Deaf Health
Task Force Report
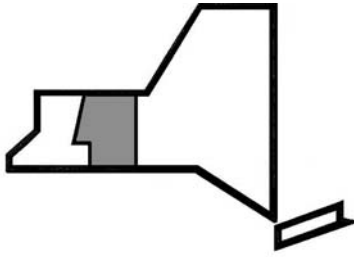
Acknowledgment:

This publication/project was made possible through a Cooperative Agreement between the Center for Disease Control and Prevention (CDC) and the Association of Teachers of Preventive Medicine (ATPM), award number TS-0817, its contents are the responsibility of the authors and do not necessarily reflect the official views of the CDC or ATPM.

FINGER LAKES HEALTH SYSTEMS AGENCY

1150 UNIVERSITY AVENUE, ROCHESTER, NEW YORK 14607-1647
(585) 461-3520, FAX 461-0997, TTY 461-4075
Email: FLHSA@FLHSA.org   Website: FLHSA.org

August 2004

On behalf of the FLHSA's Deaf Health Task Force, we are pleased to present their report to the community. This report describes barriers to health care experienced by the Deaf population in Monroe County. It also presents a series of ambitious recommendations which, if implemented, will improve the quality of health care for the Deaf population.

We would like to thank each of the Task Force members for their contributions of time, thoughtful deliberation, input and commitment. We hope that as a result of this report, the larger community will better understand the issues faced by a significant population within Monroe County.

We would also like to acknowledge and thank the staff and interpreters who facilitated the process and made it a collaborative one.

Steven Barnett, MD   Bonnie C. DeVinney
University of Rochester Medical Center   Executive Director
  Family Medical Research   FLHSA

TABLE OF CONTENTS

Deaf Health Talk Force Roster

Donna Gustina
National Technical Institute for the Deaf

Alan Hurwitz
National Technical Institute for the Deaf

Vicki Hurwitz
Rochester School for the Deaf - Outreach Center

Christopher Lehfeldt, DDS
Rushville Health Center/Elmwood Dental

Timothy Malia, MD
Lifetime Health

Jeff Mothersell
Unity Health System, Park Ridge Hospital

Harold Mowl, Jr
Rochester School for the Deaf

Steve Novak
Norris Clinic

Betty Oppenheimer
University of Rochester Medical Center

Tom Pearson, MD
University of Rochester Medical Center
  Department of Community and Preventive Medicine

Spencer Phillips, J.D.
Greater Upstate Law Project

Brian Piotrowski, MD

Robert Pollard
University of Rochester Medical Center
 Deaf Wellness Center

Susan Postlethwait
Regional Center for Independent Living

J.T. Reid
NTID

Ed Sassaman, MD
Excellus Blue Cross/Blue Shield

Jeanne Sloan
Monroe County Health Department

Lois Smiley
Rochester Black Deaf Advocate (RCDA)

Joseph Stankaitis, MD
Monroe Plan for Medical Care

Matt Starr
The Health Association

Anne Steider
Rochester Mental Health

Carolyn Stern, MD

Patrick Sullivan
Rochester School for the Deaf

Staff:

Steven Barnett, MD
University of Rochester Medical Center
  Family Medical Research

Bonnie DeVinney
Finger Lakes Health Systems Agency

Steven Levine
Finger Lakes Health Systems Agency

Chris Kelley
University of Rochester Medical Center
  Family Medicine Research

EXECUTIVE SUMMARY

Beginning in December, 2003 and completing its work in June, 2004, the Deaf Health Task Force met to examine issues related to the health and healthcare of Rochester's Deaf population, including access barriers. Composed of both Deaf and hearing persons, the Task Force identified various issues faced by Deaf patients and family members, and then developed recommendations and strategies.

Although hearing loss is one of the top ten chronic conditions in the United States, comparatively little attention has been directed towards the Deaf, and health care utilization of this population has not been well-examined. Additionally, demographics about the deaf population are limited, and in Rochester, considered one of the most "Deaf friendly" communities in the country, there are no good estimates of the size of the population.

The report focuses on Deaf persons who use American Sign Language, ASL, as their primary language. The Deaf community shares certain characteristics with other populations for whom English is not the first language; Deaf persons face barriers to health care that are increased by the language barrier. For example, there are few providers who use ASL; health promotion materials and health communications, in general, are not geared to ASL users; many providers do not understand the provisions of the American with Disabilities Act (ADA), which are applicable to the Deaf; hearing health professionals are not familiar with assistive listening devices and do not understand how to appropriately use qualified interpreters.

The Task Force made a series of recommendations as follows:
- Training and education should be provided to physicians and other patient care personnel that will enable them to understand the roles of hearing and Deaf patients and their family members and, thus, to provide effective and appropriate care.
- Education and training should be provided to physicians and other patient care personnel about communications with Deaf patients and the legal rights of Deaf patients.
- Qualified interpreters should be available in all health care settings. Physicians and patient care personnel should work collaboratively with the interpreter.
- Physicians and other patient care personnel should ensure patients' understanding of treatment, instructions, orders, etc.. Additionally, they should make information available

and refer Deaf patients to outside resources that will facilitate patient education and understanding of their health condition. Educational opportunities should be provided for Deaf patients regarding medical care and treatment, prevention, patient responsibilities, etc..

A Report to the Community about Barriers to Health Care

Faced by Deaf Patients who Communicate Using American Sign Language

INTRODUCTION

In December 2003, the Finger Lakes Health Systems Agency (FLHSA) and the Family Medicine Research Program of the University of Rochester School of Medicine and Dentistry co-convened the Deaf Health Task Force to examine issues related to the health and healthcare of Rochester's Deaf population, including access barriers faced by Deaf patients and family members and to provide a forum in which Deaf persons and health professionals could have a constructive dialogue about healthcare assess. (Note: "Deaf" refers to people who communicate using American Sign Language (ASL); "deaf" refers to people who are hard-of-hearing to varying degrees. In this report, both terms are employed.) The Task Force, which is comprised of representatives of health care organizations, private practitioners in medicine and dentistry, educational facilities, and advocacy groups, met several times to address this charge. This report is a summarization of the Task Force's work and describes the barriers to health care experienced by people who are Deaf. In addition, the report describes Deaf culture and communication, as well as societal issues, which play significant roles in defining barriers.

I. NATIONAL DEMOGRAPHICS

Approximately 1 in 10 Americans, or more than 28 million people, has some degree of hearing difficulty, and about 1 in 100 has a profound hearing loss. This makes hearing difficulty one of the top ten chronic conditions in the civilian, non-institutionalized U.S. population.[1] Of those 28 million, approximately 738,000 are profoundly deaf (8% children, 3-17 years of age, and 54% adults, 65 years of age or older). Profound hearing difficulty among children is thought to be under-reported.[2]

Demographics describing the Deaf population in the United States are limited. For example, the United States Census asks (in the Long Form) whether the respondent has a long-lasting condition such as "blindness, deafness, or a severe vision or hearing impairment". The National Health Interview Survey (NHIS) is the largest survey in the United States which asks questions about hearing. The last NHIS for which there is published data about deaf people was

administered in 2001. According to the National Center for Health Statistics, which reported information based on the NHIS, for most age groups, males had higher prevalence rates than females for deafness and other hearing difficulties. Asian adults, black adults and Hispanic adults reported lower prevalence rates than white persons for deafness and other hearing difficulties. The NHIS survey which was conducted in 1991 reported that between 1-2 of every 1000 American children have moderate to severe hearing difficulty in both ears. (Note: These estimates rarely make a distinction between those who were born deaf or hard of hearing and those who lost their ability to hear later in life.) Prevalence rates for deafness and other hearing difficulties among persons in families with incomes of under $10,000 were higher than among persons in families with incomes of $35,000 or more. Because the lower income group has a higher proportion of persons 65 years of age and over, these differences are most likely age related.[3] The incidence of hearing loss is increasing due to the aging of the general population; however, the prevalence of problems with hearing is increasing faster than the US population is aging.

The NHIS studies provide other conclusions:
- adults deafened as children (before age 3) have similarities with members of other language minority groups (poorer health status and fewer physician visits);
- people deafened later in life portray characteristics of people with chronic illness (poorer health, more frequent physician visits, fewer preventive services).

In a study based on information from the NHIS Surveys (1990 and 1991) and the National Health and Nutrition Examination Survey (1988-1994) Bonnie Blanchfield and colleagues made the following estimates:

Family Income:
Most of the severely to profoundly hearing impaired population are poorer, on average, than other Americans. Fifty-three percent of the severely to profoundly hearing impaired population (from the NHIS survey) have a family income of less than $25,000 compared to 35% of the general population.

Education:

Of the severely to profoundly hearing impaired, about 44% did not graduate from high school, compared to 19% in the general population. Forty-six percent of these hearing impaired students did graduate from high school and reported some college attendance, compared with 60% of the general population of students. Only 5% of the severely to profoundly hearing impaired population graduated from college compared with 13% of the general population.[4]

Labor Force Participation:

Although the labor force participation of the severely to profoundly hearing impaired population over 60 is similar to the general population, many working-age adults (18-64) are not in the labor force: forty-two percent of adults (18 to 44) are not working compared to 18% of the general population. Fifty-four percent of those aged 45 to 64 are not working, compared to 27% of the general population.

Insurance Coverage:

Most of the severely to profoundly hearing impaired individuals have insurance coverage; a high percentage of that coverage is in the public programs, such as Medicaid and Medicare. They are substantially less likely to have private health insurance than the general population; thirty-one percent of the severely to profoundly hearing impaired have only public insurance. Forty percent have a combination of both public and private health insurance. Only 23% have private insurance exclusively. In contrast, an estimated 13% of the general population has only public insurance, 12% have public and private insurance, and 61% have private insurance exclusively. The fact that the hearing-impaired population is less likely to be privately insured may relate to their lower participation in the labor force and lower income.

II. FINGER LAKES REGION/MONROE COUNTY

The current population of the nine-county Finger Lakes Region is 1.2 million. The largest concentration of this population is in Monroe County (approximately 735,000). Its major city, Rochester, is the third-largest city in New York State. It has been said that Rochester is the most Deaf-friendly city in the United States. Almost every aspect of life–from education to government to the arts—is deaf-accessible. Rochester has Deaf social organizations, a newspaper

for the Deaf community, Deaf advocacy groups, TTYs (text telephones) installed in pizza shops near the National Technical Institute for the Deaf (NTID) campus, and a reporter who covers the "Deaf beat" for the Rochester *Democrat and Chronicle*. However, the quality of services is variable. For example, sign language interpreters are readily available in the area's emergency departments, but accessible mental health and addiction services are limited.

No census of the Deaf population or of people with hearing loss in Monroe County has ever been taken. Estimates range from a few thousand people who were born deaf to 90,000 people with varying degrees of hearing loss.[5] Estimates based on national data do not reflect a number of facts about Rochester and Monroe County:

- The numbers do not reflect the location of deaf schools and their students and faculty and their spouses and children who are deaf.
- The numbers do not reflect the number of persons who have remained in Rochester, having come here as students or for jobs.

There are neither national nor local databases which track information about deaf people regarding their health. Analyses of national data indicate that adults who have been deaf since childhood are less likely to have seen a physician than adults from the general population.

III. DEAF CULTURE

In defining the Deaf Community, there are two opposing perspectives usually put forth: the "medical/psychosocial model" and the "cultural model"[6]. In the "medical/psychosocial" view, the behaviors and values of hearing people are the norm, and people who are deaf deviate from this norm. It is a view that generally considers differences between hearing people and deaf people as negative. It also views deaf people as having something <u>wrong</u> with them, something that can be "fixed". The other view, the "cultural model", recognizes that there is a complex set of factors to consider when defining the Deaf Community.

In contrast to the "medical/psychosocial" model, the "cultural" model defines the Deaf community as a group who share a common means of communication (sign language) that provides a basis for group cohesion and identity. It acknowledges that Deaf people view

themselves as competent individuals with a common method of communication and cultural history and a shared set of cultural values. However, Deaf culture is not passed down directly from parents to children since 90% of Deaf children are born to hearing parents who have no other connection to the Deaf world. Deaf culture is passed on from peers and from older deaf adults. The "cultural" model is used for this discussion.

Use of sign language is more important in defining community membership than is the lack of hearing, or ability to hear. Since the Deaf community's primary means of relating to the world is visual, they share a language that is visually received and produced with gestures. People who are deaf but who communicate primarily orally, through voicing and speech reading, are not usually considered to be members of the Deaf community. Children of Deaf parents (CODAs) who usually have learned sign language as their first language are members of the Deaf community, even if they have normal hearing. (Adapted from Barnett, *Family Medicine.*)

IV. COMMUNICATIONS

Because the Deaf Health Task Force (DHTF) is concerned with barriers to health care for the Deaf community, it is important to understand how vital communication is in providing health care. Two-way communication–between patient and provider--is a critical factor in providing good health care. People with profound hearing loss sometimes have difficulty communicating and interacting with those who can hear and the inability to communicate effectively can have adverse effects on health. Therefore, it is important to understand how Deaf people communicate, and how information is acquired and passed on.

People are most likely to communicate in the language they learned while growing up. Thus, those who had normal hearing in their childhood grew up with spoken language. They continue to use that language if they became deafened later in life. In contrast, children who have been deafened when young are likely to communicate in sign language. American Sign Language (ASL) is the primary language of many in the American deaf community. Estimates range from 100,000 to 1 million users in the United States.[7] Although it is used in the United States and Canada, ASL is a completely separate language from English; different sign languages are used in different countries or regions, and there is no single form of sign language that is universal.

While it was not recognized by linguists as a proper language until the 1960s, ASL is, in fact, a complete, complex language, with its own syntax, structure and grammar. ASL also employs signs made with the hands and other movements, including facial expressions and postures of the body. ASL sentences do not follow English sequential patterns. As a result, direct translation of English, as with written notes, into ASL will not necessarily convey the intended message. Moreover, much of English idiomatic speech would be lost on the ASL user whose frame of reference for idiom is significantly different from the hearing person. ASL does not have a written form.

People who were deafened in adulthood are likely to have better English-speaking and communication skills than those deafened as young children; English speaking and reading is somewhat easier for adults than for individuals who are prelingually deafened. People deafened at an early age are more likely to use ASL as a primary language instead of English. For those who have never heard English or those who were deafened before the acquisition of language (which occurs at around 3 years of age), sign language is more easily acquired than for adults. Acquisition of any language becomes much more difficult with advancing age; this is as true for ASL as it is for spoken languages. [9]

The average English literacy level of Deaf high school graduates in the United States is estimated at 4th-5th grade.[10] Low literacy in English is probably related to several factors for Deaf children who have English as a second language:

- The grammatical structure of ASL, a manually communicated language, uses different structure, grammar and syntax than English. For ASL users, English is as much a foreign language as is French or German to an English-speaking person.
- Learning to read is difficult when it is not possible to hear words that need to be sounded out.
- Language acquisition for deaf children with hearing parents is delayed. This may be because the disability is not identified sufficiently early to give the child the opportunity to begin learning as a Deaf child, rather than as a child for whom hearing expectations are imposed.
- There is lack of consensus about educational methods and content for deaf children;

there is limited exposure to some topics and there are gaps in general information/knowledge.

- Access to "ambient information", i.e., overheard conversations, radio information, television information, etc., is limited.

Dr. Steven Barnett described the similarities between the Deaf community and other linguistic minority communities as follows:

Table 1: Similarities between the Deaf community and some other language minority groups[10]

Social	• Use of a non-English language; English as a second language
	• Socialize and partner/marry within the community
	• Sociocultural norms different from those of the majority community
	• Children often become bicultural/bilingual
	• Isolation of growing up Deaf in a hearing family
Power	• Lower education level, socioeconomic status, and literacy than general population
	• Often encounter prejudices that limit opportunities
	• Limited access to English language-based information
Healthcare	• Infrequently encounter a doctor from their own cultural group
	• Language differences and health knowledge limitations are often barriers to appropriate health care
	• Poorer health than the general population
	• Less likely to visit a physician than the general population.

V. DEAF HEALTH TASK FORCE—IDENTIFICATION OF BARRIERS TO HEALTH CARE

Comparatively little attention has been focused on medical needs and access to care of the Deaf and hard-of-hearing population in Monroe County. The Task Force provided a first step to discussion about access barriers faced by Deaf patients and family members. There is some degree of animosity towards health care systems historically; Deaf people have not had a voice in making health care systems work better for them and for their families. The Task Force was intent on providing an opportunity for Deaf persons and health professionals to meet in a forum in which they could have a constructive dialogue about health care access.

Given the diversity in the Deaf community in Rochester, the Task Force's challenge in identifying barriers and developing recommendations to improve assess was great. The Task Force that was created included members from various health and behavioral health entities (including private practicing physicians and dentists), educational institutions, health insurers, community organizations, and Deaf advocacy groups. Task Force participants represented both Deaf and hearing individuals. All meetings of the Task Force were interpreted. However, in spite of interpreters, we cannot assume that the communication gap was fully resolved as people were speaking from different life experiences and perspectives.

During its meetings, the members identified a large number of specific barriers to health care that could be grouped into the following categories:

- Issues related to health care in physicians' offices which include technology (assistive listening devices, communication systems) and information systems.

- Deaf Culture issues and how they affect health care delivery in physicians' offices. Aside from issues pertaining to the nature of physicians' interactions with Deaf patients, this also includes literacy levels in English and "medical literacy" of Deaf patients.

- Communication issues related to sign language interpreters, which includes availability, skill level of interpreters, and understanding by physicians and other health care professionals of how to work with interpreters.

- Health care system issues such as inappropriate use of emergency departments, transportation and insurance availability.

It should be noted that the Finger Lakes Health Systems Agency has had experience with other task forces that have been defined by culture, notably the African American Health Status Task Force and the Hispanic Health Task Force. In both, frequently cited barriers to care included language, insufficient or inadequate translation services, lack of cultural competence/sensitivity on the part of health care institutions and providers, and insufficient numbers of health care providers who are culturally similar to the populations they serve. The barriers identified by the DHTF are almost mirror images of those identified by the previous groups.

After the barriers to care were identified, the Task Force asked its members to identify 1) the importance of each barrier; and 2) how easy it would be to resolve or fix each barrier. The survey was conducted via the internet. Twenty-nine surveys were distributed; there were 23 respondents. Given the representation on the Task Force, the information was analyzed by looking at the total membership (both hearing and Deaf respondents) and by looking at the responses from the Deaf respondents only. There were no issues that stood out as either extremely important or extremely easy to fix by either group. Most responses fell into the same level of importance and ease of solution.

For both groups, major issues of importance were related to communications, understanding Deaf culture, and how to effectively work with interpreters; there was some overlap in terms of specific items selected. The total Task Force responses indicated only two items that were not included by the Deaf respondents in terms of importance, namely:
- Doctors do not have TTY lines, or do not answer the TTY.
- The computer systems for patient contact information do not have space to add TTY numbers, relay number, or any labeling for charts.

Importance: Total Task Force	Importance: Deaf Respondents
• Doctors do not have TTY lines, or do not answer the TTY • Interpreters do not interpret for Deaf parents when their hearing child is talking to the doctor • Doctors do not understand roles of hearing and Deaf family members • Many interpreters at the doctor's office are not qualified or skilled • The Deaf patient does not understand the doctor's instructions • Doctors and patients do not understand each other's communication choices • The computer systems for patients do not have space to add TTY numbers, relay number, or any labeling for charts.	• Doctors do not understand roles of hearing and Deaf family members • Many interpreters at the doctor's office are not qualified or skilled • Many times interpreters are not available • Interpreters' schedules are limited and they cannot stay late if appointment goes over time • Interpreters do not interpret for Deaf parents when their hearing child is talking to the doctor • The Deaf patient does not understand the doctor's instructions • Deaf patients do not understand "preventive" care • Doctors and patients do not understand each other's communication choices • Deaf patients go to emergency rooms when they shouldn't

In terms of ease of solution, both the Deaf respondents and the total Task Force membership agreed that two issues would be most easily solved:

• Interpreters are not usually asked to interpret for Deaf parents when their hearing child is present. In some cases, the child fills the role of interpreter. In other instances, even though an interpreter is present, when the child speaks, the interpreter does not interpret.

• The computer systems for patients do not have space to add TTY number, relay number, or any labeling for charts. The total Task Force indicated that the absence of TTY lines was easily solved; and the Deaf respondents indicated that assistive listening devices in doctors' offices could be accommodated.

Issues related to understanding communication styles and Deaf culture are probably the most difficult issues to "solve" in terms of changes for the medical community.

VI. RECOMMENDATIONS

A series of four problem statements, recommendations and suggested interventions were formulated by the Task Force. The interventions include those which are community-specific; others are global in nature. The interventions also suggest a number of training opportunities—for physicians and health care staff, for Deaf patients, and for community members. For many training opportunities, members of Rochester's Deaf community would be available to volunteer for role playing, as mock patients, in medical offices, the Medical School, hospitals, etc..

The problem statements, recommendations and suggested interventions are as follows:

1. **Problem Statement: Communications with Deaf patients and their family members in the healthcare setting is difficult because physicians and other healthcare professionals do not understand the roles of hearing and Deaf members in a family.**

   <u>Recommendation:</u> Training and education should be provided to physicians and other patient care personnel that will enable them to understand the roles of hearing and Deaf patients and their family members and, thus, to provide effective and appropriate care.

Suggested Interventions:

Local interventions:
- Organizations such as the Health Association and the Monroe County Medical Society should offer workshops and continuing medical education (CME) courses for physicians, medical students, and patient care personnel on such topics as; what to expect and what to do when seeing Deaf patients; communication; Deaf culture.

- Publish articles and resources/references about communication with Deaf patients and Deaf culture in the Medical County Medical Society publications.

Global interventions:
- Educate physicians on family dynamics such as CODAs (Children of Deaf Adults), deaf children of hearing parents, etc..

- Persuade medical boards and licensing examination boards to include questions on treating Deaf patients, etc..

- Mandate that medical schools, medical residency programs and allied health programs require students to be exposed to diverse cultures, differences in communications, etc..

- Provide information for physicians on internet sites about accommodating the Deaf patient; parents of Deaf children; strategies on better information gathering for family health histories, etc.. Create a link "For Medical Providers" on a web side (like WebMD.com) for physicians to seek information on Deaf culture, interpreters, etc..

2. Problem statement: Physicians and Deaf patients do not understand each other's communication needs, rights or methods.

Recommendation: Education and training should be provided to physicians and other patient care personnel about communications with Deaf patients and the legal rights of Deaf patients.

Suggested Interventions:

Local interventions:

- Notify physicians that a policy of charging a nominal fee for broken appointments for both Deaf and hearing patients is possible. This may prevent the provider from having to incur the unnecessary expense of an interpreter if the Deaf patient does not show up for the appointment. BUT – it must be stressed that use of a broken appointment policy must be for ALL patients. Adding the cost of hiring an interpreter to this broken appointment fee is not legal.

- Educate physicians and other patient care providers on the options available to contact Deaf patients. Deaf patients use the relay service and e-mail messages as alternate forms of communication with the medical office.

- Because the comprehension level of many Deaf patients in written English is low, ensure that physicians and other patient care providers using any written communication with Deaf patients understand appropriate phrasing for Deaf patients using English.

- Place prominently in the medical record information about patient's desired communication strategy and other related personal preferences.

- Educate Deaf patients, if not able to self-advocate effectively, to ask for an advocate to accompany them to medical appointments.

- Organizations such as Lifetime Health and the Health Association should offer a course for Deaf patients on "Medical Visits 101" about what to expect at the medical office visit, how to work with interpreter, how to be assertive, etc..

- Include articles on successful, effective communication in the health care setting, in <u>Deaf Rochester News.</u>

- Provide information to eligible physicians and health care providers about tax credits for expenses incurred in the course of accommodating patients with disabilities.

- Create a new website (like WebMD.com) designed for the Deaf patient, with video clips in ASL on office visits, assertiveness, etc..

3. Problem statement: Many interpreters at doctors' offices are not skilled or qualified, especially in medical terminology.

<u>Recommendation:</u> Qualified interpreters should be available in all health care settings. Physicians and patient care personnel should work collaboratively with the interpreter.

Suggested Interventions

Local interventions:

- Educate physicians and Deaf patients on the role of the interpreter as a professional. Educate physicians that a family member is neither a skilled nor a qualified interpreter in any medical setting. Using the phrase "use an interpreter"—instead of "working with interpreters", "hire an interpreter", "bring in an interpreter", etc.—allows physicians to ignore the fact that the interpreter is a professional, thus creating a situation that enables physicians to work with family members as interpreters. If physicians acknowledge interpreters as professionals in the medical setting, then they will not be inclined to use a family member or someone with little or no qualifications in interpreting for the Deaf in the healthcare setting.

- Provide physicians and other patient care personnel with information on how to find interpreting services and how to get a qualified and certified interpreter as well as information on how to check accreditation for interpreters.

- Teach physicians and staff to ask the patient when making an appointment how they would prefer to communicate in the medical office: ASL, PSE (Pidgin Signed English), loop, etc..

- Train physicians on how to evaluate the accuracy of communication between the Deaf patient and the physician.

- Organizations such as the Health Association should offer consultations in medical offices regarding ADA accommodations.

4. **Problem statement: Deaf patients do not understand the doctor's instructions regarding prescriptions, follow-up treatment or other medical issues, need for preventive care, etc..**

> <u>Recommendation</u>: Physicians and other patient care personnel should ensure patients' understanding of treatment, instructions, orders, etc.. Additionally, they should make information available and refer Deaf patients to outside resources that will facilitate patient education and understanding of their health condition. Educational opportunities should be provided for Deaf patients regarding medical care and treatment, prevention, patient responsibilities, etc..

Suggested Interventions:

For physicians and other patient care personnel:

- As medical offices are now switching over to electronic format from paper charts, educate physicians and other patient care personnel about how to increase access to information for Deaf patients by cutting, pasting or printing out medical notes from their charts for the patient to take home for review.

- Provide physicians and other patient care personnel with information about reliable health education/information sources that are easily accessed by Deaf people (e.g., WebMD.com).

- Create a new website (like WebMD.com) that is designed for the Deaf patient, with video clips in ASL on medical conditions, etc. that can be watched on home computers. Video clips should demystify medical jargon by providing easy-to-understand signs.

- Publish articles and resources/references in the Medical Society of Monroe County publications.

- Train the physician to understand Deaf "mannerisms" that indicate understanding – or lack of understanding. Ensure that the Deaf patient understands instructions, and that the physician or other patient care personnel are available for follow-up and clarification.

For patients:

- Educate Deaf patients, if not able to effectively self-advocate, to ask for a knowledgeable advocate to accompany them on medical appointments.

- Organizations such as Lifetime Health or the Health Association should offer workshops or classes on self-advocacy at medical visits, which would improve communication at visits, increase assertiveness, etc..

- Provide articles for Deaf people (like "Ask The Doctor", a nationally syndicated newspaper column) in Deaf Rochester News to allow Deaf people to ask questions and gain additional information.

- Enlist teachers and others to educate Deaf children about visiting medical offices, roles and responsibilities of the RN, NP, MD, etc., how to communicate effectively when they grow up to be independent adults, and assume responsibility for their health care decisions.

- Schools and Parent Teacher Organizations should organize peer education for parents of Deaf children on health care issues and access. Topics should include such things as family health history. Deaf children should be given a wallet sized list of family health history to bring to medical appointments.

- Deaf education programs (BOCES, RSD, etc.) should have teachers and others teach children about health prevention strategies and the importance of Deaf children knowing their family's health history.

- Create PSAs (public service announcements) on radio designed towards families with Deaf relatives or children to inform them of challenges experienced by Deaf patients in seeking medical care.

- Provide emergency room personnel with updated lists of Deaf-friendly primary care providers to be given to Deaf patients who habitually use the Emergency Room for primary care because they know that an interpreter will be available.

- Train Deaf patients on how to be assertive in medical offices and to understand that the patient is the focal point of the visit – not the physician and/or the interpreter.

- Offer classes in "Your Visit to the Doctor 101" to members of Deaf community, on medical systems, insurance companies, roles and responsibilities of RN, NP, MD, appropriate reasons to visit the Emergency Room (ER), selection of a primary care provider, etc..

For the community:
- Create a work group to start a project to locate health videos in ASL and captions for Deaf patients, and make a referral list for the Deaf patient to take home.

- Work with Independent Living Centers (there are 43 in New York State) and outreach specialists working with rural, isolated Deaf patients to seek to establish a medical home instead of using the emergency services at hospitals for primary care treatment.

- Work with medical insurance companies to support initiatives to produce better health care for Deaf patients and improve Deaf patients' low fund of knowledge about health issues.

- The Office of Emergency Preparedness should create radio messages to ask neighbors or families to check on the health of a Deaf neighbor or relative/child in the event of a local or national emergency.

- Partner with deaf education programs (BOCES, RSD, RAHA (Rochester Area Home Schools Association), CSE (Committee on Special Education), etc. to work on unique health care issues of Deaf children.

References

1 Lucas, J.W., Schiller, J.S., and Benson, V. (2004, January) Summary health statistics for U.S. adults: National Health Interview Survey, 2001. (National Center for Health Statistics, DHHS publication no. [PHS] 2004-1546) *Vital Health Statistics*, 10 (218).

2 Blanchfield, Bonnie B., CPA, SC.D, Jacob J. Feldman, PhD, Jennifer L. Dunbar, MHS, and Eric N. Gardner, " The Severely to Profoundly Hearing-Impaired Population in the United States: Prevalence Estimates and Demographics," *Journal of the American Academy of Audiology*, 12: 183-189 (2001).

3 Collins, JG "Prevalence of Selected Chronic Conditions: United States, 1990-92." *Vital and Health Statistics*, Series 10, No. 194. 1997.

4 Blanchfield, Bonnie B, CPA, SC.D., J J. Feldman , Ph.D, Jennifer L. Dunbar, MHS, "Key Findings: Prevalence, Age, Insurance Coverage, Family Income, Education, Labor Force", Project HOPE Policy Analysis Brief, October 1999.

5 Livadas, Greg, "Area Deaf Haven't Been Counted", *Rochester Democrat and Chronicle*, March 26, 2002.

6 "American Deaf Culture", Signmedia, Inc., 2002.

7 Barnett, Steven and Peter Franks, "Health Care Utilization and Adults Who Are Deaf: Relationship with Age at Onset of Deafness," *HSR: Health Services Research*, 37:1 (Feb. 2002).

8 Woodcock, Kathryn, PhD, Peng and Miguel Aguayo, MSW, CSW, "The Duality of Communication as a Barrier Between People Who Hear and People Who Don't" from the Fourth Rochester Conference on Human Rights and Responsibilities: Communicating among Nations and Peoples" M. Prosser and K. Sitaram (Eds.), July, 1999.

9 Barnett, Steven, MD, "Clinical and Cultural Issues in Caring for Deaf People", *Family Medicine,* 31:1 (January 1999).

10 Ibid.

Select Bibliography

Aguayo, Miguel, MSW, CSW and Kathryn Woodcock, PHD, PEng, "The Duality of Communication as a Barrier Between People Who Hear and People Who Don't", from M. Prosser and K. Sitaram (Eds.) *The Fourth Rochester Conference on Human Rights and Responsibilities: Communicating among Nations and Peoples*.

Andrulis, Dennis, PhD., Nanette Goodman, MA, and Carol Proyr, MPH, "What a Difference an Interpreter Can Make: Health Care Eperiences of Uninsured with Limited English Proficiency", April 2002, *The Access Project.*

Avery, Maria-Paz Beltran, PhD., "The Role of the Health Care Interpreter: An Evolving Dialogue," April, 2001, *The National Council on Interpreting in Health Care, Working Papers Series.*

Barnett, Steven, MD, "Clinical and Cultural Issues in Caring for Deaf People", *Family Medicine,* 1999; 31 (1): 17-22.

Barnett, Steven, MD, and Peter Franks, "Health Care Utilization and Adults Who Are Deaf: Relationship with Age at Onset of Deafness", *HSSR: Health Services Research,* 37:1 (February 2002).

Blanchfield, Bonnie B, Jacob J. Feldman, and Jennifer L. Dunbar, "The Severely to Profoundly Healing Impaired Population in the United States: Prevalence and Demographics", *Project Hope Analysis Brief*, October 1999.

Blanchfield, Bonnie B, Jacob J. Feldman, Jennifer L. Dunbar, and Eric N. Gardner, "The Severely to Profoundly Hearing-Impaired Population in the Untied State: Prevalence Estimates and Demographics", *Journal of the American Academy of Audiology*, April 2001, 12: 183-189.

Calderon, Jose L, MD and Robert A. Beltran, MD, MBA, "Pitfalls in Health Communication: Healthcare Policy, Institution, Structure and Processes", *Medscape General Medicine* 6 (1), 2004.

Collins, JG "Prevalence of Selected Chronic Conditions: United States, 1990-92." *Vital and Health Statistics*, Series 10, No. 194. 1997.

Deaf Rochester News, February-March 2004, Vol 8, Number 1.

Iezzoni, Lisa I., MD, MSc, Bonnie L. O'Day, PhD, Mary Killeen, MA, and Heather Harker, MPA, " Communicating about Health Care: Observations from Persons Who are Deaf or Hard of Hearing, *Annals of Internal Medicine,* 10 (140), March2, 2004.

Livadas, Greg, "Area Deaf Haven't Been Counted", *Rochester Democrat and Chronicle*, March 26, 2002.

Lucas, J.W., Schiller, J.S., and Benson, V. (2004, January) Summary health statistics for U.S. adults: National Health Interview Survey, 2001. (National Center for Health Statistics, DHHS

publication no. [PHS] 2004-1546) *Vital Health Statistics*, 10 (218).

McEntee, Maureen K., "Deaf and Hard-of-Hearing Clients: Some Legal Implications," *Social Work*, 40 (2), March 1995.

Parise, Nicole, "Breaking Cultural Barriers to Health Care: The Voice of the Deaf", Thesis published by the National Library of Canada, March ,1999.

Pollard, R., "Ethical Conduct in Research Involving Deaf People", in V.A.Gutman (Ed.), *Ethics in Mental Health and Deafness* (pp. 162-178). Washington, DC: Gallaudet University Press.

Steinber, Annie G., MD, Erin A. Wiggins, MBA, MS, Carlin Henry Barmada, MA, and Vicki Joy Sullivan, "Deaf Women: Experiences and Perceptions of Healthcare System Access, *Journal of Women's Health*, 11 (8), 2002.

Zazove, Philip, MD and David J. Doukas, MD, "The Silent Health Care Crisis: Ethical Reflections of Health Care for Deaf and Hard-of-Hearing Persons", *Family Medicine*, 1994 (26), 387-90.

There are numerous websites. Amongst the ones consulted during the writing of this paper are:

Deaf Today: Communication Through Sign Language: http://www.deaftoday.com

Deaf World Web: http://www.deafworldweb.org

The Deafened People Page: http://www.deafened.org

Gallaudet University: http://www.gallaudet.edu

Hearing Speech and Deafness Center: http://www.hsdc.org

The National Association of the Deaf: http://www.nad.org

National Technical Institute for the Deaf: http://www.ntid.rit.edu

Registry of Interpreters for the Deaf: http://www.rid.org

SignMedia: http://www.signmedia.com

Appendix I

Abbreviations and Terms

ADA: Americans with Disabilities Act

ASL: American Sign Language

BOCES: Board of Cooperative Education Services

CME: Continuing Medical Education

CODA: Children of Deaf Adults

CSE: Committee on Special Education

deaf: Refers to persons who have any hearing impairment

Deaf: Refers to persons who communicate with American Sign Language

DHTF: Death Health Task Force

ER: Emergency Room

FLHSA: Finger Lakes Health Systems Agency

NHIS: National Health Interview Survey

NTID: National Technical Institute for the Deaf

PSE: Pidgin Signed English

RAHA: Rochester Area Home Schools Association

RSD: Rochester School for the Deaf

TTY: Text telephone

Appendix II

STANDARD PRACTICE PAPER

PROFESSIONAL SIGN LANGUAGE INTERPRETING

Standard Practice Papers are available in brochure format through the national office. RID encourages use of these brochures for public distribution and advocacy.

Registry of Interpreters for the Deaf
333 Commerce Street
Alexandria, VA 22314
703/838-0030 (V)
703/838-0459 (TTY)
703/838-0454 (Fax)
www.rid.org

PROFESSIONAL SIGN LANGUAGE INTERPRETING

What is interpreting?
Interpreting, simply stated, is receiving a message in one language and delivering it in another. Not as simple as it sounds, interpreting is a complex process that requires a high degree of linguistic, cognitive and technical skills.

Professional sign language interpreters develop interpreting skills through extensive training and practice over a long period of time. Interpreters continue to actively improve their skills, knowledge, and professionalism through membership in RID. An increasing number of interpreters have completed college or university interpreter education programs, earning associates, bachelors, and/or masters degrees in interpreting. Some interpreters have also obtained advanced degrees in related fields such as linguistics or cultural studies.

Sign language interpreting is a highly specialized field; simply knowing both sign language and English does not qualify a person as an interpreter. The professional sign language interpreter is able to adjust to a broad range of deaf consumer preferences and/or needs for interpretation. Some deaf individuals use American Sign Language, a natural language with its own grammar and structure that is distinct from English. Others prefer a form of signing that more closely follows the grammar and structure of spoken English. The professional interpreter is expected to work comfortably along this wide spectrum. Sometimes it is necessary to have two or more interpreters working simultaneously in order to satisfy the preferences and needs of a varied audience.[1] On occasion, one of the interpreters may be a deaf individual[2] or a person fluent in a language other than English or American Sign Language. Interpreters should be aware of and sensitive to ethnic/cultural and linguistic concerns.

Where professional interpreters work
Interpreters work in a variety of settings and situations. Many interpreters work in private practice; they are self-employed. From scheduling assignments to handling billing, the interpreter is responsible for all business aspects.[3] The private practice interpreter may also receive assignments through interpreter service agencies. Others interpreters are salaried staff of an agency, institution, or corporation.[4] Still others interpret in educational settings—from pre-school to graduate school and any level in between. Interpreters work in settings as intimate as a private therapy session or as public as a televised address at a national political convention. The interpreter must be a versatile, flexible, skilled professional.

Interpreter Ethics
Professional interpreters adhere to the RID Code of Ethics. This Code, shown on the final page of this brochure, holds interpreters to a high level of professionalism in matters of interpretation and business practices.

Interpreting Credentials
In the field of interpreting, as in other professions, appropriate credentials are an important indicator of an interpreter's qualifications. The Registry of Interpreters for the Deaf (RID) awards certification to interpreters who successfully pass national tests. The tests assess not only language knowledge and communication skills, but also knowledge and judgment on issues of ethics, culture and professionalism. An interpreter may hold one or more certifications. Information on certifications is available from RID.

Some common sign language interpreting certifications are:

- CI - Certificate of Interpretation
- CT - Certificate of Transliteration
- CSC - Comprehensive Skills Certificate
- SC:L - Specialist Certificate: Legal
- IC - Interpretation Certificate
- TC - Transliteration Certificate
- CDI - Certified Deaf Interpreter

To verify an individual interpreter's current certification status, contact the Association's national office.

The Association has played the leading role in establishing a national standard of quality for interpreters and is committed to continued professionalism in the practice of sign language interpretation. Local interpreter service agencies, individual interpreters or the Association's national office can provide information on certified interpreters and interpreting throughout the United States.

RID has a series of Standard Practice Papers available upon request. Footnotes frequently reference these materials.

[1]see *Team Interpreting*
[2]see *Use of a CDI*
[3]see *Business Practices: Billing Considerations*
[4]see *Multiple Roles*

Registry of Interpreters for the Deaf

Search the RID Web Site   RID Home Page

How to Become an Interpreter   Online Store   FAQs   Contact RID

Membership   Testing System   CMP/ACET   Publications   About RID   Searchable Databases

RID's Code of Ethics

The Registry of Interpreters for the Deaf, Inc. has set forth the following principles of ethical behavior to protect and guide interpreters and transliterators and hearing and deaf consumers. Underlying these principles is the desire to ensure for all the right to communicate.

This Code of Ethics applies to all members of the Registry of Interpreters for the Deaf, Inc. and to all certified non-members.

1. Interpreters/transliterators shall keep all assignment-related information strictly confidential.

2. Interpreters/transliterators shall render the message faithfully, always conveying the content and spirit of the speaker using language most readily understood by the person(s) whom they serve.

3. Interpreters/transliterators shall not counsel, advise or interject personal opinions.

4. Interpreters/transliterators shall accept assignments using discretion with regard to skill, setting, and the consumers involved.

5. Interpreters/transliterators shall request compensation for services in a professional and judicious manner.

6. Interpreters/transliterators shall function in a manner appropriate to the situation.

7. Interpreters/transliterators shall strive to further knowledge and skills through participation in work-shops, professional meetings, interaction with professional colleagues, and reading of current literature in the field.

8. Interpreters/transliterators, by virtue of membership or certification by the RID, Inc., shall strive to maintain high professional standards in compliance with the Code of Ethics.

Revised Code of Ethics

As the NAD and RID move to create a new joint generalist interpreting test, the NCI felt it was necessary to undertake a total review of ethical behavior among interpreters in order to create a new code of ethics. A committee consisting of RID and NAD members was formed to begin the process of creating a new Code of Ethics for the interpreting profession that would reflect the changes in the field since the creation of the NAD and RID codes. What follows is a WORKING DRAFT of the new code. We are soliciting your input on this document.

DEADLINE FOR FEEDBACK IS 10/18/04

2nd Draft Revised Code of Ethics (Word File)