

Deaf People and Healthcare

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## 2. Structured Abstract

**Purpose:** The grant's objective is for Steven Barnett to become a leading expert and independent researcher in the area of health of deaf people. The research project's objective is to assess healthcare access and quality experienced by deaf people who primarily communicate with American Sign Language (ASL).

**Scope:** Deaf ASL users comprise understudied and medically underserved language minority populations. Health research with these populations is best conducted in ASL. The pilot research surveyed 99 deaf adult ASL users in Rochester, NY, about their healthcare experiences using a computer-based version of CAHPS® that presented survey items in ASL via video. Deaf people comprise an **AHRQ Priority Population**.

**Methods:** Mentored career development methods included individualized curricula developed with mentors, formal coursework, and attending selected scientific conferences. Research methods consisted of qualitative and quantitative methods, translation, back-translation, cognitive interviews, and respondent driven sampling.

**Results:** Dr. Barnett is recognized as a leading expert on health research with deaf people. He led the team that successfully adapted CAHPS for use in ASL and piloted that instrument with 99 deaf adult ASL users. The research identified important domains not measured by the source English survey and found a high prevalence of emergency department use reported by participants. Findings from the survey adaptation process and pilot administration of CAHPS-ASL inform future research and healthcare with deaf ASL users and identify potential changes to the source English survey and surveys with other language-minority populations.

**Key Words:** health services research, prelingual deafness, sign language, healthcare disparities, CAHPS

## 3. Purpose (Objectives)

The objective of the grant is for Steven Barnett to become a leading expert and independent researcher in the area of health of people who are deaf. The objective of the research project is to assess healthcare access and quality experienced by deaf people who primarily communicate with American Sign Language (ASL).

Dr. Barnett's career development objective had two main goals:

**Goal 1:** Dr. Barnett will enhance his research skills in order to design and conduct independent research.

**Goal 2:** Dr. Barnett will augment his research skills by developing advanced ASL skills and fluency in the sociocultural aspects of deafness.

The research objective had two technical aims and one research aim:

**Technical Aim 1:** To adapt CAHPS ambulatory surveys for use with adults who communicate in American Sign Language (ASL).

**Technical Aim 2:** To pilot an adapted CAHPS (CAHPS-ASL) with deaf adult ASL users who receive care in four different healthcare settings (ASL-skilled family physicians, interpreted outpatient offices, interpreted emergency department services, and non-interpreted healthcare services).

**Research Aim 1:** To study the healthcare experiences of deaf adult ASL users using CAHPS-ASL.

This grant helps develop necessary resources to achieve an overarching goal to address disparities in health and healthcare experienced by deaf ASL users, their families, and their communities. Deaf people are included in the **AHRQ Priority Populations** (people with disabilities).

## 4. Scope

**Background:** Deaf ASL users comprise an understudied and a medically underserved language-minority population. American Sign Language is not English, and English is a second language for many ASL users. Health research with these populations is best conducted in ASL.

**Context:** The Rochester Deaf Health Task Force (2002-2003), composed of leaders from the local deaf, healthcare, and health research communities, identified healthcare communication barriers as an important topic and acknowledged the dearth of relevant data on the healthcare experiences of deaf ASL users.

**Settings:** We recruited deaf adult ASL users from community settings and healthcare settings in Rochester, NY. Rochester has a large per capita population of deaf people who use sign language.

Participants: The pilot research surveyed 99 deaf adult ASL users in Rochester, NY, about their healthcare experiences using a computer-based version of CAHPS® that presented survey items in ASL via video. Deaf people are considered an **AHRQ Priority Population** (people with disabilities).

Incidence/Prevalence: We do not have data on the size or demographics of the Rochester (or US) deaf community. The lack of the most rudimentary data from deaf populations thwarts efforts to engage deaf communities and healthcare systems in setting priorities for health improvement and chronic disease prevention programs.

## 5. Methods

Mentored Career Development Methods (Goals 1 & 2): Dr. Barnett worked with his primary mentor, team of co-mentors, and other teachers to identify and select activities to help achieve his research skills development goals. Activities include coursework, seminars, summer programs with intensive experiences (in ASL, survey methods, and epidemiology), selected national and international conferences, and individualized curricula and guided readings, including on the responsible conduct of research. Additionally, Dr. Barnett worked with his mentors regarding his roles and responsibilities as Associate Director of a CDC-funded prevention research center; chair of a multidisciplinary research committee; and mentor to students, fellows, and junior faculty. Dr. Barnett met weekly with his primary mentor and his co-located co-mentors. Dr. Barnett consulted with off-site co-mentors via email and during in-person meetings during national and international conferences.

Research Methods, CAHPS-ASL pilot:

Approach: The process to adapt CAHPS for use with deaf ASL users (**Technical Aim 1**) included collaboration with the CAHPS team throughout the process and stakeholder engagement to prioritize survey topics and identify new topics/domains, add deaf-related demographic items, translate/adapt survey items and back-translate, and conduct in-depth individual cognitive interviews. We also developed outreach and recruitment approaches, because the usual triggers for a CAHPS survey do not indicate if the individual is a deaf sign language user. To better evaluate our adaptation and approach, we conducted exit interviews with many of the survey participants.

Data Collection: Researchers from the University of Rochester and Rochester Institute of Technology worked with community members and programmers to design the computer kiosk-based software interface for surveys that used video to present survey items in sign language. We recruited from healthcare and community settings.

Measures: CAHPS-ASL is based primarily on the CAHPS Physician and Group Surveys. Stakeholders identified hospital emergency department use as a priority topic, so we also used CAHPS questions on emergency department use from the CAHPS Health Plan Surveys. We included items on deaf-related demographics (e.g., age-at-onset of deafness, preferred language, and childhood school setting) and developed new items based on recommendations from stakeholders.

Pilot (Technical Aim 2): Over 12 months, 99 deaf adults sign language users participated in the survey. Survey items allowed us to determine emergency department use, visits with and without interpreter services, and visits with an ASL-skilled clinician.

Data analyses (Research Aim 1): We used SPSS software to determine frequency distributions for each survey item related to sociodemographics, healthcare, and health and conducted some subgroup analyses.

Limitations: The pilot was conducted in Rochester, NY, a city with many deaf ASL users. The Rochester deaf community is not typical of deaf communities in other US cities – Rochester has many highly educated deaf ASL users, including deaf physicians and other clinicians, and a large number of deaf social and professional organizations. The size of the deaf population and its engagement with the healthcare and health research infrastructure creates opportunities for community-engaged health research. It is likely that disparities identified in Rochester underestimate the magnitude of the disparities experienced by deaf people in other cities.

Additional mentored research skills development (Goals 1 & 2):

Secondary data analyses: Dr. Barnett worked with mentors to continue to develop his research skills in secondary data analyses of large national datasets. These projects include work with the National Health Interview Survey and linkages to the National Death Index (NDI) (some of this work is a follow-up to Dr. Barnett's previous **AHRQ/AHCPR** funded research **R03 HS009539**), National Health and Nutrition Examination Survey (NHANES), and AHRQ's Healthcare Cost and Utilization Project (HCUP). Status: Dr. Barnett has

presented some research findings at national conferences (see Products). Dr. Barnett is in the process of preparing other abstracts and manuscripts.

**Surveillance:** Dr. Barnett worked with mentors to develop research skills relayed to survey methods and surveillance. This includes Dr. Barnett’s role in the Rochester Deaf Health Survey 2008, a broad, sign language public health surveillance modeled after the Behavioral Risk Factor Surveillance System (BRFSS). Status: Dr. Barnett has presented on methods and findings at national conferences and is an author on some publications (see Products). Dr. Barnett is in the process of preparing other abstracts and manuscripts.

**Prevention programs:** Dr. Barnett worked with mentors to develop skills related to clinical trials and intervention research. This includes Dr. Barnett’s role in the Deaf Weight Wise clinical trial, the first randomized trial of a healthy lifestyle intervention adapted for use with deaf adult ASL users. Status: The trial is ongoing. Dr. Barnett has presented on methods at national conferences (see Products) and is in the process of preparing other abstracts and manuscripts.

**Community-based participatory research (CBPR):** Dr. Barnett worked with mentors to develop skills related to community engagement and participatory research. Dr. Barnett used and developed these skills in all of his research projects. Status: Dr. Barnett has presented on this topic at national conferences, is an author on some publications (see Products), and is in the process of preparing other abstracts and manuscripts.

**Other research methods:** Dr. Barnett worked with mentors to develop additional research skills to examine the adaptation of research methods for use with deaf ASL users. Dr. Barnett is a co-investigator on a project to study research informed consent with deaf adult ASL users. This study brings together skills related to translation, back-translation, health literacy, use of video, and clinical trial design. Status: The trial is ongoing. Dr. Barnett has presented to University of Rochester audiences about this research project.

**Deaf-related competencies:** Dr. Barnett worked with mentors, colleagues and other teachers, including members of the research team and community board, to further develop his ASL skills and cultural appropriateness. In addition to directed learning, the number of opportunities to see and use ASL in Dr. Barnett’s primary work environment increased during the course of this K08. Status: Skills development is ongoing.

**Mentoring:** Dr. Barnett worked with mentors to develop skills related to mentoring others. During this K08, Dr. Barnett mentored students, fellows and junior faculty, some of whom are deaf or from another group underrepresented in research. Status: Dr. Barnett is an author on some publications (see Products).

**6. Results**

**Career Development Outcomes:** Dr. Barnett is recognized for his expertise as a researcher working with deaf populations. Evidence for this includes invitations to present on the topic (**AHRQ 2012 Annual Conference** and the 2012 Deaf Mental Health Research Priority Consensus-Planning Conference co-sponsored by SAMSA), invitations to review research grant proposals on the topic, and invitations to participate on research grant proposals. After the 5-year AHRQ K08 early career Mentored Clinical Scientist Development Award, Dr. Barnett was successful in obtaining a NIH-funded K18 Mid-career Short Term Mentored Research Career Development Award on the topic of suicide risk, social networks, and deaf sign language users. Suicide risk was a priority topic selected by the Rochester, NY, deaf community, and this subsequent research career development allows Dr. Barnett to develop additional research skills in order to better conduct research with this AHRQ Priority Population.

<b>Research funding in place at the end of Dr. Barnett AHRQ K08</b>		
<b>Role</b>	<b>Topic</b>	<b>Funder</b>
PI	Suicide risk, social networks, deaf adult ASL users	NIH (NIDCD, OD)
Associate director, research chair	Community-based public health research with deaf ASL users and people with hearing loss	CDC Prevention Research Centers Program
Contract researcher	Suicide risk and v eterans with hearing loss	Veterans Administration
Co-investigator	Informed research consent with deaf adult ASL users	NIH (NCATS, NIDCD)

Principal Research Findings: Overarching lessons and findings from the K08 research project include:

- It is possible to successfully adapt and administer a healthcare experience survey for use with deaf ASL users.
- A healthcare experience survey in ASL was well received by deaf adult ASL users.
- The process of translating survey items from English into ASL identified some ambiguities in the source English.
- Domains suggested by the deaf community for inclusion in CAHPS ASL (communication outside of an appointment and anxiety about communication for a scheduled visit) yielded important findings.
- We successfully recruited a broad age range, but recruitment challenges exist and warrant more exploration.
- Collaboration with the CAHPS team (source survey) was essential for the success of this project.

Important findings from analyses of the CAHPS ASL survey data include:

- Very low prevalence of current smokers in our sample (consistent with earlier research findings).
- High prevalence of emergency department use in our sample (consistent with earlier research findings).
- Many participants report being anxious about communication in the doctor's office.
- Approximately one third (36%) report always having interpreter services when needed.

Discussion: This K08 Mentored Clinical Scientist Development Award helped to develop necessary resources---an expert researcher and an accessible survey---to achieve an overarching goal to address disparities in health and healthcare experienced by deaf ASL users, their families, and their communities. Ongoing work needs to develop processes that use evolving technology to make the accessible CAHPS (CAHPS-ASL) widely available for use by healthcare systems, researchers, and deaf communities. Additional studies in partnership with deaf communities outside Rochester, NY, may identify new important survey domains as well as opportunities to improve the survey design.

Conclusions: Healthcare surveys, and systems for their administration, can successfully be adapted for use with deaf ASL users.

Significance: Deaf ASL users, their families, and their communities represent populations with limited access to healthcare and health communication and a component of the **AHRQ Priority Populations** (people with disabilities). Accessible surveys can be used with deaf communities to identify strengths and disparities and can also be used to follow progress as we implement and evaluate new programs to address disparities. The process of creating surveys in ASL has identified areas for improvement in the source English-language surveys. Domains identified by the deaf community for inclusion in this pilot CAHPS research are likely relevant for use with other limited English proficiency populations. Having a health researcher with expertise in work with deaf communities, and an accessible healthcare survey, supports the development of programs to achieve the **Healthy People 2020** goal to promote the health and well-being of people with disabilities.

## 7. List of Publications and Products

Publications (7):

**Barnett S.** Children/families with hearing loss - more research needed. [invited commentary] *Annals of Family Medicine*. 2007 December 24; 5. <http://www.annfammed.org/cgi/eletters/5/6/528>

Pollard RQ, **Barnett S.** Health-related vocabulary knowledge among deaf adults. *Rehabil Psychol*. 2009 May;54(2):182-5. PMID:19469608.

**Barnett S**, McKee M, Smith SR, Pearson TA. Deaf sign language users, health inequities, and public health: opportunity for social justice. *Prev Chronic Dis*. 2011 Mar;8(2):A45. PMC3073438. [http://www.cdc.gov/pcd/issues/2011/mar/10\\_0065.htm](http://www.cdc.gov/pcd/issues/2011/mar/10_0065.htm)

Mathews JL, Parkhill AL, Schlehofer DA, Starr MJ, **Barnett S.** Role-reversal exercise with Deaf Strong Hospital to teach communication competency and cultural awareness. *Am J Pharm Educ*. 2011 Apr 11;75(3):53. PMC3109807. <http://www.ajpe.org/doi/pdf/10.5688/ajpe75353>

Pandhi N, Schumacher JR, **Barnett S**, Smith MA. Hearing loss and older adults' perceptions of access to care. J Community Health. 2011 Oct;36(5):748-55. PMC3197225.

McKee MM, **Barnett S**, Block RC, Pearson TA. Impact of communication on preventive services among deaf American Sign Language users. Am J Prev Med. 2011 Jul;41(1):75-9. PMC3117257.

**Barnett S**, Klein JD, Pollard RQ Jr, Samar V, Schlehofer D, Starr M, Sutter E, Yang H, Pearson TA. Community participatory research with deaf sign language users to identify health inequities. Am J Public Health. 2011 Dec;101(12):2235-8. PMC3222424.

[Dr. Barnett continues to work on other manuscripts on research methods and findings.]

#### Films (2):

**Barnett S**, McKee M, Smith SR, Pearson TA (2011). Examining Deaf population health inequities from a social justice perspective [film]. Preventing Chronic Disease. Video in American Sign Language with English captions to accompany the English language journal article: **Barnett** et al., Deaf sign language users, health inequities and public health: Opportunity for social justice. Video development oversight by Robert Pollard PhD, University of Rochester. [http://www.cdc.gov/pcd/issues/2011/mar/10\\_0065.htm#Appendix](http://www.cdc.gov/pcd/issues/2011/mar/10_0065.htm#Appendix)

Kelstone K, Chin C, Hackbarth J, DeWindt L, Graybill P, Kelstone A, Barnett S. (2011). Community participatory research to identify health inequities with deaf sign language users [film]. American Journal of Public Health. Video in American Sign Language with English captions to accompany the English language journal article: **Barnett** et al., Community participatory research to identify health inequities with deaf sign language users. <http://ajph.aphapublications.org/page/VideoArchive> [scroll to bottom of webpage]

#### Presentations (36 national and international):

Finigan E, Sutter E, Samar V, **Barnett S**, Pollard R, Havens C, and Klein J. Development of a linguistically accessible health behavior survey for deaf students. American Public Health Association Annual Meeting, Boston (November 7, 2006).

Sutter E, Finigan E, Samar V, **Barnett S**, Pollard R, Havens C, and Klein J. Measuring health risk behaviors of deaf and hard-of-hearing students: considering language difference. American Public Health Association Annual Meeting, Boston (November 7, 2006).

**Barnett S**. Using National Health Interview Survey Data to demonstrate disparities experienced by deaf people. CDC conference "50 Years of Measuring the Public's Health: Conference to Commemorate the National Health Interview Survey's 50th Anniversary." CDC National Center for Health Statistics, Hyattsville, MD (June 25, 2007).

**Barnett S**. Adapting the BRFSS to survey deaf sign language users. CDC 25th Annual Behavioral Risk Factor Surveillance System (BRFSS) Conference, Orlando (March 18, 2008).

Aggas J, **Barnett S**, David T, Graybill P, Kelstone K, Lomeo C, Sullivan JP, Pearson TA. Working collaboratively for the first community-based comprehensive health survey of a U.S. Deaf community. CDC Prevention Research Centers Annual Program Meeting, Atlanta (March 26, 2008).

**Barnett S**. Deaf people and healthcare: Adapting CAHPS® to be accessible for sign language users. Presented as part of the "OEREP Panel Session on Successful Career Development in Health Services Research" during the Agency for Healthcare Research & Quality (**AHRQ**) 2008 Annual Conference: Promoting Quality – Partnering for Change, Bethesda, MD (September 10, 2008)

**Barnett S**, McKee M, Samar VJ, Thompson H, on behalf of the NCDHR Research Committee, Deaf Health Community Committee, Translation Working Groups, Filming Teams, & Interface Development Teams.

Adapting the Behavioral Risk Factor Surveillance System (BRFSS) to survey deaf sign language users. American Public Health Association Annual Meeting, San Diego (October 26, 2008).

**Barnett S**, David T, McKee M, Pearson TA on behalf of NCDHR. Identifying and addressing disparities through community-based participatory research with deaf people: Experiences of a Prevention Research Center. NIH Summit: The Science of Eliminating Health Disparities. National Harbor, MD (December 16-17, 2008).

**Barnett S**, Schlehofer D, David T, Sutter E, on behalf of NCDHR. Identifying and addressing disparities through community-based participatory research with deaf people. CDC 20th National Conference on Chronic Disease Prevention and Control: Cultivating Healthy Communities. National Harbor, MD (February 23, 2009).

Schlehofer D, **Barnett S**. Surveying adults deaf since childhood: Identifying and addressing disparities through community-based participatory research. CDC 8th Annual Early Hearing Detection & Intervention (EHDI) Conference. Dallas (March 10, 2009).

**Barnett S**, Schlehofer D, Sutter E on behalf of NCDHR. Health outcomes for deaf children: Results of a survey of deaf adults. CDC 8th Annual Early Hearing Detection & Intervention (EHDI) Conference. Dallas (March 10, 2009).

Pearson TA, **Barnett S**, Chin N, David T, Smith S, Starr M. Health outcomes of deaf children: Review of CDC-funded health research in adolescents and adults. CDC National Center on Birth Defects & Developmental Disabilities Science Seminar. Atlanta (June 9, 2009).

Pearson TA, **Barnett S**, Chin N, Cuculick J, David T, McKee M, Pollard R, Schlehofer D, Smith S, Starr M (2009). Working with the Deaf community to identify health priorities. CDC Prevention Research Center Programs Seminar Series. Atlanta (June 10, 2009).

**Barnett S**. Issues in adapting the Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys for use with deaf people. École Libre des Hautes Études (ELDHE) Disability Study Group Meeting: Improving the Situation of Disability at Home and in the Community. Chicago (July 1, 2009).

Samar VJ, Oyzon E, **Barnett S**, Schlehofer D, Finigan EG, Lalley P, Sutter E. Interactive computerized sign language health survey for Deaf adults: Interface design and functionality. American Public Health Association Annual Meeting, Philadelphia (November 10, 2009).

O'Hearn A, Samar VJ, **Barnett S**. Odds of self reported suicide behaviors in deaf and hard of hearing college entering adults. American Public Health Association Annual Meeting, Philadelphia (November 10, 2009).

Sutter E, **Barnett S**, Pearson TA, on behalf of the Rochester Prevention Research Center: National Center for Deaf Health Research. Identifying people who are deaf and hard-of-hearing for inclusion in public health surveillance: Experiences piloting a BRFSS telephone module. CDC 27th Annual Behavioral Risk Factor Surveillance System (BRFSS) Conference, San Diego (March 22-23, 2010).

**Barnett S**, Sutter E, Pearson TA, on behalf of the Rochester Prevention Research Center: National Center for Deaf Health Research. Adapting the BRFSS to survey deaf sign language users: Experience and findings. CDC 27th Annual Behavioral Risk Factor Surveillance System (BRFSS) Conference, San Diego (March 22-23, 2010).

**Barnett S**, Schlehofer D, Sutter E. Adapting CAHPS® for Use in American Sign Language (ASL). **AHRQ** 12<sup>th</sup> CAHPS & 2<sup>nd</sup> SOPS User Group Meeting: Patient Experience & Patient Safety Culture, Baltimore MD (April 20, 2010).

Ramchandran R, Sutter E, Pollard RQ, **Barnett S**, Sterns G. Deaf adult self-reported quality of vision and use of eye care. Association for Research in Vision and Ophthalmology, Fort Lauderdale, FL (May 4, 2010).

**Barnett S** (symposium moderator), Sutter E, Kushalnagar P. Adapting PROMs for use with diverse populations: Experiences with American Sign Language. International Society for Quality of Life Research (ISOQOL) 17<sup>th</sup> Annual Conference, London, UK (October 30, 2010).

**Barnett S**. Deaf consumers' healthcare experiences: The need for accessible PROM. International Society for Quality of Life Research (ISOQOL) 17<sup>th</sup> Annual Conference, London, UK (October 30, 2010).

**Barnett S**. Healthcare experiences of deaf sign language users: Experiences adapting a written English survey. North American Primary Care Research Group (NAPCRG) 38<sup>th</sup> Annual Meeting, Seattle WA (November 16, 2010).

Mowl C, Sutter E, **Barnett S**. Adverse experiences and adult health conditions: Findings from a sign language survey with deaf adults. CDC 28th Annual Behavioral Risk Factor Surveillance System (BRFSS) Conference, Atlanta (March 22, 2011).

Reid JT, Starr MJ, **Barnett S**. Adapting public health interventions for use with a new community: Experiences working with deaf adult sign language users. CDC Prevention Research Centers Program Annual Conference, Atlanta (April 13, 2011).

Mowl C, Panko T, Kelstone K, **Barnett S**, Pearson T, and the Research Committee of the National Center for Deaf Health Research. Design of Deaf Weight Wise: A healthy lifestyle intervention for Deaf adults. CDC Prevention Research Centers Program Annual Conference, Atlanta (April 12 & 13, 2011).

Samar V, Finigan E, **Barnett S**. Early-life adverse conditions may epigenetically dysregulate physical and language development of deaf adults: Anthropometric evidence. Association for Psychological Science Meeting, Washington DC (May 26, 2011).

Samar V, Finigan E, **Barnett S**. Deaf young adults from low childhood socioeconomic backgrounds display intercorrelations among language skills and body composition suggesting early-life epigenetic dysregulation of neurocognitive development. Federation of European Societies for Neuropsychology Congress, Basel, Switzerland (September 8-9, 2011).

**Barnett S**, Winters P. Mortality and self-rated health of US adults deaf since birth or early childhood: findings from national data. International Society for Quality of Life Research (ISOQOL) 18th Annual Conference, Denver (October 27, 2011).

Mowl C, O'Hearn A, Panko T, Sutter E, **Barnett S**. Collecting research data from Deaf ASL users: How do we know we're asking the right questions? American Public Health Association (APHA) Annual Meeting, Washington DC (November 2, 2011).

**Barnett S**, Winters P. Mortality of US adults deaf since birth or early childhood: Findings from national data. North American Primary Care Research Group (NAPCRG) 39<sup>th</sup> Annual Meeting, Banff, Alberta, Canada (November 14, 2011).

**Barnett S**. Research infrastructure [related to mental health research with deaf people] (invited plenary). Deaf Mental Health Research Priority Consensus-Planning Conference, co-sponsored by National Association of State Mental Health Program Directors (NASMHPD) and Substance Abuse and Mental Health Service Administration (SAMSA), Gallaudet University, Washington DC (January 28, 2012).

David T, Tuttle J, **Barnett S**, Kitzman HJ. Potential barriers to cardiovascular disease risk assessment among deaf young adults. American Heart Association/American Stroke Association EPI/NPAM 2012 Scientific Sessions, San Diego (March 2012).



**Barnett S**, Mowl C, Sutter E, O’Hearn A, Samar V. Violence and suicide attempts: Results of a survey of adults deaf since birth or early childhood. CDC 11th Annual Early Hearing Detection & Intervention (EHDI) Meeting, St. Louis (March 5, 2012).

**Barnett S**. Healthcare experiences of deaf sign language users: Adapting CAHPS. Invited panelist for session “Innovative approaches for improving healthcare accessibility, quality, and patient safety for people with disabilities.” Agency for Healthcare Research and Quality (**AHRQ**) 2012 Annual Conference, Bethesda, MD (September 10, 2012).

Pollard RQ, Fasone S, Panko T, Dean R, Kelstone K, **Barnett S**. Examining Deaf population health inequities from a social justice perspective. American Public Health Association (APHA) 140th Annual Meeting, APHA Film Festival, San Francisco (October 31, 2012).

Prototype of CAHPS ASL:

The project successfully developed and piloted a prototype for CAHPS in ASL. Technology changed dramatically over the course of the grant funding period. The initial prototype design does not use the internet. Dr. Barnett and the University of Rochester continue to work with computer programmers to develop the next generation survey interface for use with ASL. An internet-based version of CAHPS that uses sign language will expand reach and access.

CAHPS survey items video library:

CAHPS items used in this pilot were translated into both ASL and English-based signing, and all the survey items were video recorded with three sign models. The PI and the University of Rochester are developing a library of sign language survey items. A library of CAHPS items as sign language video clips expands reach and access of a sign language CAHPS.