

Final Report
Improving Access and Quality of Health Care for Deaf Populations
A Collaborative Project of the Sinai Health System and
Advocate Health Care
July 1, 2002 – December 31, 2012

Introduction

Communication barriers in healthcare are a subject of concern. They can lead to misdiagnosis, non-compliance with treatment and, ultimately, poor health outcomes. For more than ten years, Advocate Health Care (AHC) and the Sinai Health System (SHS) have researched and tested interventions to overcome communication barriers with Deaf patients. The over-arching goal of this research was to increase access to quality health and mental health care for Deaf and Hard of Hearing people both locally and regionally. These two Illinois healthcare institutions are the major providers of health services to patients who are deaf and hard of hearing in the Chicago area. Evaluation of the project was led by the Sinai Urban Health Institute. Each institution drew on its diverse resources, environment and patient demographics. Together, AHC and SHS provide care for thousands of Deaf people from a broad range of demographic groups. Results of the project's interventions clearly demonstrated a need for "deaf-friendly" health information and the effectiveness of that education when tailored to meet the needs of Deaf people. The project also uncovered the need for provider training and the receptiveness of providers to such training. The ten-year collaboration was funded by the Michael Reese Health Trust, with additional funding from the Augustana Henze Fund at Advocate Health Care, the Sinai Health System Employee's Fund and an anonymous funder.

Overview

Deaf persons are a cultural/linguistic minority, prone to health disparities experienced by other low-literacy and minority populations. The Deaf community shares a common language that requires face-to-face contact for full comprehension (American Sign Language or ASL). Ninety percent of Deaf people also share the unique experience of growing up in families who can hear, the majority of whom are unable to communicate in ASL. These communication barriers lead to significant gaps in a Deaf person's health and patient role knowledge and contribute to poorer outcomes. Deaf patients have

fewer doctor visits than those in the general population.¹ Yet they have more bed days due to illness or injury, have more days of disability and assess themselves as less healthy than the general population.

Over the course of ten years, the project worked with patients and advocates in the Deaf community, as well as health care providers, and health institutions to gain a better understanding of the needs of the Deaf patient and the resources needed by providers to better serve patients who are deaf or hard of hearing. With this information the project team then developed and evaluated interventions to address the identified barriers. The strategies undertaken during the ten years included assessment, health education, provider training and research.

The starting point, in 2002, was a detailed literature review followed by a survey of Deaf patients. The project conducted a ground-breaking survey of the health status, experiences and knowledge of a group of 203 Deaf patients. The survey revealed gaps in knowledge and a subsequent impact on health behavior. With this data in hand, the project undertook two tracks for further intervention and research: one track led to the development of patient health education curricula on three topics, the second track led to assessment, training and process improvement for providers and healthcare institutions.

The patient education intervention covered the topics of depression management, cardiovascular disease prevention and management, and patient activation and self-efficacy. Each of these three curricula proved effective in increasing participant knowledge and intent to change behavior.

The provider and institutionally-focused interventions included two approaches. The first approach was an educational training program for staff of Emergency Departments, Guest Services and Risk Management staff. The second approach was a process improvement project covering seven Chicago-area hospitals and seven outpatient clinics in which barriers to effective and efficient care for Deaf patients were identified, recommendations were made and process improvement plans were implemented to address those barriers.

Each step of the project included a rigorous evaluation. The products and tools produced for this work are listed at the end of the report and are available for use by others upon request. Numerous professional presentations and published articles resulted from this work and are also listed at the end of this report.

¹ Barnett S, Franks P. Health care utilization and adults who are deaf: relationship with age at onset of deafness. *Health Services Research*. 2002 Feb; 37(1): 105-120.

Health Survey of Deaf Patients

In order to better understand Deaf people's health status, health care experiences, health knowledge and communication styles, the project's first venture, or Phase I, was to conduct a face-to-face survey in ASL with 203 Deaf participants. An in-depth literature review revealed that there is scant professional literature documenting the relationships among health education, attitudes, behavior and risk factors in the Deaf community or the effectiveness of strategies to influence prevalence/incidence of chronic disease or other illnesses among this group. The survey was conducted in 2002 and 2003.

The survey instrument was a standardized face-to-face interview conducted in ASL by trained, ASL-fluent research-assistants, who are deaf themselves. The four domains of content were: 1) demographics, 2) access to and quality of care (e.g., interpreter use, methods of communication with provider), 3) health knowledge/attitudes/behavior (e.g. smoking, heart attack, HIV), and 4) health-related quality of life (SF-12, version 2). In order to allow for comparisons between the findings of the survey and the general population, as many questions as possible were selected from existing standardized or widely used questionnaires. This was the first time most of these questions had been used with a Deaf population.

The final survey instrument consisted of 139 questions and took about an hour to complete. Deaf participants were recruited according to criteria from the patient population of the two participating institutions. Informed consent was obtained and participants were given \$50 each for completing an interview.

Results: In terms of race and socioeconomic status, respondents from the two sites were very different. The resulting diversity of the surveyed population is an asset to the study. Specifically, the two groups differed significantly with respect to:

- race/ethnicity - SHS respondents were predominately non-Hispanic black (51%), whereas AHC respondents were predominately non-Hispanic white (82%)
- urban/suburban residence - SHS respondents resided primarily in the city of Chicago (86%), whereas AHC respondents resided primarily in the suburbs (70%)
- level of education - 61% of AHC respondents reported some education beyond high school compared to only 31% of SHS respondents

- employment status - 63% of AHC respondents reported they were employed versus only 29% of SHS respondents
- insurance status - 50% of SHS respondents reported being insured by Medicaid compared to only 18% of AHC respondents. Conversely, 66% of AHC respondents reported either employer sponsored or private insurance versus only 19% of SHS respondents.

Survey findings revealed gaps in knowledge when compared to the general population and barriers to accessing quality care. The results of five topic areas are discussed below.

1. Access to and Quality of Care. The interviewees were relatively well connected to two health care institutions that offer specialized services for Deaf persons. But even at these institutions, over one-third of those who had been hospitalized or seen in an Emergency Department (ED) indicated they had never had a certified interpreter present to assist them in communicating with the doctor. Respondents indicated a lack of knowledge of preventive health information. We could not conclude from this data whether physicians are not speaking with their Deaf patients about these topics or are presenting the information in a way that their patients do not completely comprehend.
2. Health Knowledge, Attitudes and Behaviors. The level of knowledge of survey respondents about their health and healthy behaviors was generally low across most topic areas. When comparison data was available for the general population, survey respondents had lower levels of knowledge than their counterparts.
 - a. Cardiovascular disease: nearly half of respondents (40%) could not identify any of the 7 most common warning signs of a heart attack, while 62% could not identify any of the 7 most common warning signs of a stroke. This is especially disconcerting given the known benefit associated with early treatment. We also asked respondents to identify the factors that increase one's risk for having a heart attack or a stroke. Approximately one-third of respondents (32%) could not identify any risk factors for a heart attack or stroke. Additionally, approximately 1 in 4 respondents (27%) could not identify any ways to control blood cholesterol levels. A paper has been published specifically on this topic and can be found at: <http://www.suhichicago.org/files/publications/A.pdf>.

- b. Knowledge of medical terms: One of our hypotheses when the study was initiated was that Deaf patients may not understand common English medical terms and therefore may miss important health information based simply on that fact. We sought to test this hypothesis by asking respondents to tell us what certain medical terms mean. The terms were finger spelled to the respondents, and four possible definitions were read. Findings suggest that 1 in 3 respondents could not correctly define the term “cancer”, and that even fewer could correctly define the term “cholesterol” (38%). Also, less than half of women surveyed correctly defined the term “pap smear”. Clearly, these results are indicative of a shortfall in the knowledge of English medical terms.
- c. Preventive Screenings: When the proportion of individuals undergoing routine cancer screening was assessed, findings were similar to reported rates in the general U.S. population. For example, a little more than half of the respondents 50 years of age and older indicated they had EVER been screened via sigmoidoscopy or colonoscopy. These numbers are about the same as the 48% of the general U.S. population 50 years of age and older. The proportion of women over 50 indicating that they had ever had a mammogram was over 90%. This compares well with the 89% of women between the ages of 50-59 nationwide. However, it is concerning that knowledge regarding these same tests was notably low among Deaf respondents. In other words, Deaf persons reported having invasive screening tests in the absence of information regarding the purpose of those tests. A publication focusing specifically on this topic can be found at:
<http://www.suhichicago.org/files/publications/CDP403.pdf>.
- d. Depression: It was not possible to estimate the potential prevalence of depression in the general Deaf patient population from the survey data given half of the respondents were recruited from a mental health setting. We therefore inferred the potential prevalence of Depression using some proxy measures:
 - i. Among those who were recruited from a general health setting (as opposed to a mental health setting), 16% reported that they had ever seen a counselor or psychiatrist for depression. Depression is often a missed diagnosis even among hearing people and is probably more likely to be missed in the Deaf population given

communication barriers with health care providers. Thus, the true prevalence is likely higher.

- ii. When we considered the same group of those recruited from the general health setting and asked who reported ever having seen a mental health counselor for any reason, not just depression, we found that 27% had.
- e. HIV: 40 % of survey respondents did not recognize that sharing intravenous drug needles placed them at higher risk for contracting HIV and 56% did not recognize that anal sex without a condom increased their risk. While intervention into HIV risk factors was beyond the scope of this project, this data was used by both SHS and AHC to develop interventions at their respective institutions.

3. Prevalence of Risk Factors

- a. Smoking: nearly 1 in 4 SHS respondents (24%) reported being current smokers, compared to only 1 in 10 AHC respondents (11%) ($p < 0.0001$). In other words, Deaf clients of SHS had smoking rates similar to those for the general US population (23%, BRFSS 2000), while AHC Deaf clients had significantly lower rates. Interestingly, the prevalence of former smokers at AHC was quite high (57%), implying a larger proportion had successfully quit.
- b. Cholesterol: 31% of those surveyed reported having high cholesterol levels. This is comparable to the 30% of the general U.S. population.
- c. High blood pressure: 43% of respondents reported that they had ever been told that they have high blood pressure. This figure is considerably higher than the 26% of people from the general U.S. population.

- 4. Sources of Health Information and Relationship with Health Knowledge. The relationship between sources of information about health and level of knowledge was explored. Analysis suggests that those reporting multiple sources of information about their health have a greater level of knowledge, even after controlling for level of education. When looking at the individual sources of information, only Internet access was statistically related to knowledge. For example, the 48% of respondents with Internet access on average reported more of the 7 most common warning signs of a heart attack (1.4 vs. < 1 ; $p < 0.005$), were more likely to call 911 if they thought they were having a heart attack or

stroke (70% vs. 53%; $p < 0.05$), and were more likely to correctly define the term “cholesterol” (55% vs. 24%; $p < 0.0001$) than were those without Internet access.

5. Health-Related Quality of Life. In recent years the concept of Health-Related Quality of Life (HRQOL) has established that people assess their own physical, mental and social well-being relatively well. While several inventories that measure HRQOL (e.g., SF-36, SF-12) have been developed and studied in different populations, we were unable to identify any which had been used with Deaf persons. We therefore felt it important to measure HRQOL as a part of our survey. The instrument we used was the SF-12, version 2. The translation of the SF-12, version 2 into ASL and its use with a Deaf population is in and of itself a major contribution of this research effort.

This instrument consists of 12 items, and yields an 8-scale health profile and 2 summary scores, a Physical Composite Score (PCS) and a Mental Composite Score (MCS). Respondents with higher socioeconomic status had significantly higher PCS than those with a lower socioeconomic status. In terms of their MCS, the two groups were nearly identical. These results suggest that SF-12 scores correlate well with other measures of physical and mental health status.

This survey demonstrated that even in optimal healthcare environments, Deaf patients do not always have access to effective communication with their provider. The result is a deficit in health information and less adherence to provider advice. These results point to a need for the development of more “deaf-friendly” health education materials and for the provider to be more proactive in eliciting information and feedback from the patient than is the norm for the general patient population.

A comprehensive report and publications resulting from the survey can be found at: <http://www.suhichicago.org/reports-publications/access-to-health-healthcare>.

Health Education for Deaf Persons: Cardiovascular Disease Prevention and Depression Self-management

Responding to the need for more relevant health education materials for Deaf people than was demonstrated in the 2002-2003 survey, the project proceeded to the development, delivery and evaluation of “deaf-friendly” health education materials on cardiovascular disease prevention (CVD) and depression self-management. Both curricula were intended to increase knowledge, improve self-efficacy and result in positive behavior change around these two health topics. Both interventions consisted of six, two-hour educational sessions held on a weekly basis over six weeks, with two additional weeks for collecting pre- and post-test data. Each two hour session was divided into three parts: 1) 80 minutes of participatory presentation (including role-

playing, role modeling and practice) of new material; 2) 20 minute break for socialization and a healthy snack; and 3) 20 minutes for review and homework. All classes were taught by health educators fluent in ASL, who are deaf themselves.

The success of each intervention was evaluated using a pre-post test methodology with each participant serving as her/hers own historical control in order to determine changes over time. We also brought participants together for another assessment 3 months following the 8-week session to assess whether improvements noted at Week 8 were maintained. One hundred fifty Deaf individuals completed all 8 weeks of the CVD classes (131 completed the 3-month follow-up assessment). Fifty-six Deaf individuals completed the eight-week depression self-management curriculum (39 completed the 3-month follow-up assessment).

Results of the Self-Management of Depression Health Education Intervention

1. Respondents' depression knowledge improved significantly over the 8-week course and at the 3-month follow-up when compared to Baseline. For example, participants were more likely to know the definition of clinical depression, how depression medication acts within the brain, and the best way to communicate thoughts and feelings to others, at the Week 8 and 3-month follow-up when compared to Baseline.
2. Participants reported significantly more confidence in their ability to control/manage depression at Week 8 and the 3-month follow-up when compared to Baseline. However, participants' level of perceived stress did not change throughout the intervention or at the 3-month follow-up.
3. Participants were significantly more confident in their ability to improve their mental health and engage in responsible health practices at both the Week 8 and 3-month follow-up when compared to Baseline. Participants also felt empowered to engage in physical activity at the conclusion of the intervention.
4. Participants reported significantly fewer depressive symptoms at Week 8 and the 3-month follow-up when compared to Baseline. Furthermore, those who were most depressed at Baseline saw the most significant decrease in symptoms, meaning that the intervention was especially helpful for those most in need.
5. There was no improvement in patient role knowledge among participants at Week 8 or the 3-month follow-up when compared to Baseline. This finding could be due to the relatively small amount of time spent on this topic in comparison to self-management of depression during the course.

Results of the Prevention of Cardiovascular Disease Health Education Intervention

1. Participants' knowledge surrounding cardiovascular disease and nutrition improved significantly over the 8-Week intervention and at the 3-month follow-up compared to Baseline. For example, significantly more participants knew to call 911 and take an aspirin if they thought they were having a heart attack at the Week 8 and 3-month follow-up compared to Baseline. Furthermore, a significantly higher proportion of participants knew that baked fish is a healthy alternative to red meat at Week 8 and the 3-month follow-up when compared to Baseline.
2. Participants were more confident in their ability to eat healthy, exercise, and engage in responsible health practices at Week 8 and the 3-month follow-up when compared to Baseline. Participants were also significantly more confident in their ability to respond to a heart attack or stroke at Week 8 and at the 3-month follow-up.
3. Participants were more engaged in improving their diet and participating in physical activity at Week 8 and the 3-month follow-up when compared to Baseline. Participants reported eating significantly more fiber and were more likely to consume the appropriate amount of calories from fat at Week 8 and the 3-months following the intervention when compared to Baseline. Participants also significantly reduced the amount of total fat and saturated fat they consumed. Even while participants were more confident in their ability to participate in physical activity, there was no significant increase in self-reported frequency of exercise at Week 8 or the 3-month follow-up when compared to Baseline.
4. Participants significantly improved their knowledge of the patient role at Week 8 and the 3-month follow-up compared to Baseline. For example, participants were more likely to know that they should ask for an interpreter when making a doctor's appointment.

Health education classes that integrate evidence-based practices for CVD prevention and self-management of depression into a linguistically and culturally sensitive model for Deaf persons are effective and well-accepted. Further research with a more stringent study design is needed to determine if these findings can be replicated and if they are generalizable to the entire Deaf community.

A comprehensive report of the process and evaluation findings can be found at: http://www.suhichicago.org/files/publications/PhaseII_Final_Report.pdf.

Health Education for Deaf Persons: Patient Activation

In partnership with a number of Deaf professionals working at social service agencies in the Chicago area, a Patient Activation group education program in ASL was developed, implemented and evaluated. The earlier findings indicated that Deaf patients experienced a knowledge deficit with regard to the patient role. Many Deaf patients may not know the right questions to ask of their provider, or even that they can ask questions. They may not know the appropriate information to share with their provider. They may not know much about their family's medical history. They may not know to request an interpreter when making an appointment. A curriculum to address this need was developed, based on work by Hibbard and Lorig² with the general population. It consisted of four consecutive modules. Content included: patient/provider communication, patient rights and responsibilities, informed consent, when to schedule a health care visit, preparing for the visit, communicating medical history, the risks and benefits of medication and other treatment options, making informed decisions about one's health, and understanding and managing chronic disease. The educational approach incorporated didactic presentations, participatory activities, take-home materials and interactive web-based activities. All Deaf adults enrolled in the class series participated in Modules 1, 2, and 3. Only those adults who had a chronic condition participated in Module 4. In total 214 participants enrolled in the patient activation class series, of which 198 (92.5% of enrolled) completed the entire series. Seven Trainers received the patient activation education and 6 Trainers were trained.

The classes were hosted by six organizations serving a Deaf population. Thirty class series were held. Each of the six participating organizations provided at least one staff person who received Train-the-Trainer training in the curriculum and then independently taught classes. All trainees/health educators were Deaf or Hard of Hearing and fluent in ASL.

A pre- and post-test design was utilized in evaluating the effectiveness of the Patient Activation class series. The pre-test was taken during the first class and the post-test was taken during the last class of the three- or four-class series, as appropriate. The evaluation was repeated six months after the last class, allowing for an assessment of sustained impact. One hundred forty-three (72.2%) participants returned for and completed the 6-month evaluation session.

² Hibbard JH, Stockard J, Mahoney ER, and Tusler M. Development of the Patient Activated Measure (PAM): Conceptualizing and Measuring Activation in Patients and Consumers. *Health Services Research*. (2004) 39(4):1005-1026; and Lorig K. Chronic Disease Self-Management: A Model for Tertiary Prevention. *American Behavioral Scientist* 1996; 39(6):676-683.

Participants were evaluated on the following:

- Patient Activation (PAM-13^{3,4})
- Health Services Navigation (Health Education Impact Questionnaire (heiQ): Health Services Navigation⁵)
- Patient Self-Efficacy Communicating with Physician (Lorig Scale – Knowledge Communicating with a Physician⁶)
- Patient Behaviors Communicating with Physician (Lorig Scale – Behaviors when Communicating with a Physician⁶)

The testing and validation of the evaluation tools used in this project was a lengthy and time-consuming process. Steps included translating the materials from English to ASL with the use of a gloss, validating the translated tools with the help of a group of bi-lingual Deaf persons who did not participate in this project, and the development of video materials in ASL for use in administering the evaluation.

Results of the Patient Activation Patient Education Intervention – Group Classes

1. Participants became more “active” participants in their healthcare and health decisions following participation in the Patient Activation class series. Specifically, Patient Activation scores improved significantly between the pre-test and post-test, with the improvement being sustained through six-months.
2. As evidenced by significant improvements in heiQ scores between the pre-test and post-test, participants were significantly more confident in their ability to interact with healthcare organizations and professionals, and to work with

³ Hibbard JH, Mahoney E, Stockard J, Tusler M. Development of the Patient Activation Measure (PAM): Conceptualizing and Measuring Activation in Patient and Consumers. *Health Services Research* 2004; 39 (4): 1005-1026.

⁴ Hibbard JH, Mahoney E, Stockard J, Tusler M. Development and Testing of a Short Form of the Patient Activation Measure (PAM). *Health Services Research* 2005; 40(6): 1918-1930.

⁵ Osborne RH, Elsworth GR, Whitfield K. The Health Education Impact Questionnaire (heiQ): an outcomes and evaluation measure for patient education and self-management interventions for people with chronic conditions. *Patient Educ Couns* 2007; 66(2): 192-201.

⁶ Lorig K, Stewart A, Ritter P, Gonzalez V, Laurent D, Lynch J. Outcome Measures for Health Education and Other Health Care Interventions. 1996, Thousand Oaks: Sage Publications. 97.

providers to meet their needs following participation in the Patient Activation class series. While scores decreased slightly between the post-test and the 6 month follow-up, they remained significantly higher than the pre-test score suggesting that improvements were largely maintained.

3. Confidence in communicating with a physician improved significantly between the pre-test and the post-test. Furthermore, the score continued to improve through the 6-month follow-up. The fact that the 6-month follow-up score was higher than even the post-test scores suggests that participants became more confident in their abilities as they had the opportunity via physician encounters to apply what they had learned.
4. Evaluation findings suggest that participants realized significant and sustained improvements in their behaviors when communicating with a physician. Scores were significantly higher at post-test than at pre-test, and remained significantly elevated at the time of the 6-month follow-up.
5. During the six month follow-up session qualitative information was solicited on seven questions via a group discussion. The qualitative information gathered via these 6-month feedback sessions reinforces the quantitative findings, further supporting the utility of the approach. As one example, when asked “What was the most important thing you learned from these classes?,” the three most prominent themes concerned interpreters (licensing, best practices and how to request), the importance of effective communication with a doctor, and the importance of asking questions, being assertive and working in partnership with a doctor. Each of these topics was emphasized in the curriculum. As a second example, responses to the question “How would you define an ‘active/assertive’ patient?” reinforce that participants were taking to heart key messages relating to more effective communication with healthcare providers, being proactive in health and treatment decisions, and asking questions.

Results of the Patient Activation Patient Education Intervention – One-on-one Instruction

Portions of the curriculum were adapted for use outside the classroom environment in a one-on-one approach with patients needing more individualized attention. Patients were recruited from a clinic that has an ASL fluent doctor. Informed consent was obtained after a face-to-face ASL explanation by a health educator who is herself deaf and fluent in ASL. The doctor outlined several goals for the patient intended to improve his/her health knowledge, health behaviors and ability to interact with healthcare systems and professionals. The most frequently set goals concerned taking medications

as prescribed or directed, creating a medication list and carrying it, and showing up to scheduled doctor's appointments on time. The health educator used portions of the existing curriculum related to the doctor's goals in educating the patient via one or two individualized educational sessions.

Eight patients were referred to participate in the pilot study, of whom six completed at least one session with the health educator. Three of the six received one session, while the remaining three required two sessions. The average participant received 105 minutes of education time (range: 60-180 minutes).

At the completion of the session, the health educator used an evaluation form to record the process utilized and her perceptions of whether or not the goals were met, to explain why goals may not have been met (if that was the case), and to record the time spent on each concept. The form then went back to the doctor who used it to document his perceptions of whether or not the goals were met following his next appointment with the patient. Five of the six participants in the Individualized Sessions returned to the doctor within three months and were assessed for their progress towards the goals emphasized during the session.

There was significant discordance between the opinion of the health educator and the opinion of the physician regarding whether goals were met, partially met, or not met. The degree of concordance varies by the goal, with the highest levels of agreement concerning the goals to "take medications as prescribed or directed", a goal that both the health educator and the physician felt was met or partially met in all cases (concordance=75%), and the goal to "refill medications in a timely manner" (concordance =100%). Conversely, the health educator was more likely to conclude that the goal to "create a medication list and carry it at all times" was met than was the physician (concordance=20%). Given that the health educator created the list with the participant, the issue most likely concerned the participant having the list with them when meeting with the doctor. In fact, of the 15 goals set for the 5 participants who completed an individualized session and returned to see the doctor within 3 months, the health educator concluded that 9 (60.0%) were met, and 6 (40.0%) were partially met. The physician concluded that 8 (53.3%) were met, 3 (20.0%) were partially met, and 4 (26.7%) were not met. There was concordance for 7 of the 15 (46.7%) between the physician and the health educator.

The goal in piloting the individualized approach was to determine its feasibility and to get a sense of the possible effectiveness. We found that participants were generally receptive to participating in the individualized sessions. We also found that progress was made towards most of the goals whether the health educator's or the physician's assessment was utilized (11/15 were either met or partially met when considering either

the health educator's or physician's assessment). Given the lack of concordance between the health educator and the physician regarding the degree to which goals were met, it does seem that the process should be improved before being implemented on a larger scale. For example, in situations where the health educator feels goals were only partially met, an additional session could be scheduled. Furthermore, if possible, the health educator and physician should sit down together following the physician's assessment of the participant's progress. At such time, they could discuss any differences in their assessments of whether or not the goals were met. A follow-up plan could also be established for situations in which a goal was not successfully met. The follow-up plan would likely involve an additional session with the health educator.

Availability of the Patient Activation Materials in an On-line Format

With the lessons learned from developing the curriculum, teaching Deaf individuals and training Deaf trainers, project staff believed the materials could be useful to others. Consequently, we adapted the materials used in our evaluation to an on-line format that can be used by individuals or by trainers in educating others. The on-line components include the patient activation materials from the project in 4 modules each containing a power point curriculum, video examples, a workbook and forms for patient use. These materials are available at:

<http://www.advocatehealth.com/immc/deafandhardofhearingprogram>

Training and Process Improvement for Health Professionals and Institutions

Results of the Training Curriculum for Emergency Department and Guest Services Staff and Risk Managers

Following the findings of the survey and the lessons learned in the CVD and depression health education classes, the project team convened a Deaf Advisory Council and held forums with Deaf advocates to get their input on how best to reduce the barriers uncovered in these two interventions. The most urgent need identified during these discussions was a reduction in barriers to effective and responsive communication in the Emergency Department (ED). The need was supported by the findings in the Robert Wood Johnson Foundation's (RWJF) issue brief *Speaking Together*, which finds that lack of quality interpreter services impacts adherence to medications, use of preventive services and understanding of diagnosis and treatment. The report concluded that, "Most hospital staff are not trained to work with interpreters and have little or no education in linguistic or cultural issues related to clinical care."⁷

⁷ Robert Wood Johnson Foundation. Addressing language barriers in health care: what is at stake – An Issue Brief from *Speaking Together*, <http://www.speakingtogether.org/5667/175585>, accessed 4/1/07.

In 2007, an intervention began, the goal of which was to increase providers' communication skills with Deaf patients. The project created and pilot tested an educational curriculum for key health professionals aimed at creating a more "deaf-friendly" hospital environment. The curriculum was developed after reviewing recent national guidelines. Among them were: the Delmarva guidelines for Services to Deaf and Hard of Hearing developed by the Delmarva Foundation for Medical Care, Gallaudet University and the Health Care Financing Administration; the Joint Commission on Healthcare Accreditation; the CLAS standards (National Standards on Linguistically and Culturally Appropriate Services from the US Office of Minority Health) and the RWJF *Speaking Together* materials.

The curriculum covered six content areas: 1) information about the pre-lingually Deaf population and American Sign Language, 2) regulatory requirements and risk management consequences, 3) how to identify and use certified ASL interpreters, 4) the use of technology for more efficient and effective communication (TTY, Video Relay, Video Remote Interpreting (VRI), Telemedicine, Web sites, fax and email), 5) how to establish "deaf friendly" procedures and protocols within your organization, and 6) resources for Deaf people seeking health care services. Emergency Department nurses, risk management staff and guest services staff were the target audience. The curriculum was presented to 134 staff from two institutions in 13 separate trainings.

Results from pre- and post-test evaluations of the ED and Guest Services staff, with each participant serving as his or her own control, showed that median knowledge scores improved significantly. Among the Risk Management staff, knowledge was high at pre-test resulting in no significant knowledge gain at post-test. Feedback from participants revealed that the most important lessons learned during the educational sessions were: how to communicate with a Deaf patient and an interpreter, that ASL is not the same as English – it has different grammar and syntax, that the average Deaf high school graduate reads at the 4th grade level, that not having an interpreter is a patient safety concern, and that family members are not sufficient as interpreters. Risk Management staff urged further training to increase awareness among unit and outpatient staff and the creation of a patient advisory board.

Results of a Process Improvement Intervention in Care Settings

Project members reviewed a number of recent studies that have analyzed barriers to effective communication in the health care setting and made recommendations for improvement. They were:

- 1) the Delmarva guidelines for Services to Deaf and Hard of Hearing developed by the Delmarva Foundation for Medical Care, Gallaudet University and the Health Care Financing Administration;

- 2) the Joint Commission on Healthcare Accreditation;
- 3) the CLAS standards (National Standards on Linguistically and Culturally Appropriate Services from the US Office of Minority Health) and
- 4) the Robert Wood Johnson Foundation *Speaking Together* materials.

In 2012, the National Quality Forum (NQF) adopted two measures to assess the effectiveness of language services in the hospital setting. These measures were developed and tested through a Robert Wood Johnson Foundation initiative, "Aligning Force for Quality." The two measures adopted were: 1) providing language services from a qualified medical interpreter, and 2) screening for each patient's preferred language.

In keeping with these efforts to establish standards, our project organized an institutional process improvement project with seven hospitals and seven outpatient centers in the Chicago-area. We also developed recommendations for the Advocate Medical Group Corporate level based on the interviews at five of their sites and four staff at their central office. The seven hospitals were: Advocate Good Samaritan, Advocate Lutheran General, Advocate Illinois Masonic Medical Center, Mount Sinai, Schwab Rehabilitation, Stroger and University of Illinois Medical Center. The seven outpatient clinics were: Advocate Medical Group Arlington Heights, Advocate Medical Group Beverly, Advocate Medical Group, Nesseset, Advocate Medical Group Olympia Fields, Advocate Medical Group Ravenswood Family Practice, Sinai Medical Group North Lawndale, and Sinai Medical Group Touhy.

The objective of this phase of the project was to increase the number of best practice guidelines related to increasing Deaf patient access that are implemented at each hospital or outpatient center. An assessment tool, "Effective Communication and Patient Safety Guidelines When Treating Deaf Patients," was developed after reviewing available reports that detail guidelines for assuring effective communication in the healthcare setting.

Two tools were used in conducting the assessment at each institution. The first was an assessment tool. The assessment tool covered seven topics: the existence of policy and procedure, staff knowledge of policy and procedure, staff education on that policy and procedure, actual practice in certain medical situations, patient education, community outreach and organizational support. Face to face interviews were conducted using this tool. The second tool was an anonymous, self-administered survey of ten questions on similar topics which front-line staff were asked to complete. At the beginning, the surveys were paper surveys and supervisors asked staff to fill them out. In hopes of getting more staff to complete surveys we altered the process to

an on-line format on “survey monkey” with supervisors asking staff to fill them out. The response was similar with both methods.

The data gathered from these two sources was compiled into reports indicating strengths, barriers and recommendations for improvement for each institution. Armed with this information each institution developed an action plan for improvement. A six-month follow interview detailed progress in achieving the goals of that action plan.

The project took place between July 2009 and December 2012. In all 157 individuals participated in face to face interviews and 305 front line staff completed the self-administered survey. All but one site completed the follow up interview to report action taken in response to the recommendations.

Table 1 summarizes the recommendations made to both hospitals and outpatient centers following the assessment and the percentage of sites that received that recommendation. It also details the percentage of those institutions receiving the recommendation that took steps to address the recommendation. As noted above, all but one of the fourteen institutions provided follow up information.

TABLE 1. Healthcare Organizational Assessment			
Process Improvement Project			
Improving Access to Care for Deaf Individuals			
Category	Recommendation	% Sites Need to Address	% Sites with Recommendation that Did Address
I. Policy & Procedure			
	1. Adopt policy to ensure that the request for & presence of an interpreter during a medical visit is routinely documented in a standard manner.	57%	100%
	2. Adopt a policy to ensure that there is a method to document a patient's refusal of an interpreter.	43%	67%
	3. Have attendings who are not directly employed by the institution formally acknowledge their role in ensuring effective communication with Deaf patients.	14%	0%
	4. Adopt policy to ensure standard and routine documentation of hearing loss and preferred mode of communication.	57%	100%
	5. Adopt a policy for assessing the need for & use of auxilliary listening devices.	14%	50%

	6. Adopt policy & guidelines to ensure availability of qualified ASL interpreters 24/7.	7%	100%
	7. Adopt policy to ensure clear, easy method for staff to access policies.	29%	100%
II. Education of Staff			
	1. Add ADA and its requirements to new employee training.	43%	100%
	2. Ensure that all employees receive training on Deaf culture and ASL as a language different than English and how to effectively communicate with Deaf persons.	71%	50%
	3. Ensure that the request for & presence of an interpreter during a medical visit is routinely documented in a standard manner.	57%	88%
	4. Ensure that there is a method to document a patient's refusal of an interpreter.	43%	67%
	5. Adopt a standard method to document hearing loss and preferred mode of communication.	57%	100%
	6. Ensure that a Deaf patient is appropriately identified as needing an interpreter when referred for further testing or care.	21%	100%
	7. Develop annual competencies on ensuring access to quality care for Deaf patients.	7%	100%
III. Access to Effective Communication			
	1. Install a video remote interpreting system & ensure access to all institutional departments.	36%	60%
	2. Adopt a picture book for communication on routine matters.	14%	100%
	3. Consider hiring staff interpreter if volume allows to ensure that interpreters are available as needed & not just in 2 hour segments.	14%	50%
	4. Ensure that institution has assisted listening devices in good working order.	50%	100%
	5. Ensure that all TV's have closed-captioning and that staff know how to activate it.	14%	50%
	6. Install a videophone for patient use.	14%	0%

IV. Patient Education Materials			
	1. Make available ASL patient education materials to Deaf patients either on the in-house system or with a link for the patient to access directly.	100%	36%
V. Organizational Support for Access for the Deaf Individual			
	1. Adopt a method to ensure that patient satisfaction data is collected from Deaf patients.	29%	25%
	2. Extend patient visit block time to allow for interpretation.	7%	0%
	3. Appoint one staff person to oversee services for Deaf patients.	7%	0%
VI. Collaboration with the Deaf Community			
	1. Conduct outreach to Deaf community to let them know of the available services.	50%	29%
	2. Post a flyer informing patients of their right to an interpreter free of charge. Include the TTY number on that flyer.	43%	100%
	3. Improve web site to be more useful to Deaf patients.	7%	0%

All fourteen institutions have a good foundation in policy or procedure and staff knowledge and experience in providing effective communication to Deaf patients. They expressed a commitment and pride in the services they provide to their Deaf patients. The discussion of the recommendations and action steps to address those recommendations is presented by each of the seven categories of the assessment questionnaire.

Policy. All hospitals had in place a policy to address effective communication with Deaf patients.

Procedure. The outpatient centers for the most part lacked formal policy but had well established procedures to guide their communication with Deaf patients.

Staff Knowledge of Policy and Procedure. Staff of the hospitals and outpatient centers interviewed was generally familiar with policy/procedure and could identify a patient with hearing loss status and determine the preferred mode of communication. A deficit was found in 10 of the sites in the standard and routine recording of that assessment in the patient's electronic medical chart. Action steps have been instituted at 8 of these 10 institutions to address this deficit.

Another deficit uncovered was the lack of routine recording of the presence of the interpreter during a visit. All staff recognized that it should be recorded, but admitted that it is not done routinely. Action steps in both hospitals and outpatient centers took the form of discussion and re-training at provider or unit meetings.

Staff Training. All staff are required to go through new hire orientation which covers the Americans with Disabilities Act. Most staff have no recollection of the ADA from this training. New hire training also includes some overview of the tools available to support effective communication with non-English speaking patients. It does not always specifically mention Deaf patients. We encouraged the hospitals and outpatient centers to consider providing annual competencies and/or trainings on these issues so as to keep the goal of effective communication front and center. Action steps taken by the participating institutions resulted in some form of trainings on the subject for this first six-month period following the assessment.

Effective Communication in Clinical Settings. Interviewees with direct patient contact were asked how they and their staff communicated with a Deaf patient about specific clinical issues including: obtaining informed consent, gathering medical history, explaining test results, diagnostic impressions, treatment choices and/or treatment recommendations, and explaining discharge plans. Most reported that they wanted to have a qualified sign language interpreter present in these situations and that they knew how to call for an interpreter. Nevertheless, there were some interviewees who thought it acceptable to write back and forth or talk slowly in these situations. Ongoing training on these issues was recommended and has been carried out in all but 2 of the institutions.

- *Qualified Sign Language Interpreters.* At the outset of the project, 2 hospitals had a Video Remote Interpreting (VRI) system in place. During the course of the project, 3 additional hospitals installed VRI. All report that the VRI has been very well received by staff and patients alike. In addition, 2 hospitals employ staff ASL interpreters, while one additional hospital conducted a fiscal review of contractual interpreter cost as a result of our assessment and concluded that it would be cheaper and more effective to hire a staff interpreter. That interpreter was hired.

- *Assisted listening devices.* The hospitals all have some assisted listening devices and most have procedures in place to ensure that they are centrally available and in good working order.
- *Picture book.* Three hospitals use a picture book to facilitate communication in non-clinical settings. One additional hospital tried the picture book with mixed patient reviews.
- *Closed caption TV's for in-patient units.* All hospitals had close captioning capability and most staff knew how to turn it on. One hospital was advised to train staff on the use of closed captioning.
- *Videophone for patient use.* Two hospitals have videophones in public areas for patient use. The suburban hospitals found that their Deaf patients have access to smart phones and do not need the public videophone. One additional inner city hospital was advised to investigate the possibility of installing such a phone.

Patient Education. All institutions reported providing their Deaf patients with the same kind of patient education as their hearing patients. That generally takes the form of handing them print materials written in English or Spanish, sometimes aided by provider overview and assisted by an interpreter. We recommended to all fourteen institutions that they provide patient education materials in ASL to their Deaf patients on a case by case basis. A list of these on-line materials available was given to participating institutions.

Outreach to the Deaf Community. Because the participating institutions all have Deaf patients and a commitment to quality service, we encouraged each of them to think about reaching out to Deaf organizations to let them know about the services available. Four of the institutions have initiated outreach.

Organizational Support. In every participating institution patient satisfaction is conducted by a written communication and/or a phone call after the medical encounter. Both methodologies leave the Deaf patient at a deficit. We encouraged the institutions to devise a method of garnering patient satisfaction in ASL. Three of the hospitals have begun discussion with the provider of their patient satisfaction surveys to develop a method to address this deficit.

In summary, staff welcomed this process improvement project and took steps to remedy deficiencies found. It should be noted that both Advocate and Sinai have a long tradition of serving Deaf patients and the results found at our institutions may not be indicative of the standards at other institutions. It should also be noted that while the staff of the sites was supportive of this process improvement project, an administrative

leader had asked them to participate. All these providers are very busy people. Securing the follow up information necessitated a lot of prodding.

Lessons Learned Summary

(A full discussion of lessons learned is contained in a separate document)

It is imperative that all local organizations serving Deaf persons be identified at the onset of any project working with a Deaf population and that time and energy be devoted to establishing connections with these organizations. These connections will facilitate acceptance of the project by the Deaf community, effective recruitment and assistance in creating a program that is effective.

Health education classes that integrate evidence-based practices into a linguistically and culturally sensitive model for Deaf persons are effective and well-accepted. Development of the linguistically appropriate health education content requires a lot of preparation and testing with the help of Deaf health educators.

The Americans with Disabilities Act requires healthcare providers – in both inpatient and outpatient settings – to take the necessary steps to ensure effective communication with their Deaf patients. Providers have received little training on how to effectively communicate with their Deaf patients. Training, when provided, is effective in promoting access to effective communication and quality care for Deaf patients.

Healthcare institutions need to develop specific policy and protocol and train staff on how to communicate with Deaf patients. Health providers need to be familiar with a variety of communication tools available to facilitate communication with Deaf patients and allow for additional time for interpretation during patient visits, even though there is no added reimbursement for this service.

The Deaf population has had little or no experience participating in research. Despite this unfamiliarity, our participants were pleased to be asked to be a part of research and enthusiastically gave of their time. The retention rate associated with our interventions was generally higher than one would experience in research with other hard-to-reach and vulnerable populations

Conducting research and health education in a Deaf population is different from performing the same tasks in the general hearing population. Considerable effort is required to ensure that materials and evaluation questions translated from English into ASL are clearly understood by the intended audience.

Project Staff

Sinai and Advocate shared the project directorship. Teri Hedding, MA, Manager of the Sinai Deaf Health Program, was with the project throughout. At Advocate leadership was provided for the first seven years by Toby Perlman, PhD, a licensed clinical psychologist and manager of Advocate Metro Outreach. For the remaining three years of the project, Barbara Giloth, DrPH, VP of the Advocate Charitable Foundation, provided leadership. Research efforts were led by Helen Margellos-Anast, MPH, of the Sinai Urban Health Institute, with guidance from the Institute's Director, Steven Whitman, PhD. and research assistance from Melanie Estarziau, MPH, Sheena Freeman, BS, and Jennifer Orsi, MPH. Research assistants included Lewis Lummer, PhD, and Melvin Patterson. Additional Advocate team members have included: Carroll Cradock, PhD; Dortehea DeGutis, MD, one of two psychiatrists in the Chicago area proficient in ASL; Lisa Foster, MA; Lisa Kivland, RID certified staff interpreter and Raymond Rogers, MSW staff therapist. At Sinai team members have included: Gary Kaufman, MD, Medical Director of Sinai Deaf Health, David Ebert, MD, and Michael Lotke MD – all three fluent in ASL; Kristin Balfanz-Vertiz, MSW, Ramon Canellada and Crystal Schwartz. Linda P. Miller, MEd, worked at different times for both Sinai and Advocate during the ten years of the project.

Input from the Deaf Community, Deaf Service Providers and Experts in the Field

Project Advisory Committee: In 2007 an advisory committee was formed. Seven service providers agreed to provide advice and insight to project management. Those providers were: Carmen Aguilar, Deaf Services Coordinator, Fox River Valley CIL, Elgin; Julie Chavez, Deaf Services Coordinator, DuPage Center for Independent Living, Glen Ellyn; Fr. Michael Depcik, Catholic Office of the Deaf, St. Francis Borgia Church, Chicago; Kim Eischen, Manager of Deaf Services, Chicago Hearing Society, Chicago; Kate Kubey, Program Director, Mayor's Office for People with Disabilities Substance Abuse and AIDs Prevention for the Deaf and Hard of Hearing, Chicago; Sarita Phadke, Deaf Services Coordinator, Schaumburg Township Center for Independent Living, Hoffman Estates; Devon Whitmore, Deaf Services Coordinator, Access Living, Chicago.

Focus Groups: In 2007 three focus groups were constituted to advise project management on future directions. Twenty-one Deaf consumers participated in two focus groups and thirteen providers participated in another focus group.

Peer Reviews: Nine Peer Reviews were held during the 10 years of the project.⁸ A core group of Chicago-area leaders of the Deaf community attended all the Peer

⁸ March 19, 2003; February 11, 2004; March 2, 2005; March 1, 2006; April 26, 2007; October 2, 2008; September 10, 2009; September 2, 2010 and November 16, 2012.

Review sessions. We thank them for their ongoing commitment, insight and support for the project.

Several nationally known experts in the field attended one or more Peer Reviews. Their advice and knowledge were beneficial to the project. They are:

Steven Barnett, MD, University of Rochester

Senda Banaissa, MPH, Gallaudet University

Elaine Jones, PhD, RN, FAANP, Arizona State University

Robert Pollard, Ph.D., University of Rochester

Howard Rosenblum, JD, National Association of the Deaf

Policy Advocates: A number of persons working in the policy arena attended one or more of the Peer Reviews. Their insights were and will continue to be helpful.

Access Living staff

Catholic Office of the Deaf

Director of the IVIN project from MCHC JCAHO policy staff

Equip for Equality staff

Health and Disability Advocates staff

Hospital leaders from Advocate, Sinai and Stroger

Illinois Deaf and Hard of Hearing Commission policy staff

Illinois Deaf Latinos Association staff

Illinois Hospital Association staff

Mayor's Office for People with Disabilities staff

Statewide Independent Living Council of Illinois & its affiliates

University of Illinois at Chicago, School of Public Health professor