# Deaf Health Task Force Report

Finger Lakes Health Systems Agency August 2004

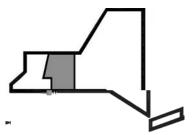
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#### FINGER LAKES HEALTH SYSTEMS AGENCY



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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,

Son Barret

Bonnie Dunny

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#### **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.<sup>1</sup> 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.<sup>2</sup>

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. 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.<sup>4</sup>

#### 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.<sup>5</sup> 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 wrong 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.

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

- 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<sup>10</sup>

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

- C 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.
- C 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:

- C Doctors do not have TTY lines, or do not answer the TTY.
- C 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
<ul> <li>Doctors do not have TTY lines, or do not answer the TTY</li> <li>Interpreters do not interpret for Deaf parents when their hearing child is talking to the doctor</li> <li>Doctors do not understand roles of hearing and Deaf family members</li> <li>Many interpreters at the doctor's office are not qualified or skilled</li> <li>The Deaf patient does not understand the doctor's instructions</li> <li>Doctors and patients do not understand each other's communication choices</li> <li>The computer systems for patients do not have space to add TTY numbers, relay number, or any labeling for charts.</li> </ul>	C Many times interpreters are not available C Interpreters' schedules are limited and they cannot stay late if appointment goes over

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..
- C 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.

<u>Recommendation:</u> 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.
- C 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

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

Recommendation: 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.
- C 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 <u>Deaf Rochester News</u> to allow Deaf people to ask questions and gain additional information.
- C Enlist teachers and others to educate Deaf children about visiting medical offices, roles and

- 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.
- C Provide emergency room personnel with updated lists of Deaf-friendly primary care providers to be given to Deaf patients who habitually

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#### 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

# RID

#### PROFESSIONAL SIGN LANGUAGE INTERPRETING

What is interpreting?
Interpreting simply stated is receiving a message in one language and delivering it in another.

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RID's Code of Ethics Page 1 of 2

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