experience?

- Did your health problem get better or worse?

Have you been told by your doctor to take a medicine that may be purchased without a prescription but were not able to purchase it?

- Why couldn't you get the medicine?

What happened as a result of that experience?

- Did your health problem get better or worse?

## **5. DISABILITY ASSISTANCE**

Are any of you currently identified as medically disabled?

- How long have you been disabled?
- Are you able to work?
- What type of work do you do?
- Do any of you not work for fear of losing benefits?

Have any of you applied for services such as food stamps and SSDI (Social Security Disability Insurance)? Can you tell us a little about your experiences with this system?

- Have you been approved for any of these services?
- What problems have you encountered with this process?
- How did you get your information and start your application?
  - Telephone
  - Computer
  - Went to the office

- If denied for any services, can you tell us why?
- If denied for any services, did you attempt to appeal that decision?
  - If no, why? (Didn't understand the appeal process or didn't know about it?)

## **6. TRANSPORTATION**

How do you get to appointments? Grocery store?

- Drive a car
- Walk
- Bus
- Taxi

Have you used public transportation? Can you tell us about your experiences with this system?

## **7. OTHER ISSUES**

At this point we would like to ask if there is anything else related to your ability to get health care or services that you would like to bring up?

## **8. SUMMARY**

Now I would like to summarize the major points from the notes the assistant moderator took during our discussion today. As I summarize I will ask the assistant moderator to list the main points on butcher block paper. We will then place the sheets of paper up so that you can see them. Please listen to the summary and look at the lists so that you can tell us if it is correct or if

there are changes or additions that we need to make.

Is that an accurate summary of what you have said today? Are there any corrections that we need to make? Is there anything you would like to add?

Before we close I would like to ask you to complete an information card. Please notice it does not ask for your name. I would also like to ask if any of you would be willing to participate in an individual interview to discuss more in depth some of the things were talked about today. We will meet for approximately 30 minutes. Those of you who are willing to meet individually please wait after the close of the group and we will set a time.

Thank you for your participation in this project.

## **APPENDIX C**

# **INFORMED CONSENT AUTHORIZATION TO PARTICIPATE IN A RESEARCH PROJECT**

**TITLE:** ACCESS TO HEALTH AND SOCIAL SERVICES FOR POVERTY LEVEL  
ADULTS WITH CHRONIC DISEASE or DISABILITY

## **I. STUDY PURPOSE**

The purpose of this study is to find out about the experiences people with a chronic disease or a disability have had in getting health and social services.

## **II. STUDY PROCEDURES**

I understand the study involves a focus group or individual interview and is voluntary. The group should last about one and a half hours or the interview about an hour and will be audio-taped. You do not have to answer any questions you are uncomfortable with. A \$10 gift certificate will be given to each person for their time and effort in participating.

## **III. RISKS AND DISCOMFORTS OF THE STUDY**

I understand the only risk to me would be if my answers were accidentally revealed to someone other than the study investigators but that no names (other than first name) or addresses will be used or recorded. I am asked to respect the privacy of other members of the group by not talking about any personal information shared during discussion.

## **IV. CONTACTS**

If you have any questions or concerns about this study, please contact Dr Kristine

Lykens' office at (817) 735-2325. If you have questions about your rights in this study, please contact Dr. Jerry McGill, Chairman of the Institutional Review Board, University of North Texas Health Science Center at Fort Worth at (817) 735-5457.

## **V. BENEFITS**

The information gained from this research may help others in getting health and social services. You will receive no direct benefit from participating in this study.

## **VI. ALTERNATIVES**

This study involves focus groups and individual interviews. There are no treatments or interventions involved in this study.

## **VII. CONFIDENTIALITY**

Your responses will be kept as confidential as possible under current local, state and federal laws. However, the Office for Human Research Protections, possibly other federal regulatory agencies, and the Institutional Review Board may examine your interview responses and the study data. In case the final results of this study should be published, your name will not appear in any published material. Participants will use only first names and no other information will be recorded. The tapes of sessions will be transcribed and the tapes destroyed after they are done.

## **VIII. COMPENSATION FOR INJURY**

Neither the investigator conducting this study nor the University of North Texas Health Science Center at Fort Worth are able to offer financial compensation nor absorb the

costs of treatment should you be harmed as a result of your participation in this research.

You should know that by consenting to this agreement you are neither waiving any of your legal rights nor releasing the principle investigator, the University of North Texas Health Science Center at Fort Worth or any of their respective agents from liability for negligence with respect to the conduct of this study. If you are harmed and you feel that this harm justifies pursuing a legal remedy, you have the right to do so.

#### **IX. LEAVING THE STUDY**

I understand this study is voluntary. I can refuse to answer any question and leave at any time.

If you are a student or employee of the University of North Texas Health Science Center, your participation (or non-participation) will in no way affect your academic standing or employment status.

#### **X. CONSENT**

I voluntarily agree to participate in this study. I have had a chance to ask the study investigators any questions I have regarding this study.

**THIS IS YOUR COPY OF THE INFORMED CONSENT AGREEMENT.**

## **APPENDIX D**

## **Key Informant Interview Guide**

### **Access to Health and Social Services for Poverty Level Adults with Chronic Disease or Disability**

#### **INTRODUCTION**

My name is \_\_\_\_\_ and I am a student in the doctoral program at the University of North Texas Health Science Center School of Public Health.

Thank you for agreeing to participate in this interview. This interview will last approximately one half hour. The purpose of this interview is to discuss your experiences with poverty level clients who have some type of chronic disease or disability. We are interested in the good experiences as well as any problems you have had. There is right or wrong answer to these questions. Please answer questions based only on your own experiences. Let me remind you that anything you say during our interview is confidential and no names will be written down that could identify you. Your participation in this interview is voluntary and you are not required to answer any questions.

I would like to ask you if we can tape record this discussion so that we do not miss any of the points that you make. The tape will be destroyed once a summary is written of our discussion today. (WITH PERMISSION, START TAPE.)

**(These interviews will be with professional individuals and may need to be individualized according to their agency and job description.)**

9.     **What is the main purpose of this agency?**
  
10.    **how do you receive your clients?**
  - **Referral- from whom?**
  - **Self referral**

11. **Do you follow a specific case load?**

- Yes/No
- How many
- How long
- Any criteria

12. **Do you make referrals for identified problems?**

- What are the common reasons for referral

13. **Do you provide any information to your clients? If so, what?**

**6. PRESCRIPTION MEDICINES**

- Do you have any services available to provide prescription medication for those who cannot afford them? What?

7. **Do you work in partnership with any other agencies to provide services for special needs individuals?**

- What agencies?

8. **What are the main problems you have found in working with this particular population?**

- Language
- Financial
- Transportation
- Housing
- employment

- 9. Are there any particular problems you have had in dealing with other agencies when working for one of your clients?**

At this point we would like to ask if there is anything else related to your ability to provide health or social services to the disabled?

That concludes our interview.

Thank you for your participation in this project.

## **APPENDIX E**

## PARTICIPANT HANDOUT, HELPFUL INFORMATION

### Resource Connection

#### Tarrant County Resource Connection

{Resource Connection of Tarrant County – Health, Education, Employment, Human Services}

#### **Promoting**

{\*} **self-sufficiency**    {\*} **self-reliance**    {\*} **wellness**

In 1995, The Resource Connection of Tarrant County was formed to share resources and solve problems together as a result of the closure of the Fort Worth State School. Believed to be the first of its kind public-private partnership in the nation, the Resource Connection co-locates a wide variety of agencies and services in a campus environment and provides the infrastructure that facilitates customers' access to services.

The mission of the Resource Connection is to provide employment, education, health & human services in one-stop environment that allows Tarrant County citizens to efficiently utilize resources that promote self-sufficiency, self-reliance and wellness. Tarrant County is the lead agency in this collaborative project and provides the administrative and management services for the agencies on the campus.

The Resource Connection is located on a 262-acre campus in southeastern Fort Worth, with regular bus service from the Fort Worth Transportation Authority.

**Directory**

**1100 Circle Drive – Welcome Center**

<u>Welcome Center – Administrative Office</u>	817-531-7612
<u>AARP Foundation/SCSEP</u>	817-536-3600
<u>Tarrant County Human Resources</u>	817-531-7616
<u>State Representative Glenn O. Lewis, House District 95</u>	817-531-7550

**1200 Circle Drive**

<u>MHMRTC – Administration</u>	Suite 100	817-569-5600
ECI (Early Childhood Intervention)- <u>MHMRTC</u>	Suite 101	817-569-5200
<u>Tarrant County Human Services</u>	Suite 200	817-531-5640
<u>Tarrant County Veterans Services</u>	Suite 300	817-531-5645
Community Learning Center	Suites 301-302	817-536-9209
NuVision Scholarship Fund	Suites 304-305	
<u>Special Olympics</u>	Suite 306	
<u>Department of Veterans Affairs</u>	Suite 400	817-534-3563

**1300 Circle Drive**

<u>Mental Health &amp; Mental Retardation of Tarrant County</u>	817-569-4141
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**1400 Circle Drive – Career Center Partners**

<u>Workforce Solutions through Tarrant County (SERCO)</u>	Suite 100	817-531-5670
<u>Tarrant County Community Supervision &amp; Corrections</u>		817-531-5670
<u>FWISD Adult Education</u>	Suite 200	817-531-4300

**1500 Circle Drive**

<u>FWISD New Lives School</u>	817-531-7770
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**1501 Circle Drive – Health & Human Services State Office Building**

<u>Texas Department of Human Services</u>	817-321-8000
<u>Department of Assistive Rehabilitative Services (DARS)</u>	817-321-8500
<u>Department of Family Protective Services (DFPS)</u>	817-321-8600
<u>Texas Department of Housing and Community Affairs</u>	817-321-8700
Texas Star Program – MAXIMUS	817-321-8024
Texas Commission on Fire Protection	817-531-8600

**1801 Circle Drive**

Tarrant County Juvenile Services 817-531-6765

**2100 Circle Drive**

Tarrant County Housing Assistance Suite 100 817-531-7640

TC Public Health –Immunization Outreach Suite 200 817-321-5400

Women, Infants & Children (WIC) Clinic Suite 200 817-321-5400

**2200 Circle Drive**

Aquatics Center 817-531-7667

**2300 Circle Drive**

Conference and Recreation Center 817-531-7612

Maintenance 817-531-7669

Tarrant County Sheriff's Office – Patrol Office 817-531-7639

Tarrant County Sheriff's Office – Academy 817-531-7634

**2400 Circle Drive – JPS Institute for Health & Career Development**

School of Radiologic Technology & Vocational Nursing 817-920-7380

JPS Human Resources (Personnel Department) 817-920-7370

**2500 Circle Drive – JPS Health Network**

South Campus Clinic Suite 100 817-920-7340

Department of Practice Management Suite 200 817-920-7350

Partners Together for Health Suite 300 817-920-7310

Health Promotions Suite 400 817-920-7300

**5000 – 5020 Circle Drive**

FWISD Adult Vocational & Occupational Training 817-531-4375

**5041 Circle Drive**

Tarrant County Sheriff's Office Laundry 817-531-7635

Tarrant County Sheriff's Office Academy 817-531-7634

**5051 Circle Drive**

Facilities Management 817-531-6796

Senior Citizen Services – Central Kitchen 817-536-0777

Sheriff's Office Warehouse 817-531-7638

## **Tarrant County Public Health Client Services**

Public Health is the first line of defense in maintaining and improving the public's health status. The Institute of Medicine says it's: "Fulfilling society's interest in assuring conditions in which people can be healthy." A productive, economically sound society relies on a safe, healthy population. Please select the appropriate link below for more information on our services.

**Breast & Cervical Cancer Screening**

**Cholesterol/Glucose Testing**

**Health Insurance Continuation Program**

**HIV/AIDS Preventive Medicine Clinical Services**

**Immunizations**

**Refugee Health Screening**

**Sexually Transmitted Diseases (STD/HIV)**

**Travel Health Services**

**Tuberculosis (TB)**

**Women, Infants and Children Program (WIC)**

Web site:

<http://www.tarrantcounty.com/ehealth/cwp/browse.asp?a=763&bc=0&c=43675&ehealthNav=7266>

### **Service Locations**

**Administration Office: Tarrant County Public Health Main Campus**

1101 S. Main Street Fort Worth, Texas 76104 817-321-4700

**Arlington Public Health Center**

536 W. Randol Mill Road Arlington, Texas 76011-5738 817-548-3990

**Bagsby-Williams Public Health Center**

3212 Miller Avenue Fort Worth, Texas 76119-1948 817-531-6738

**La Gran Plaza Mall Public Health Center**

4200 S. Freeway Fort Worth, Texas 76115-1400 817-920-5752

**Northeast Public Health Center**

813 Brown Trail Bedford, Texas 76022-7338 817-285-4155

**Northwest Public Health Center**

3800 Adam Grubb Lakeworth, Texas 76135-3506 817-238-4441

**Southwest Public Health Center**

6551 Granbury Road Fort Worth, Texas 76133-4926 817-370-4530

### **Northeast Public Health Center**

**813 Brown Trail, Bedford, Texas 76022-7338, 817-285-4155.** Located north of the intersection of Brown Trail and E. Pipeline Road.

Services Available	Days	Hours
Immunizations*	Mon – Thu	7 – 11 am / 1 – 5 pm
	Friday	8:00 – 11 am / 1 – 4 pm
	Saturday	Call for Details
Child Health <i>by appointment</i>	Tuesday	7 am – 6 pm
Woman, Infant & Child (WIC) Program <i>by appointment 817-321-5400</i>	Tue – Thu	9 am – 1 pm / 2 – 6 pm
Pregnancy Testing \$10.00	Mon – Thu	7 – 11 am / 1 – 4 pm
Tuberculosis (TB) Skin Testing \$20.00	Mon & Tue	7 – 11 am / 1 – 4 pm

\*Immunizations are on a walk-in basis, clients are accepted until capacity is reached. Please arrive early and bring shot records. Immunizations for children younger than 19 are \$14 for one immunization and \$20 for two or more immunizations per child. Medicaid is accepted. Adult immunization fees based on specific immunization received.

### **Client Services**

#### **Breast & Cervical Cancer Screening**

At Tarrant County Public Health Main Campus the following services are offered in an effort to eliminate Breast and Cervical Cancer from our community:



- Clinical breast exams
- Pap smears
- Mammograms
- Diagnostic services for abnormal findings (i.e. ultrasounds, biopsies)
- Case management for cancer treatment

## Eligibility

- Women 50-64 years old
- Total household gross income must be at or below 200 percent of the Federal Poverty Guidelines
- Referrals are accepted, but are not required

## Location

### Tarrant County Public Health Main Campus

1101 S. Main Street, Suite 1300, Fort Worth, Texas 76104

8:00 am – 5:00 pm, Monday – Friday, excluding certain holidays

By appointment only 817-321-4888

## Immunizations

Tarrant County Public Health regularly provides immunizations at all of our public health centers. Immunizations for children younger than 19 are \$14 for one immunization and \$20 for two or more immunizations per child. Fees for adult immunizations depend on the specific vaccine(s) required. Appointments are not required but immunization hours vary at each public health center. Some centers offer Saturday and evening hours. Please call the center nearest you for immunization times and locations.

## Sexually Transmitted Diseases (STD/HIV)



*This site contains sexually transmitted disease STD/HIV prevention messages that might not be appropriate for all audiences. Since STD/HIV infection is spread primarily through sexual practices or by sharing needles, prevention messages and programs may address these topics. If you are not seeking such information or may be offended by such materials, please exit this page.*

Tarrant County Public Health's Adult Health Services program provides a comprehensive, integrated approach to the prevention and control of sexually transmitted disease (STD) and HIV throughout Tarrant County. Program components include:

- STD/HIV prevention education targeting individuals engaging in high-risk behaviors
- HIV testing and counseling targeting individuals engaging in high-risk behaviors
- Clinical diagnosis and treatment of STDs and HIV at three service locations
- STD/HIV disease intervention/outreach efforts aimed at identifying individuals who

may have been exposed to STDs (partner elicitation) and HIV for the purpose of locating those at risk, facilitating appropriate testing and treatment and breaking chains of transmission.

All program activities are performed in a manner that ensures client confidentiality.

### **STD Clinical Services**

You can be tested, diagnosed and treated for STDs at any of the following locations: (click on location for map)

#### **Tarrant County Public Health Main Campus**

1101 South Main Street, Fort Worth, Texas 76104

Monday – Friday, 8 am – 5 pm, Tuesday 8 am – 7 pm

817-321-4800

#### **Arlington Public Health Center**

536 W. Randol Mill Road, Arlington, Texas 76011-5738

Tuesday and Thursday, 8 am – 5 pm

817-548-7456 or 817-275-2273

#### **Bagsby-Williams Public Health Center**

3212 Miller Ave. Fort Worth, Texas 76119

Monday (only) 8 am – 5 pm

817-531-6738

### **Making Appointments**

To schedule an appointment at clinic locations, call 817-321-4800. Phone is answered beginning at 7:45 am, Monday through Friday.

### **Affordable**

Individual charges may vary. Clinic fees are assigned according to a sliding scale, based on client income.

### **Testing and Clinical Services**

Clients are tested for syphilis, gonorrhea, ☐hlamydia, HIV, HPV (genital warts), yeast infection, trichomoniasis and bacterial vaginosis.

Other available services include:

- Herpes tests
- Immunizations for Hepatitis B (clients 19 and younger only)
- HPV treatment (genital warts)
- HIV testing and counseling by qualified technicians and experienced counselors.

If you were diagnosed with an STD:

- Take all medicine as directed.
- Refer your sex partner(s) to the STD/HIV (Adult Health Services) clinic for testing and treatment.
- If symptoms re-occur, contact the clinic immediately.
- To reduce risk of re-infection, use a condom every time you have sex.
- Call for STD test results and return for follow-up examinations as directed. You will be given a code number for getting your test results by telephone. We can only give results to patients. Test results are not given over the phone to friends or family members.

**Professional Expertise** All Adult Health Services are provided by professionals specifically trained in STD diagnosis, treatment and follow-up of all possible infections. Adult Health Service personnel conduct field investigations to insure that any person exposed to an infection is aware of the possibility and has the opportunity to be examined and treated quickly. Counseling and information are provided for anyone diagnosed with an STD. One of the program goals is to insure that anyone who is treated has knowledge about their infection and is able to take the appropriate precautions to insure that they are not reinfected or exposed to another STD. The Public Health Department identifies and treats more STDs in Tarrant County than any other medical provider.

### **Confidentiality**

Adult Health Services staff and physicians are bound by law to confidentiality regarding any diagnosis and treatment. Our staff will not discuss your health with anyone but you.

All services/information will not be released without the client's written consent. Anonymous testing is offered for HIV only. Although all testing is confidential, with anonymous testing you will be assigned a fictitious name.

### **About STDs**

STDs can be caused by bacteria, viruses or other organisms. Gonorrhea, Chlamydia, Syphilis and several other bacterial infections are usually curable with antibiotics requiring only one visit to the STD clinic. When an STD is caused by a virus, (Herpes, Genital Warts or HIV), the person can be treated; the disease managed and controlled, but not cured. Sometimes, STD infections will cause symptoms that alert the person that there is something wrong. In many

instances the symptoms are very slight and may not be noticed; or there are no signs or symptoms. Any infected person with or without symptoms is placing their health at risk and risking the possibility of infecting any other person with whom they are intimate. Waiting for signs of an infection can be a costly and sometimes fatal mistake. STD infections, left untreated can spread to areas of the body causing serious medical conditions including crippling arthritis, blindness, heart attack and death. When a pregnant woman with an STD infection is untreated, her unborn infant is at risk for serious health problems, including death.

STDs are spread through intimate person-to-person contact, such as oral, vaginal and anal sex. HIV can also be spread through the sharing of needles. Infants can be infected with HIV before birth, during birth and through breast-feeding after birth from an infected woman. STDs are not transmitted through day-to-day contact in social settings such as schools or at the workplace, nor are they transmitted through casual contact including kissing, shaking hands or hugging. Dirty toilet seats, mosquitoes, eating utensils and drinking glasses pose no risks of transmission.

An important role of Adult Health Services is the control and prevention of HIV through comprehensive evaluation, diagnosis and treatment of more common STDs. Decreasing susceptibility and infectiousness are also important goals. When someone develops an STD infection, they are also at high risk of acquiring HIV. Conversely, when an HIV-infected person is also infected with another STD, they are much more likely to transmit HIV than someone who is only HIV-infected. STD treatment reduces the ability of an HIV positive individual to transmit HIV. By targeting the identification and treatment of STDs, Adult Health Services works to reduce the transmission of HIV in Tarrant County.

### **Medical Advocacy Services for Healthcare (MASH)**

The MASH Program is an eligibility service employing seasoned social services and government program staff. MASH screens and processes patients for public benefits such as SSI disability and Medicaid. Referrals are normally through a healthcare provider, government agency, physician or a non-profit organization. Because there were many individuals contacting MASH for assistance without a referral, MASH developed an affiliated program designed to work individuals with no referral by another professional or agency. This program is called **Disability Help, Inc. or DHI**.

**Disability Help, Inc.** was founded in 1998 to assist individuals to work through the complex application process for SSI and/or Social Security disability benefits.

From offices in Austin, Fort Worth and Amarillo, Texas, **DHI** works cases throughout the United States. The company's advocates have many years of Social Security disability experience.

To learn more about **DHI** and its services, please contact **DHI** at 817-923-8900.

## **PARTICIPANT HANDOUT, HELPFUL NUMBERS**

### **FIRST CALL FOR HELP**

United Way..... 211

### **FOOD/CLOTHING/FINANCIAL ASSISTANCE**

Arlington Charities..... 817-275-1511  
Bread Basket Ministries..... 817-535-2323  
Bridge Association..... 817-332-8317  
Broadway Baptist Church/ Ctr..... 817-336-5761  
Catholic Charities..... 817-921-5381  
Northside Inter-Church Agency..... 817-626-1102  
Tarrant County Dept of Human Svcs... 817-531-5620  
Cornerstone Community Center..... 817-336-1922  
Tarrant Area Food Bank..... 817-332-9177  
Metro Food Bank..... 817-924-3333  
TX Health and Human Svcs..... 817-446-5400  
Mission Arlington..... 817-277-6620  
WIC..... 817-321-5400

### **HOUSING-LOW COST/SUBSIDIZED**

Housing Authority, City of Arlington... 817-275-3351  
Housing Authority, City of Arlington ... 817-336-2419  
Housing Office of Tarrant Cty..... 817-531-7640  
YMCA..... 817-332-6191

### **DAYCARE**

Catholic Charities..... 817-921-5381  
Center for Creative Living..... 817-534-2189  
Clayton Child Care Associate..... 817-926-9381  
CCMS, Child Care Associate..... 817-831-0374  
YMCA, Ft. Worth..... 817-332-6191

### **OTHER HELPFUL NUMBERS**

AIDS (Information/Help)..... 800-342-2437  
Alcoholics Anonymous..... 817-332-3533  
Adult Protective Services..... 817-252-5400  
Child Study Center..... 817-336-8611  
Catholic Charities, Bedford..... 817-282-6646  
Community Enrichment Center..... 817-281-1164  
Educational Opportunity Center..... 817-926-9261  
Mental Health/Mental Retardation..... 817-335-3022  
Prevent Blindness Texas..... 817-332-8125  
Parents in Crisis (2<sup>nd</sup>) 12-3..... 817-332-6399  
Planned Parenthood..... 817-332-7966  
Planned Parenthood (24HR) FACTS..... 817-882-1188  
Rape Crisis Hotline..... 817-927-2737  
Tarrant County Alcoholism/Drug Abuse 817-332-6329  
DARS, Div. For Blind Svcs..... 817-926-4646

### **TRANSPORTATION**

American Red Cross..... 817-335-9137  
American Red Cross- Wheels..... 817-336-8714  
Handitran- Arlington..... 817-459-5390  
The T Bus Service..... 817-215-8600

### **AFTER SCHOOL**

Arlington Boys & Girls Club..... 817-265-7211  
Arlington Family YMCA..... 817-274-9622  
Or ..... 817-461-9533  
Girls Incorporated..... 817-275-2120  
Ft. Worth Boys & Girls Club..... 817-834-4711  
YMCA of Tarrant County..... 817-335-6147

### **LEGAL SERVICES**

Civil Liberties Union & Foundation. 817-534-6883  
Lawyer Referral Tarrant County..... 817-336-4101

### **EMPLOYMENT & TRAINING**

Resource Connection Wkforce Ctr. 817-531-5670  
Arlington Workforce Center.... 817-804-4200  
Mid-cities Workforce Center... 817-545-1809  
Eastside Workforce Center..... 817-531-7800  
Westside Workforce Center... 817-737-0311  
Northside Workforce Center... 817-626-5262  
Alliance Opportunity Center... 817-515-2100  
Texas Women's Center..... 817-927-4000

### **SCHOOL SUPPLIES**

Catholic Charities..... 817-921-9072  
817-921-9112

### **BIRTH CERTIFICATES**

Tarrant County..... 817-871-7399

### **CHILD SUPPORT**

Tarrant Cty Child Support Office.. 817-884-1475

### **DEAF INTERPRETATION**

Goodrich Center..... 817-926-5305  
Deaf Action Center..... 817-521-0407  
Dept. of Assisted/Rehab Svcs..... 817-277-9176

Tarrant Cty. Human Svcs.....	817-548-3920
Dept. of Assisted/Rehabilitated Svcs.....	817-277-9176
Social Security Administration.....	800-772-1213
United Way, Northeast.....	817-282-1160

**Health Care**

Tarrant County Hospital District (JPS).  
817-921-3431

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